Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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2gether NHS Foundation Trust	Short	7	15	Challenging in practice as significant numbers of people we find initially do not want to receive information relating to diagnosis and stage of their condition. Would welcome greater clarity about the level of information that should be offered about prognosis to patients with early dementia. Suggest that the word 'offer' could be used rather than 'provide'.	Thank you for your comment. The committee noted that, as with all the recommendations in the guideline, people had the right to decline if they wished. However, they noted the evidence was clear that the majority of people diagnosed wanted information on and diagnosis and prognosis early, and therefore agreed the current wording in the guideline was the most appropriate.
2gether NHS Foundation Trust	Short	8	6	Challenging: at diagnosis it is often unknown which healthcare professionals and particularly social care teams will be involved. For healthcare – it would be possible for a 'dementia navigator' role to provide continuity but this would not usually be a healthcare professional – and to use healthcare professionals throughout would be challenging to the capacity of the system. For social care, in these counties, teams are not usually involved until/unless needs increase to a point where social care funding criteria are met, r if there is a crisis – and then there is only short term involvement. So to meet the recommendation would necessitate a marked increase in social care resources, which seems unlikely.	Thank you for your comment. The committee agreed it would not be possible to give full information on all the teams that will be involved in their care, but it should at least be possible to give information on those services that will be involved in providing post-diagnostic support and follow-up.

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2gether NHS Foundation Trust	Short	9	17	Wish for clarification: it would be helpful if the document could provide clarity about whether or not dementia diagnosis in non-specialist settings (for example, by General Practitioners) is envisaged (so, for example, should the title read 'initial assessment and diagnosis in non-specialist settings?'	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
2gether NHS Foundation Trust	Short	10	25	Wish for clarification: it would be helpful if the document could provide clarity on the usefulness of structural imaging to guide subtyping of dementias using findings such as lobar atrophy or hippocampal atrophy.	Thank you for your comment. No evidence was identified on these imagine findings, and therefore the committee agreed it was not possible to make any recommendations.

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2gether NHS Foundation Trust	Short	11	17	This would necessitate a resource allocation for sampling CSF – perhaps a service level agreement with the local neurology service - and also for the lab testing service.	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these test could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations.
2gether NHS Foundation Trust	Short	12	6	More frequent use of DAT scans would have resource implications: this is not currently commissioned on a routine basis, just for a limited number of patients. Also, the proportion of DLB cases with normal DAT scans is, I understand, uncertain.	Thank you for your comment. The committee agreed that the diagnostics accuracy of DAT scans for detecting DLB was high, and therefore it was an appropriate diagnostic investigation if a clear diagnosis had not been made by this stage. In order to clarify that such scans should only be undertaken if they are needed to secure a diagnosis, the committee added an additional recommendation for after initial specialist assessment: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
2gether NHS Foundation Trust	Short	13	17	For the primary care based service to be multidisciplinary would require additional resources.	Thank you for your comment. The committee noted that, wherever reviews are carried out for people living with dementia, it was important they are able to provide the multidisciplinary support the person is likely to need.
2gether NHS Foundation Trust	Short	13	23	See comment number 2	Thank you for your comment. The committee agreed it would not be possible to give full information on all the teams that will be involved in their care, but it should at least be possible to give information on those services that will be involved in providing post-diagnostic support and follow-up.

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2gether NHS Foundation Trust	Short	15	9-14	On a population basis, provision of these measures would require a large injection of resources.	Thank you for your comment. This recommendation has been amended from that in the draft version of the guideline, and now reads: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia"
2gether NHS Foundation Trust	Short	20	22	Instead of 'inappropriate care' it might be better to mention physical or psychological needs not being met.	Thank you for your comment. The committee discussed this but decided to keep the original wording as the clearest available.
2gether NHS Foundation Trust	Short	22	11	Challenge in practice: once non-drug measures have been tried, most alternative drug treatments (eg Z drugs) carry well-known adverse effects, while some patients do seem to benefit. Short courses of melatonin may be preferable to either the alternative drugs or to escalating carer stress.	Thank you for your comment. The committee noted this concern, but agreed there was not sufficient evidence on other pharmacological treatments to be able to make recommendations (either positive or negative), and agreed that an absence of alternatives was not a reason to promote the use of a drug (melatonin) where there is evidence of a lack of efficacy.
2gether NHS Foundation Trust	Short	22	13	Challenge in practice: resources are not widely available to implement these.	Thank you for your comment. The committee noted this concern, but agreed that with no robust evidence of any benefits from pharmacological interventions, non-pharmacological management, which did show benefits, was important to recommend.
2gether NHS Foundation Trust	Short	26	15	Challenge in practice: needs for respite care and short breaks are seldom funded locally. To assess carers' needs with no prospect of securing	Thank you for your comment. The committee noted that an assessment for respite care would often form part of a standard Carer's assessment, with the corresponding obligations to provide services deemed to be necessary.

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				provision is usually unhelpful to carers and uses professionals' time unfruitfully.	
Action on Hearing Loss	Short	7	7-9	**Recommendations regarding involving people in decision making should take into consideration the communication requirements of people with hearing loss.** Since hearing loss and dementia are both linked to ageing it is likely that they will both occur together, it is therefore crucial that communication support is provided for people with hearing loss to ensure that they are able to fully participate in discussions about their treatment and care. **Question 1:** Recommendation 1.1.1 *'Encourage and enable people living with dementia to give their own views and opinions about their care'* may be challenging to implement without the appropriate communication support if the person also has hearing loss. In addition, research from Action on Hearing Loss's *'Nursing Practice Project'*[1] identified that issues with hearing loss and communication were also very common in elderly care wards. 71% of participants stated that they did not fully	Thank you for your comment. The committee noted all these concerns, and agreed that in the absence of any dementia specific evidence on these topics, the most appropriate way to address these issues was with a cross-reference to the NICE guideline on hearing loss, which has now been included in this section.

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[1] Action on Hearing Loss and Heart of England NHS Foundation Trust. (2014). Caring For Older People with Hearing Loss. A toolkit for change. London: Action on Hearing Loss

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				understand what staff were saying and 43% felt that they were not fully involved in decision-making regarding their care. The staff who were questioned also stated that they experienced difficulty communicating with patients, possibly due to hearing loss. **Question 3** Users working in secondary care should refer to Action on Hearing Loss's nursing practice toolkit to ensure people with hearing loss receive high quality care in hospitals. The toolkit provides recommendations and resources, based on the findings from our research undertaken in a hospital elderly care assessment unit,[1] and should be cited within the tools and resource within *'Putting this guideline into practice section'*.	
Action on Hearing Loss	Short	7	10-11	**We welcome recommendation 1.1.2 *'If needed, use additional or modified ways of communicating (for example visual aids or simplified text).'*** This recommendation should be extended to capture the needs of those who may have hearing loss in addition to dementia. People who have hearing loss who use British Sign Language should be provided with a qualified sign	Thank you for your comment. The committee agreed that the appropriate management of identified hearing loss should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				language interpreter. As mentioned in comment 2 our research shows that often this requirement is not met. People with hearing loss should be provided with a qualified interpreter for all NHS appointments under the Accessible Information Standard.**Error! Bookmark not defined.**	
Action on Hearing Loss	Short	7	18 - 19	**We welcome the recommendation to provide accessible information as detailed in the NHS Accessible Information Standard.** **Question 1:** Although all organisations that provide NHS services are legally required to follow the Accessible Information Standard,[2] research shows that often this is not the case. Findings from NHS England's review[2] on the Accessible Information Standard showed that although there was widespread support for the Standard, significant challenges remained in terms of its implementation. For example, more than half (53%) of patients who responded to NHS England's survey said they had not experienced any improvement in getting accessible information or communication support	Thank you for your comment and your support for this recommendation. The committee agreed it was important that all services meet the responsibilities set out in the NHS Accessible Information Standard.

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[2] NHS England, 2017. Accessible Information Standard: post-implementation review – report. Available at: www.england.nhs.uk/accessibleinfo

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				over the last six months. Many people who are deaf or have hearing loss who provided feedback to NHS England as part of their review also said they were still experiencing barriers to communication when accessing health and social care. Recent research by Action on Hearing Loss outlined in comment 2 shows that further work is still required to ensure organisations are providing accessible information in line with the Accessible Information Standard.[2]	
Action on Hearing Loss	Short	9	17 - 23	**Section 1.2.1 should explicitly state that hearing screening should be included as part of the initial assessment for the diagnosis of dementia in a non-specialist setting.** The BMJ best practice, a Clinical Decision Support Tool for healthcare professionals' states that for the assessment of dementia, a physical examination should be undertaken and this should include a hearing test.[3]	Thank you for your comment. The committee agreed with this suggestion, and therefore hearing loss was added to the recommendation on the reversible causes of cognitive decline that should be investigated in primary care for someone with suspected dementia. The committee also agreed it was appropriate to add a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia.

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[3] Tampi R, et al. (2017) Assessment of dementia. BMJ Best Practice. Available at: http://bestpractice.bmj.com/topics/en-gb/242

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				Hearing loss and dementia both have common symptoms, which can result in hearing loss being misdiagnosed as dementia.[4] Unaddressed hearing loss in people with dementia can accelerate cognitive decline.[19] Since hearing loss and dementia often co-occur, failure to recognise hearing loss in those who have dementia can exacerbate the symptoms of dementia. Hearing loss can also adversely affect performance on cognitive testing and can cause a diagnostic challenge for dementia. The most commonly used test to determine cognitive status, the Mini-Mental State Examination (MMSE), relies on the individual's ability to fully hear the instructions.[5] Findings from Jorgensen et al (2016) showed that reduced audibility significantly reduces scores on the MMSE, resulting in greater apparent cognitive deficits as audibility decreased.[6] Cohort studies investigating hearing loss have shown that even mild levels of hearing loss can increase the long-term risk of cognitive decline and dementia in	

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[4] Kricos PB. (2009). Providing hearing rehabilitation to people with dementia presents unique challenges. The Hearing Journal, 62(11):39-40; Weinstein B. (2013). Geriatric Audiology, Chap 3 p.62 Psychosocial Changes with Ageing, Thieme, Publishers.NY

[5] Alzheimer's Society. (2017). The MMSE test. Available at: https://www.alzheimers.org.uk/info/20071/diagnosis/97/the_mmse_test.

[6] Jorgensen L, Palmer C, Pratt S, et al. (2016). The Effect of Decreased Audibility on MMSE Performance: A Measure Commonly Used for Diagnosing Dementia. Journal of the American Academy of Audiology. 27(4):311-323.

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				individuals who are cognitively intact but hearing impaired at baseline.[7] Further evidence from the recent Lancet Commission (2017) on dementia prevention, intervention and care identifies hearing loss as the largest modifiable risk factor for dementia.[8] In light of this evidence, it is important that all adults with diagnosed or suspected dementia or mild cognitive impairment undergo a hearing assessment.	
Action on Hearing Loss	Short	13	19-21	**The recommendation '*When people living with dementia or their carers have a primary care appointment, assess for any emerging dementia-related needs and ask them if they need any***	Thank you for your comment. The committee agreed that hearing loss was a relevant issue to consider at all stages of the process, including at diagnosis and review appointments. The committee agreed the best way to appropriately cover these

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[7] Deal JA, et al (2017) Hearing impairment and incident dementia and cognitive decline in older adults: the Health ABC Study. J Gerontol A Biol Sci Med Sci. 72(5): 703–709; Lin FR, et al (2011) Hearing loss and incident dementia. Arch Neurol, 68: 214–20; Gallacher J, Ilubaera V, Ben-Shlomo Y, et al (2012) Auditory threshold, phonologic demand, and incident dementia. Neurology, 79: 1583–90; Lin FR, Ferrucci L, Metter EJ, et al (2011) Hearing loss and cognition in the Baltimore Longitudinal Study of Aging. Neuropsychology, 25: 763–70; Lin FR (2011) Hearing loss and cognition among older adults in the United States. J Gerontol A Biol Sci Med Sci, 66:1131–36; Deal JA, Sharrett AR, Albert MS, et al (2015) Hearing impairment and cognitive decline: a pilot study conducted within the atherosclerosis risk in communities neurocognitive study. Am J Epidemiology, 181: 680–90; Kiely KM, Gopinath B, Mitchell P, et al (2012) Cognitive, health, and sociodemographic predictors of longitudinal decline in hearing acuity among older adults. J Gerontol A Biol Sci Med Sci, 67: 997–1003; Fritze T, Teipel S, Óvári A, et al (2016) Hearing impairment affects dementia incidence. An analysis based on longitudinal health claims data in Germany. PLoS One, 11: e0156876; Gurgel RK, Ward PD, Schwartz S, et al (2014) Relationship of hearing loss and dementia: a prospective, population-based study. Otol Neurotol, 35: 775–81; Amieva H, Ouvrard C, Giulioli C, et al (2015) Self-reported hearing loss, hearing aids, and cognitive decline in elderly adults: a 25-Year Study. J Am Geriatr Soc, 63: 2099–104.

[8] Livingston G, Sommerlad A, Orgeta V, et al (2017) Dementia prevention, intervention, and care. The Lancet.16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6

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				***more support'* should be expanded to state what an 'emerging dementia-related need' includes.** Hearing loss should be included in the assessment for emerging dementia-related needs at primary care appointments, carers should also be asked if they notice any changes in the person's hearing. Failing to address hearing loss in people with dementia could accelerate cognitive decline,[9] and could make the symptoms of dementia appear worse. It is therefore crucial that hearing loss is diagnosed and managed as early as possible. **Question 1:** Research shows that adults with hearing loss wait on average 10 years before seeking medical advice, and when they do visit their GP, 30 to 45 percent are not referred on for a hearing assessment.[10] In addition, there is also considerable variation across England in access to audiology services. The NHS England Atlas of Variation shows an 11-fold variation in the rate of	issues was by adding a cross-reference to the NICE guideline on hearing loss within the comorbidities section of this guideline.

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[9] Kricos, P.B., 2009. Providing hearing rehabilitation to people with dementia presents unique challenges. The Hearing Journal, 62(11), pp.39-40

[10] Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. Health Technology Assessment 11:1–294; Audit Commission (2000) Fully equipped: the provision of equipment to older or disabled people by the NHS and social services in England and Wales. Audit Commission, London

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				audiology assessments,[11] suggesting that there is significant variation in referrals made by GPs for people with hearing loss.[12] In recognition of this, early diagnosis and management of hearing loss has been identified as a key objective in the Action Plan for Hearing Loss.[13] **Question 3:** To help overcome challenges users should refer to the Commissioning Framework for Adult Hearing Loss Services,[24] which states that *"GPs and other health and social care professionals should regularly check people's hearing as they get older (10, 23) to encourage people to seek help, and to ensure they get a prompt referral on to audiology services"*. The Framework also recommends that *"CCGs should plan to ensure services tackle unmet need and ensure that GPs are aware of the evidence and national guidance, as well as local referral pathways"*.	

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[11] Public Health England (2013). NHS Atlas of Variation in Diagnostic Services: Reducing unwarranted variation to increase value and improve quality.

[12] Davis et al (2012). Diagnosing patients with age-related hearing loss and tinnitus: Supporting GP clinical engagement through innovation and pathway redesign in audiology services. International Journal of Otolaryngology, available at: http://www.hindawi.com/journals/ijoto/2012/290291/

[13] NHS England and Department of Health (2015) Action Plan on Hearing Loss. London: NHS England and Department of Health. Available at: https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf

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				Further guidance on referral is available from the British Academy of Audiology at http://www.baaudiology.org/index.php/download_file/view/302/178/ , and professional practice guidance from the British Society of Hearing Aid Audiologists can be found at http://www.bshaa.com/Publications/BSHAA , which should be included within 'tools and resources' under the section *'Putting the guideline into practice'* on page 29 of the short version of the guideline.	
Action on Hearing Loss	Short	13	28	**We welcome the recommendation to *'provide information about available services and how to access them.'*** This should include providing people with dementia who may have hearing loss with information on Assistive Listening Devices, such as personal loops, personal communicators, TV amplifiers, telephone devices, smoke alarms, doorbell sensors, and technologies such as streamers and apps. These equipment's are usually provided by local authority sensory services, and can help people who are deaf or have hearing loss communicate well and live	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed that once a person was identified as having hearing loss, they would be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				safely and independently in their own home, and manage their condition more effectively. **Question 1:** Evidence from our '*Under Pressure*' report[14] shows that people who are deaf or have hearing loss might not know that these services are available and referral routes are often underutilised. These findings are consistent with patient survey results from Monitor's report on NHS adult hearing services in England,[15] which showed that only one in ten respondents surveyed said that they were provided information about additional services and equipment. Providers who were interviewed stated that it is difficult to identify all other services which are available locally, and that significant investment is needed to build awareness and knowledge of those services. **Question 3:** NHS services and local authorities should work together to ensure assistive equipment is available to everyone who needs it. For guidance, users should refer to the	

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[14] Lowe C. (2015). Under Pressure. London: Action on Hearing Loss. Available from: https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/under-pressure-report/

[15] Monitor. (2015). NHS adult hearing services in England: exploring how choice is working for patients. London: Monitor

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				Commissioning Framework for Adult Hearing Loss Services[24] which recommends health and social care organisations work closely together and consider innovative solutions to help people access assistive equipment and other forms of support.	
Action on Hearing Loss	Short	22	19-23	**We welcome recommendation 1.8.1 *'Ensure that people living with dementia have equivalent access to treatments and care for comorbidities to people who do not have dementia'*.** There is a high prevalence of long-term conditions such as diabetes and cardiovascular disease in older people, often these conditions are not experienced in isolation.[25] For example, 71% of people over 70 years are estimated to have some degree of hearing loss,[18] many of whom will have one or more other long-term conditions. **Question 1:** It may be challenging for people living with dementia who have hearing loss to access treatments and care. Evidence shows that people with hearing loss experience greater difficulty in accessing health services and receive lower standard of care when compared to the	Thank you for your comment. The committee noted this point, and agreed it was appropriate to include a cross-reference to the NICE guideline on hearing loss to address these issues.

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				general population.[16] Action on Hearing Loss's recent research showed that people with hearing loss still experience unnecessary difficulties and poor communication when trying to access healthcare (please refer to comment 2) **Question 3:** Better communication and improved access to health services are needed to reduce inequalities in health outcomes and improve the diagnosis and management of long-term conditions for people with hearing loss. (Please refer to comment 2)	
Action on Hearing Loss	Short	25	1-9	**Recommendation 1.10.8 *'When thinking about admission to hospital for a person living with severe dementia, carry out an assessment that balances their current medical needs with the additional harms they may face in hospital…'* should also state communication difficulties as an example.** Research from Action on Hearing Loss's *'Nursing Practice Project'*[1] identified that issues with hearing loss and communication were very	Thank you for your comment. The committee noted this recommendation already covered aspects such as disorientation and the effects of being in an impersonal or institutional environment, which could result from communication difficulties. The committee also agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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[16] The Deaf Health Charity Sign Health. (2016). How the Health Service is Failing Deaf People: Sick of it.

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				common in elderly care wards (please refer to comment 2). **Question 3:** To overcome challenges users working in secondary care should refer to Action on Hearing Loss's nursing practice toolkit to ensure people with hearing loss receive high quality care in hospitals. The toolkit provides recommendations and resources, based on the findings from our research undertaken in a hospital elderly care assessment unit.[1]	
Action on Hearing Loss	Short	25	10-13	**Recommendation 1.10.9 *'When thinking about admission to hospital for a person living with dementia, take into account…'* should also include communication needs** Please refer to comment 2.	Thank you for your comment. The committee noted this recommendation already covered aspects such as disorientation and the effects of being in an impersonal or institutional environment, which could result from communication difficulties. The committee also agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Action on Hearing Loss	Short	26	19	**Section 1.12 *'Moving to different care settings'* should also recommend the inclusion of social and sensory problems within individual care**	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified on this topic, it

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				plans. As outlined in NHS England's Healthy Ageing *'What Works'* Guide[17] this should include the assessment and management of hearing, management of hearing technology and communication needs. **Question 3:** To overcome challenges users should refer to NHS England's Healthy Ageing *'What Works'* Guide[17] designed for commissioners and medical and social care providers working with older people with hearing loss. The guide provides evidence based recommendations for providers, to ensure older people with hearing loss are supported in maintaining good health, wellbeing and independence.	was not possible to include specific comments on sensory impairment within these recommendations.
Action on Hearing Loss	Short	27	1-2	**Recommendation 1.12.2 to *'Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition'* is welcomed.** Management of hearing loss, hearing technology and communication needs should be included in the individual's care plan. Clear procedures need to be in place for referral, recording and	Thank you for your comment. The committee agree with this suggestion, and the guideline has been amended to make clear that care and support plans should contain information on "the management of any comorbidities the person has", which would include hearing loss.

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[17] NHS England. (2017). What works: hearing loss and healthy ageing. London: NHS England

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				consistent management of hearing problems and technology and it should be mandatory for staff to follow recording procedures consistently.[17] People with hearing loss should also be provided with communication support if needed, to allow them to participate in their review and convey their needs effectively.	
Action on Hearing Loss	Full & Short	General	General	Action on Hearing Loss (formerly the RNID) is the largest charity in the UK representing people with hearing loss. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We provide information, advice and support for people with hearing loss, we campaign for equality and better services, and we support research efforts to find new treatments and improve the management of hearing loss. We welcome the opportunity to respond to the consultation on NICE's draft guideline on *'Dementia - assessment, management and support for people living with dementia and their carers'*. Throughout this response we use the term 'people with hearing loss' to refer to people	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia"

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				with all levels of hearing loss, including people who are profoundly deaf. Hearing loss is very common in old age. 55% of people aged over 60 years of age are estimated to be affected by some degree of hearing loss, this increases to 71% for those over 70 years.[18] Considering dementia primarily affects older adults, it is likely that a large proportion of this population will also experience hearing loss. Of this group, many people will not have recognised or addressed their hearing loss, which could further accelerate cognitive decline,[19] and make the symptoms of dementia appear worse. It is therefore imperative that the guideline recommends hearing screening in the initial assessment for the diagnosis of dementia. In England, enhancing the quality of life for people with multiple long-term conditions is a key focus of both the *NHS Five Year Forward View*[20] and the *NHS Outcomes Framework 2016/2017.*[21]	

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[18] Davis A. (1995). Hearing in Adults. London: Whurr.

[19] Deal JA, Sharrett AR, Albert MS, Coresh J, Mosley TH, Knopman D, Wruck LM, Lin FR. (2015). Hearing impairment and cognitive decline: a pilot study conducted within the atherosclerosis risk in communities neurocognitive study. American journal of epidemiology, 181 (9) pp. 680-690.

[20] NHS. (2014). Five Year Forward View. Available at: https://www.england.nhs.uk/publication/nhs-five-year-forward-view/

[21] Department of Health. (2016). NHS Outcomes Framework 2016 to 2017 at-a-glance. Available at: https://www.gov.uk/government/publications/nhs-outcomes-framework-2016-to-2017

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				Both of these documents emphasise the need for early intervention and diagnosis, a focus on the health and wellbeing of the individual patient, and the need for better integration between services. Improving early diagnosis and management of hearing loss is particularly important in the prevention and management of dementia.[22] Hearing loss is a growing public health challenge and is increasingly seen as a national priority. This is demonstrated by the Department of Health and NHS England's Action Plan on Hearing Loss[23] published in March 2015, and NHS England's Commissioning Framework for Adult Hearing Loss Services[24] published in April 2016. However, ensuring earlier identification and management of hearing loss in the diagnosis and management of long term conditions such as dementia are not always realised in practice.	

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[22] Livingston G, Sommerlad A, Orgeta V, et al (2017) Dementia prevention, intervention, and care. The Lancet.16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6

[23] NHS England and Department of Health. (2015). Action Plan on Hearing Loss. London: NHS England and Department of Health. Available at: https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf

[24] NHS England, Office of the Chief Scientific Officer. (2016). Commissioning Services for People with Hearing Loss: A Framework for Clinical Commissioning Groups. London: NHS England. Available at: https://www.england.nhs.uk/wp-content/uploads/2016/07/HLCF.pdf

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				Furthermore, improved rates of early diagnosis and better integrated management of hearing loss alongside dementia would not only improve the quality of life of many people but it would also lead to significant cost savings. For example, it is estimated that at least £28 million per year could be saved in England if hearing loss is managed properly in people with dementia.[25] In addition, further evidence shows that the use of hearing aids and implants for increased amplification leads to lower usage of health and social care.[26] With significant pressures on the health and social care system to reduce costs it is imperative that health and social care professionals, commissioners and providers recognise hearing loss in the assessment, diagnosis and management of dementia.	
Action on Hearing Loss	Full	257-301	General	**Section 13 *'Non- pharmacological interventions for people living with dementia'* should include the use of hearing aids as a non-pharmacological intervention for people living with dementia who have hearing loss.**	Thank you for your comment. The committee noted that only very limited RCT evidence was identified on the use of hearing aids specifically in a population of people living with dementia. The committee agreed therefore that, in the absence of evidence, people living with dementia should receive the same

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[25] DCAL and Action on Hearing Loss. (2013). Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions.

[26] O'Neill C, Lamb B, Archbold S. (2016). Cost implications for changing candidacy or access to service within a publicly funded healthcare system? Cochlear implants international, 17(sup1): 31-35.

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				There is a significant body of evidence to show the improvements to health and wellbeing from using hearing aids. Most recently, a Cochrane review on the effectiveness of hearing aids in mild to moderate hearing loss showed that hearing aids are effective at improving hearing specific and general health related quality of life and listening ability in adults with mild to moderate hearing loss.[27] Furthermore, a systematic review by Ciorba et al (2012) found that people benefited from hearing aids on a variety of different quality of life measures.[28] Health improvement benefits were also found by Swan et al (2012) and Barton et al (2004) using quality of life outcome measures.[29] Further evidence shows better social engagement, mental and physical health in	access to interventions for hearing loss as people without dementia. Specifically, they agreed this was covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." The committee also agreed it was appropriate to add a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia.

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[27] Ferguson MA, Kitterick PT, Chong L, Edmondson-Jones M, Barker F, Hoare DJ. (2017). Hearing aids for mild to moderate hearing loss in adults. Cochrane Database of Systematic Reviews.

[28] Ciorba A, Bianchini C, Pelucchi S and Pastore A. (2012). The impact of hearing loss on the quality of life of elderly adults. Clinical Interventions in Aging. 7:159–163.

[29] Swan IR, Guy FH, Akeroyd MA. (2012). Health-related quality of life before and after management in adults referred to otolaryngology: a prospective national study. Clinical Otolaryngology. 37(1):35-43; Barton GR, Bankart J, Davis AC, Summerfield QA. (2004). Comparing utility scores before and after hearing aid provision: results according to the EQ-5D, HUI3 and SF-6D. Applied Health Economics and Health Policy 3(2):103-5.

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				hearing aid users than compared to non-users.[30] Additionally, findings from recent studies show that the rate of cognitive decline decreases with the use of hearing aids which may reduce the risk of developing dementia.[31] Please also refer to comment 18 which cites evidence on the use of hearing aids and cognitive decline.	
Action on Hearing Loss	Full	376 - 393	General	**Section 18 *'Assessing and managing comorbidities'* fails to address hearing loss as a comorbidity of dementia.** Hearing loss and dementia are likely to co-occur since they both commonly arise in old age. A growing body of evidence suggests that hearing loss is associated with an increased risk of developing dementia and an accelerated rate of cognitive decline.[32]	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be

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[30] Kochkin S and Rogin CM. (2000). Quantifying the obvious: The impact of hearing instruments on quality of life. The Hearing Review. 7(1).

[31] Amieva H, Ouvrard C, Giulioli C, et al. (2015). Self-Reported Hearing Loss, Hearing Aids, and Cognitive Decline in Elderly Adults: A 25-Year Study. J Am Geriatr Soc. 63(10):2099-104. doi: 10.1111/jgs.13649.

[32] Deal JA, et al (2017) Hearing impairment and incident dementia and cognitive decline in older adults: the Health ABC Study. J Gerontol A Biol Sci Med Sci. 72(5): 703–709; Lin FR, et al (2011) Hearing loss and incident dementia. Arch Neurol, 68: 214–20; Gallacher J, Ilubaera V, Ben-Shlomo Y, et al (2012) Auditory threshold, phonologic demand, and incident dementia. Neurology, 79: 1583–90; Lin FR, Ferrucci L, Metter EJ, et al (2011) Hearing loss and cognition in the Baltimore Longitudinal Study of Aging. Neuropsychology, 25: 763–70; Lin FR (2011) Hearing loss and cognition among older adults in the United States. J Gerontol A Biol Sci Med Sci, 66:1131–36; Deal JA, Sharrett AR, Albert MS, et al (2015) Hearing impairment and cognitive decline: a pilot study conducted within the atherosclerosis risk in communities neurocognitive study. Am J Epidemiology, 181: 680–90; Kiely KM, Gopinath B, Mitchell P, et al (2012) Cognitive, health, and sociodemographic predictors of longitudinal decline in hearing acuity among older adults. J Gerontol A Biol Sci Med Sci, 67: 997–1003; Fritze T, Teipel S, Óvári A, et al (2016) Hearing impairment affects dementia incidence. An analysis based on longitudinal health claims data in Germany. PLoS One, 11: e0156876; Gurgel RK, Ward PD, Schwartz S, et al (2014) Relationship of hearing loss and dementia: a prospective, population-based study. Otol Neurotol, 35: 775–81; Amieva H, Ouvrard C, Giulioli C, et al (2015) Self-reported hearing loss,

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				Question 1: The symptoms of dementia can make the assessment and management of hearing loss challenging This is because firstly, when testing for hearing loss the individual relies on their memory to recognise how their hearing compares with their hearing in the past.[33] They also rely on their memory to tell them how long they have been experiencing hearing loss for. Secondly, diagnosing hearing loss relies on the individual's ability to understand the instructions from the audiologist. This becomes difficult when the individual has symptoms of dementia, and as a result may feel confused. Additionally, there is a risk that hearing loss may be misdiagnosed as dementia,[34] since dementia itself can cause communication problems, such as difficulty in finding the right words.	investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia"

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hearing aids, and cognitive decline in elderly adults: a 25-Year Study. J Am Geriatr Soc, 63: 2099–104; Livingston G, Sommerlad A, Orgeta V, et al (2017) Dementia prevention, intervention, and care. The Lancet.16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6; Kricos PB. (2009). Providing hearing rehabilitation to people with dementia presents unique challenges. The Hearing Journal, 62(11):39-40; Weinstein B. (2013). Geriatric Audiology, Chap 3 p.62 Psychosocial Changes with Ageing, Thieme, Publishers.NY

[33] Echalier M. (2012). A World of Silence. The case for tackling hearing loss in care homes. London: Action on Hearing Loss. Available from: http://www.actiononhearingloss.org.uk/-/media/ahl/documents/research-and-policy/reports/care-home-report.pdf

[34] Boxtel van M, Beijsterveldt van C, Houx P, et al. (2000). Mild Hearing Impairment Can Reduce Verbal Memory Performance in a Healthy Adult Population. Journal of Clinical and Experimental Neuropsychology 22(1):147-154.

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				Furthermore, hearing impairment can adversely affect performance on cognitive testing and can cause a diagnostic challenge resulting in misdiagnosis. The most commonly used test to determine cognitive status, the Mini-Mental State Examination (MMSE), relies on the individual's ability to fully hear the instructions.[35] Findings from Jorgensen et al (2016) showed that reduced audibility significantly reduced scores on the MMSE, resulting in greater apparent cognitive deficits as audibility decreased.[36]	
Action on Hearing Loss	Full	354 - 369	General	**Section 16 *'Staff training'* should also acknowledge the difficulties older people living with dementia in care homes may face when seeking help for hearing loss or when using hearing aids.** Action on Hearing Loss's '*A World of Silence*'[37] report shows that older people in care homes are less likely to want to address their hearing loss	Thank you for your comment. The committee agreed that in the absence of any specific evidence around staff training for hearing loss, it was not possible to include this in the recommendations. However, a reference to "adapting communication styles" is included within this section. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes

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[35] Alzheimer's Society. (2017). The MMSE test. Available at: https://www.alzheimers.org.uk/info/20071/diagnosis/97/the_mmse_test.

[36] Jorgensen L, Palmer C, Pratt S, et al. (2016). The Effect of Decreased Audibility on MMSE Performance: A Measure Commonly Used for Diagnosing Dementia. Journal of the American Academy of Audiology. 27(4):311-323.

[37] Echalier M. (2012). A World of Silence. The case for tackling hearing loss in care homes. London: Action on Hearing Loss. Available from: http://www.actiononhearingloss.org.uk/-/media/ahl/documents/research-and-policy/reports/care-home-report.pdf

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				without support – and that care staff found it difficult to encourage them to seek help. The report found that staff had a lack of training in this area and that hearing loss was often seen as less important compared to other issues such as sight loss, pain or safeguarding. Some care staff also lacked the know-how to carry out basic hearing aid maintenance. Our '*Under Pressure*'[38] report also found that less than half (46%) of NHS audiology services in England offer hearing aid support to older people living in care homes. Many older people with hearing loss have other health problems such as frailty and physical impairments so they may need additional support to visit their audiologist or look after their hearing aids. Alternatively, if they are unable to attend appointments due to other conditions, they will need access to hearing aid assessments or aftercare in the care home itself. **Question 3.** To help overcome challenges users should refer to NHS England's Healthy Ageing	recommendations on hearing assessments for people with suspected and diagnosed dementia. Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." This would include people living in care homes, and the committee agreed it was important these people not be denied treatment for comorbidities.

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[38] Lowe C. (2015). Under Pressure. London: Action on Hearing Loss. Available from: https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/under-pressure-report/

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				'What Works' Guide,[39] which recommends training for care staff on the communication and hearing needs of older people. Additional guidance can be found in the Action Plan on Hearing Loss,[40] which states that properly diagnosing and managing hearing loss is essential for improving the health and wellbeing of older people living in care homes. The Action Plan also lists *"Improved communication experience in mainstream care homes"* as a key outcome measure for service improvement. Action on Hearing Loss has also developed a nursing practice toolkit to tackle issues with communication in elderly care wards. Please refer to comment 2.	
Action on Hearing Loss	Full	179 - 190	General	**Section 10 *'Modifying risk factors for dementia progression'* fails to acknowledge hearing loss as a modifiable risk factor.** There is strong evidence of a link between hearing loss and dementia. People with mild	Thank you for your comment. The guideline only contained a section on modifying risk factors to slow the progression of established dementia. The guideline did not contain a section

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[39] NHS England. (2017). What works: hearing loss and healthy ageing. London: NHS England

[40] NHS England and Department of Health (2015) Action Plan on Hearing Loss. London: NHS England and Department of Health. Available at: https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf

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				hearing loss have nearly twice the chance of going on to develop dementia as people without any hearing loss. The risk increases to threefold for those with moderate hearing loss and fivefold for those with severe hearing loss.[41] Evidence from a number of cohort studies have shown that even mild levels of hearing loss can increase the long-term risk of cognitive decline and dementia in individuals who are cognitively intact but hearing impaired at baseline.[42] The guideline should cite recent evidence from the Lancet Commission (2017)[43] on dementia prevention, intervention and care which identifies hearing loss as the largest modifiable risk factor for dementia. The study estimates that 9% of new dementia cases could be eliminated if hearing loss	on risk factors for the development of dementia, and therefore it was not possible to consider this evidence within the review. However, the committee noted that the recently published NICE guideline hearing loss did contain a research recommendation on this issue; specifically: "In adults with hearing loss, does the use of hearing aids reduce the incidence of dementia?" The committee agreed this was a relevant question to be addressed, the results of which could inform an update of either this guideline or the hearing loss guideline.

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[41] Lin FR et al. (2011). 'Hearing loss and incident dementia'. Archives of Neurology 68 (2): 214-220.

[42] Deal JA, et al (2017) Hearing impairment and incident dementia and cognitive decline in older adults: the Health ABC Study. J Gerontol A Biol Sci Med Sci. 72(5): 703–709; Lin FR, et al (2011) Hearing loss and incident dementia. Arch Neurol, 68: 214–20; Gallacher J, Ilubaera V, Ben-Shlomo Y, et al (2012) Auditory threshold, phonologic demand, and incident dementia. Neurology, 79: 1583–90; Lin FR, Ferrucci L, Metter EJ, et al (2011) Hearing loss and cognition in the Baltimore Longitudinal Study of Aging. Neuropsychology, 25: 763–70; Lin FR (2011) Hearing loss and cognition among older adults in the United States. J Gerontol A Biol Sci Med Sci, 66:1131–36; Deal JA, Sharrett AR, Albert MS, et al (2015) Hearing impairment and cognitive decline: a pilot study conducted within the atherosclerosis risk in communities neurocognitive study. Am J Epidemiology, 181: 680–90; Kiely KM, Gopinath B, Mitchell P, et al (2012) Cognitive, health, and sociodemographic predictors of longitudinal decline in hearing acuity among older adults. J Gerontol A Biol Sci Med Sci, 67: 997–1003; Fritze T, Teipel S, Óvári A, et al (2016) Hearing impairment affects dementia incidence. An analysis based on longitudinal health claims data in Germany. PLoS One, 11: e0156876; Gurgel RK, Ward PD, Schwartz S, et al (2014) Relationship of hearing loss and dementia: a prospective, population-based study. Otol Neurotol, 35: 775–81; Amieva H, Ouvrard C, Giulioli C, et al (2015) Self-reported hearing loss, hearing aids, and cognitive decline in elderly adults: a 25-Year Study. J Am Geriatr Soc, 63: 2099–104.

[43] Livingston G, Sommerlad A, Orgeta V, et al (2017) Dementia prevention, intervention, and care. The Lancet.16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6

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				is prevented at mid-life, with 55 years being the youngest mean age in which the presence of hearing loss is shown to increase dementia risk. The study calls for better management and prevention strategies of hearing loss and other risk factors, to tackle the rising number of people with dementia.	
Action on Hearing Loss	Full	407 - 418	General	**Section 19 *'Palliative care: care towards and at the end of life'* should acknowledge the key requirement for good communication for people nearing the end of life**. An additional recommendation should be included in the guideline to address the communication needs of people who have dementia and hearing loss undergoing palliative care. Recommendation 114 suggests to involve the person and their family members or carers, however without proper communication support a person with hearing loss may be unable to share their needs and preferences. Promoting good communication can allow patients to feel empowered, and enhance patient autonomy and dignity, helping to improve the quality of their remaining life.[44]	Thank you for your comment. No evidence was found on hearing loss in palliative care, so the committee agreed it was not possible to make specific recommendations on this topic. However, they agreed this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." The committee agreed hearing loss would be a key comorbidity to address under that recommendation.

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[44] Feinberg LF. (2014). Moving toward person- and family-centered care. Public Policy Aging Rep, 24(3):97-101.

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				Question 3: Health and care professionals caring for people undergoing palliative care should be informed on the use and maintenance of hearing aids and should ensure hearing aids are working and being utilised effectively. Similarly, patients and carers should also be informed about assistive listening devices which can help reduce the stress and burden associated with difficulty communicating.	
Action on Hearing Loss	Full	163 - 172	General	**Section 8.1 aims to review how people living with dementia may be cared for when admitted to hospital, but fails to identify the additional communication needs that people with dementia may have due to hearing loss**. Please refer to comment 2.	Thank you for your comment. The committee noted this as an issue, but agreed that since no evidence was identified on hearing loss in people living with dementia admitted to hospital, it was not possible to make specific recommendations on this issue.
Action on Hearing Loss	Full	402	5-12	**The use of hearing aids and incidence of dementia is an important research recommendation which should be prioritised.** The significance of this research area is recognised by the James Lind Alliance, Priority Setting Partnership on Mild and Moderate Hearing Loss, which identifies the effect of early	Thank you for your comment. The committee noted this issue was already covered by the NICE guideline on hearing loss, which contains the following research recommendation: "In adults with hearing loss, does the use of hearing aids reduce the incidence of dementia?"

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				fitting of hearing aids on the rate of cognitive decline as a key research question.[45] Although currently evidence on the association between hearing aids and cognition is limited, existing evidence suggests a positive association. For example, a prospective study by Amieva et al (2015) showed no difference in the rate of change in MMSE score over the 25 year follow up period in participants with hearing loss using hearing aids compared to the control group (participants without hearing loss). In contrast, participants with hearing loss who did not use hearing aids declined more rapidly on the MMSE than the control group, the findings suggest that hearing aid use decreases cognitive decline.[46] Findings from Dawes et al (2015) study showed hearing aids to be associated with better cognition, which was independent of social isolation and depression. Suggesting that positive effects of hearing aid use on cognition may be due to improvements in audibility or associated	

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[45] James Lind Alliance. (2018). Mild to Moderate Hearing Loss Top 10. Available at: http://www.jla.nihr.ac.uk/priority-setting-partnerships/mild-to-moderate-hearing-loss/top-10-priorities.

[46] Amieva H, Ouvrard C, Giulioli C, et al. (2015). Self-Reported Hearing Loss, Hearing Aids, and Cognitive Decline in Elderly Adults: A 25-Year Study. Journal of the American Geriatrics Society, 63(10):2099-2104.

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				increases in self-efficacy, rather than social isolation or depression.[47] Furthermore, in a cohort study by Deal et al (2015) decline in cognitive function was found to be greatest among participants who did not wear hearing aids then compared to those who did.[48] The need to understand the association between hearing loss and incidence of dementia is imperative for reducing inequalities in health, in light of the proposals to decommission hearing aid provision across the country by several CCGs in recent years.	
Alzheimer's Research UK	Short	9	16	In England, the August 2017 diagnosis rate for over 65s was 68.2%, the diagnosis rate for under 65s was 39.2%. We welcome the inclusion of cerebrospinal fluid examination (CSF) and FDG-PET as methods to help diagnose dementia. Alongside other tests, such as cognitive tests, these diagnostic tests are an important method to get a more accurate	Thank you for your comment and your support for this recommendation. The committee noted there was already considerable research ongoing in the areas of early dementia diagnosis, and that therefore it was not appropriate to make additional research recommendations in this area, other than the one on amyloid imaging included in the draft version of the guideline.

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[47] Dawes P, Emsley R, Cruickshanks K, et al. (2015). Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. PLOS ONE, 10(3), p.e0119616.
[48] Deal J, Sharrett A, Albert M, et al. (2015). Hearing Impairment and Cognitive Decline: A Pilot Study Conducted Within the Atherosclerosis Risk in Communities Neurocognitive Study. American Journal of Epidemiology, 181(9):680-690.

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				diagnosis of Alzheimer's disease, especially in the earliest stages of the disease. Diagnosing dementia is a complex challenge, and doctors have to gather a range of clues to create a picture of what is going on in the brain. Most often, doctors will make a dementia diagnosis by assessing a person's symptoms and ruling out other potential causes of memory and thinking problems, but this approach doesn't always provide conclusive results. Alzheimer's disease is a progressive neurodegenerative disease, and the hallmarks of the disease are present years before any symptoms might occur. Current approaches to diagnosis are focused on the mild, moderate and severe stages and it is important healthcare professionals have a focus on diagnosing in the early stages. According to the Royal College of Psychiatrists' most recent National Audit of Memory Clinics 2014, only 52% patients received an early diagnosis. This is important as when new treatments become available they will be most effective in the earliest stages. In addition to the inclusion of CSF and FDG-PET, the Guideline should reference the importance of the NHS being responsive to developments in technology	

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				and ways to diagnose dementia, as they become available. A lumbar puncture is one of very few options available for getting a biological indication of processes that may be underway in the brain. As with any medical procedure, doctors need to carefully weigh the risk of side effects against the benefits a lumbar puncture can yield, and patients need to be fully informed about what is involved. It is important that the introduction of tests such as CSF and FDG-PET, and the use of existing cognitive tests, are accompanied by training for healthcare professionals, as well as training to improve their understanding of the pathology of Alzheimer's disease and being able to recognise the earliest signs. There also needs to be a focus on building sufficient capacity in the system to be able to improve diagnosis and support the use of these tests. The most recent Audit of Memory Clinics found that between 2013 and 2014, the number of patients seen by memory clinics increased by 31% on average, although available capacity did not increase significantly. This is a concerning	

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				trend if we are going to effectively support better, earlier and more accurate diagnosis for people living with dementia. We suggest there is a research recommendation focused on preparing the NHS for earlier diagnosis and the use of new technologies and cognitive assessment to develop the evidence base in this area.	
Alzheimer's Research UK	Short	9	16	We are concerned that a routine physical examination, including blood tests, is no longer recommended in the guideline. It is important to be able to rule out other possible causes of memory loss. This was part of the 2006 guideline and we think it should be retained. • The 2006 Guideline included a recommendation for a "physical examination and other appropriate investigations" NHS Choices recommends that your 'GP will ask about your symptoms and other aspects of your health, and will give you a physical examination. To help rule out other causes of memory problems, your GP will organise blood tests.'	Thank you for your comment. The committee agreed with the suggestion that it was appropriate to retain this recommendation from the previous guideline, and therefore "conduct a physical examination and undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline" has been added to the recommendation for initial assessment in non-specialist settings.

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Alzheimer's Research UK	Short	10	11	The current phrasing of the guideline implies that all suspected cases of dementia should be referred to a specialist memory assessment service. While we would support this approach, we would question whether there is sufficient current capacity in memory services to ensure all people with suspected dementia can be seen in a timely manner – especially if we are to improve diagnosing in the earliest stages. According to the most recent audit of Memory Clinics, published by the Royal College of Psychiatrists: • "Between 2013 and 2014, the number of patients seen by memory clinics increased by 31% on average, although available capacity did not increase significantly." • "The average waiting time from referral to assessment increased from 5.2 weeks in 2013 to 5.4 weeks in 2014, and waiting time from assessment to diagnosis increased from 8.4 to 8.6 weeks." While referral to a specialist memory service should be offered to all people with memory	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."

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				problems we recommend the Guideline allows more flexibility for people to be diagnosed in an appropriate setting, for example if a person is in the more severe stages, before being referred. This could speed up diagnosis for some patients and offers local level flexibility.	
Alzheimer's Research UK	Short	10	25	We are concerned that the language in the revised Guideline may result in the reduction in use of structural imaging where it is appropriate, by changing the wording from '***should***' to '***consider***' (see below). It is important clinicians use a range of tests to make an accurate diagnosis and structural imaging plays an important part in building that picture. We recommend keeping the wording used in the 2006 Guideline. 2018 Guideline: Dementia diagnosis in specialist dementia diagnostic services: "***Consider*** structural imaging to rule out reversible causes of cognitive decline." 2006 Guideline: "Structural imaging ***should*** be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."

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				establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear."	
Alzheimer's Research UK	Short	11	15	We think the Guideline should have greater reference to the different stages and severity of dementia, recognising diseases such as Alzheimer's as progressive neurodegenerative diseases. This includes greater reference to the mild, moderate and severe stages, and that the hallmarks of the disease are present years before any symptoms might occur. For example, recognising the difference between Alzheimer's Dementia and Alzheimer's disease. This will support greater understanding and awareness among healthcare professionals. Understanding severity of dementia is also important for the later guideline section on use of pharmacological interventions, as prescribing decisions are in part made according to the severity of the condition. In addition, given that the mental health care clusters, through which	Thank you for your comment. The committee noted that in many areas the evidence base only covered with particular dementia subtypes and at particular stages of severity. The committee agreed that wherever possible it was appropriate to try and extrapolate this evidence to the more general population of people living with dementia, as otherwise there was a risk of particular groups or dementia subtypes not being covered, solely because studies happened not to have been done in those populations (in particular in people with severe dementia). They agreed this in places led to a lack of specific recommendations for different settings, but believed this was a more acceptable situation than for whole situations not be covered due to a lack of evidence.

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				many mental health trusts, and therefore memory assessment clinics, get paid need to define stage of dementia, guidance on this would be helpful to support clinical practice.	
Alzheimer's Research UK	Full	General	general	Alzheimer's Research UK is the world's leading dementia research charity dedicated to causes, diagnosis, prevention, treatment and cure. Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, uniting the big thinkers in the field and funding the innovative science that will deliver a cure. Our mission is to bring about the first life-changing dementia treatment by 2025. Our vision is a world where people are free from the fear, harm and heartbreak of dementia. We focus our energies in four key areas of action to make this mission a reality. • Understand the diseases that cause dementia. • Diagnose people earlier and more accurately. • Reduce risk, backed by the latest evidence.	Thank you for taking the time to comment on the draft guideline.

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				- Treat dementia effectively. Through these important strands of work, we're bringing about breakthroughs that will change lives.	
Alzheimer's Research UK	Full	General	general	Alzheimer's Research UK welcomes the opportunity to comment on the revised 'Dementia: assessment, management and support for people living with dementia and their carers' guideline. We recognise there have been great advances in awareness and understanding of dementia in recent years, supported by initiatives such as the Prime Minister's challenge on dementia and associated implementation plan, as well as a focus on awareness and training for all healthcare staff through Health Education England. Overall, we are concerned that the revised guidelines for consultation somewhat retreat from the 2006 guideline, particularly in terms of ambition and breadth of coverage. We are also concerned at the short timescale in which to review and respond to the revised guideline, we urge NICE to give organisations	Thank you for your comment. The committee agreed it had made recommendations in those areas where there was clear evidence of benefits to people living with dementia and their carers. The committee noted that there were a number of recommendations in this guideline (such as providing a single point of contact, and those around staff training) that were supported by clear evidence and had the potential to make a major difference to people living with dementia, and hoped the focus on a smaller number of robust recommendations would help to ensure these were properly implemented. The consultation timescales for this guideline are standard ones for new guidelines or full updates of guidelines that NICE produces.

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				sufficient time to fully consider the impact of suggested changes, especially those that engage with people living with dementia.	
Alzheimer's Research UK	Full	General	general	As part of practitioner skills and competencies we note that no mention is made of the potential to encourage people to participate in dementia research. Given that recruitment of people to dementia studies is a well-recognised challenge in the field, we would highlight the need for all practitioners to promote research opportunities. These may be local studies but there is also Join Dementia Research, which as a national initiative, offers all people (both those with and without a diagnosis of dementia) an opportunity to register their interest in getting involved in research. Given the current lack of disease modifying treatments for dementia, research is the only way that we are going to make progress. According to a YouGov poll commissioned by Alzheimer's Research UK in 2015, whilst almost two thirds of the general public (62 per cent) would be willing to take part in dementia research, more than four out of five people (81 per cent) would not know how to volunteer. This is improving with the introduction of Join Dementia Research and this Guideline should play	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				a key role in further promoting and enabling opportunities to get involved in research. More than 34,000 people took part in dementia research in 2015/16, an increase of 156% over the previous two years. So far 187 NHS, University and commercial sites have used JDR. **There is a national target set by the Department of Health and Social Care for 25% of people with a diagnosis of dementia involved in research by 2020 (approximately 100,000 people), if we are to meet this target it is crucial that encouraging people to take part in research is part of the guideline.** The willingness of people to help research is vital for us to make progress. Join Dementia Research makes it easier for people to get involved in dementia research studies, we must embed Join Dementia Research in core NHS diagnostic pathways to ensure all people with a dementia diagnosis are offered the opportunity to take part in research. Alzheimer's Research UK's booklet 'Getting involved in dementia research' is a useful resource for those working across healthcare. It also outlines the benefits and reasons why people choose to take part in research, which benefits	

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				not only research but critically the individual taking part: - Studies can provide an opportunity to learn more about dementia and health. - People often feel research is something positive they can do in the face of a progressive condition. - Volunteers may feel part of a community with other people taking part. - Some studies involving people with dementia include regular monitoring by doctors. - Research will lead to outcomes that could benefit those taking part or future generations. We would also urge the Guideline to align with the Dementia Statements, relaunched in 2017 led by Alzheimer's Society alongside people living with dementia and their carers, which detail a right for people to know about research opportunities and be supported to take part: "We have the right to know about and decide if we want to be involved in research that looks at	

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				cause, cure and care for dementia and be supported to take part."	
Alzheimer's Research UK	Full	General	general	In 2016 Alzheimer's Research UK published 'Treatments of Tomorrow: preparing for breakthroughs in dementia'. The report made a number of recommendations for the system, including the need to set the foundations for early detection of the diseases that cause dementia. We urge the NICE Guideline to have a stronger focus and reference to the importance of early diagnosis, with the need to prepare the NHS for a cultural shift towards earlier detection of pathological changes in diseases like Alzheimer's, as when new treatments become available they will be most effective in the early stages. "As concluded by the National Screening Committee in 2015, it is not appropriate to introduce screening for dementia at this point, given the paucity of robust biological markers to identify those with or at risk of dementia, along with the lack of an effective early treatment that could improve outcomes. However, it is important that the health system is prepared for early detection when improvements in diagnostic	Thank you for your comment. The committee agreed with the importance of early and accurate diagnosis, both to ensure people living with dementia are fully informed about their condition, and so this information can be used to tailor treatment and management. The guideline contains a number of recommendations around tests to ensure an accurate subtype diagnosis. The committee agreed that, whilst at the current time there are only a limited number of treatments for particular dementia subtypes, this is likely to change in the future, and it would be important for this guideline to then be updated to reflect those changes.

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				technology make this a possibility. This is because the pathology of most of the diseases that cause dementia appear to develop years before symptoms occur and early treatments are likely to work best if they are given at the earliest possible stage. It is important to consider this now, because it is likely that capacity for infrastructure (e.g. brain imaging or cerebrospinal fluid testing) could be necessary, which will require additional resources, cultural changes and closer working between clinical disciplines. Early detection of the hallmarks of Alzheimer's disease is already required for several of the current large clinical trials of new treatments, learning from NHS sites where this is done well would help consider what changes could be needed."	
Alzheimer's Research UK	Full	General	general	The revised guidelines no longer make a recommendation regarding factors and interventions in mid-life for dementia risk reduction (2006 guidance 1.3.1.2), we think this should be reinstated. Given that risk factors for dementia are part of the scope of this guideline, and that since 2006 the evidence base in this area has been strengthened (ADI report 2014, Lancet Commission on Dementia 2017) there should be a	Thank you for your comment. The guideline did not contain a recommendation on risk factors for preventing dementia, and therefore it was not possible to make recommendations or research recommendations on this topic. However, the comments raised by stakeholders on the importance of this issue have been fed back to the commissioning team within NICE for consideration in the planning of future NICE guidance.

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				reference to dementia risk reduction for all ages within the guideline. We would also suggest that there should be a research recommendation to consider how individuals identified at high risk of developing dementia, through services such as the NHS Health Check, could be tracked and monitored to determine if they are at greater risk of developing dementia.	
Alzheimer's Research UK	Full	General	general	We are concerned that the recommendations in the guidelines do not reference the Dementia Core Skills Education and Training Framework (2015) that was developed by Skills for Health, Health Education England and Skills for Care. The framework offers a tiered approach to the range of skills and competencies that health and care practitioners should develop in a range of clinical settings for dementia care. Given that many patients in a range of acute clinical settings have dementia it is crucial that health and care staff across the NHS have consistent skills and competencies. A more explicit reference to this Framework would strengthen the guideline.	Thank you for your comment. The committee decided not to refer to this document as part of the recommendations themselves, as these needed to be based on the evidence identified from the literature review. However, it was agreed to be appropriate to refer to this document within the list of relevant other guidance at the start of the document, alongside other Department of Health frameworks.

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Alzheimer's Research UK	Full	P161/2	general	We support the approach that regularity of follow-up should be flexible according to need and preferences. However the guideline should specify a minimum follow-up interval to ensure patients are not lost in the system and are monitored. Including monitoring use of medications and care and support plans, and an individual's ability to cope with their dementia. We also note that there is no guidance about primary care responsibilities should a memory assessment service (or equivalent) discharge a patient.	Thank you for your comment. The committee considered whether it could specify a minimum follow-up interval, but agreed there was currently no evidence to inform that decision. They were also concerned that such a minimum standard would be interpreted as applying to a large section of the population living with dementia, when in fact people with complex needs would need to be seen considerably more often. The committee also noted the guideline already contained a recommendation around the monitoring of care and support plans, and specified that review dates needed to be clearly specified within those. The committee agreed that there was no evidence to make specific recommendation on how to follow-up people discharge from specialist services but noted that a key issue was that areas had a suitable route for people to get back in to specialist services if their needs changed.
Alzheimer's Research UK	Full	98	general	We note that a range of diagnostic assessments are recommended for primary care and that they have similar specificity and sensitivity. We also recognise that many of the tests focus on simple memory recall and therefore can be less helpful in cases where memory loss is not the predominant symptom. We suggest there is a research recommendation made to develop the evidence base in this area.	Thank you for your comment. The committee agreed this was an area of potential future research. However, they noted that, compared to many other areas of the guideline, a reasonable number of studies had been conducted here, and more were known to be ongoing. Therefore, they agreed it was not as high a priority to recommend future research here as in other areas of the guideline.

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Alzheimer's Research UK	Full	170	General	We are concerned that the approach of the committee to potential change to clinical practice is weighted towards pragmatism rather than clinical excellence. To dismiss the TEAM trial model of care because it would be hard to deliver and result in significant acute care reorganisation suggests that the practical challenges of service delivery have more priority than optimising care pathways.	Thank you for your comment. The committee agreed that if the TEAM trial had demonstrate meaningful benefits from the model of care studied, these would justify the potential difficulties in transitioning to such a model of care. However, they noted that the trial had not found a meaningful difference in the outcomes of people living with dementia and their carers, and there was therefore no evidence on which to make a positive recommendation for this approach at this time.
Alzheimer's Research UK	Full	189	Quality of evidence	Given that the committee noted a lack of evidence for the evaluation of interventions for diet, obesity, alcohol and smoking, we would suggest that there should be a research recommendation to address this gap in the evidence base.	Thank you for your comment. The committee discussed this and agreed that currently research around preventing dementia was likely to be of higher priority than research in slowing the progression of established dementia. However the committee were unable to make research recommendations on preventing dementia, as this topic was beyond the scope of the guideline.
Alzheimer's Research UK	Full	208	23-24	We recognise that costs related to informal care can be hard to quantify, however for a condition such as dementia, which relies so significantly on informal carers, to not adequately consider these costs could result in an under-representation of the scale of the problem. We recommend further research to understand how wider cost impacts, including informal care costs, could be measured and the impact this	Thank you for your comment. Although we recognise that costs related to informal care are significant, the NICE reference case does not include informal care costs not borne by the NHS, as set out in the NICE guide to the methods of technology appraisal: https://www.nice.org.uk/process/pmg9/chapter/the-reference-case

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				could have on assessing cost-effectiveness for interventions for dementia. The total cost of dementia is over £26bn. The majority of dementia costs per year are due to informal care at £11.6bn (44.2%), with social care costing £10.3bn (39.0%) and healthcare costs £4.3bn (16.4%).	
Alzheimer's Research UK	Full	376	general	We are concerned that there is a lack of detail regarding the challenge of dementia as a multi-morbidity. While the NICE guidance on multi-morbidities offers an overview, there are specific and unique considerations of how dementia may impact on other conditions - for example someone may forget to take a prescription for diabetes or may not remember to attend a clinical appointment to manage their blood pressure. We would suggest that more detailed guidance should be developed on dementia and co-morbidities. We recommend building on advice included in the 2006 Guideline: "At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression	Thank you for your comment. The committee agreed that the management of comorbidities in people living with dementia was an important issue, and were disappointed with the lack of evidence available on which to make recommendations. They therefore made a number of research recommendation, in the hope that more evidence will be available for future updates of the guideline. Since the draft version of the guideline, additional recommendations have been added around hearing tests and eye tests for people living with dementia, as these were identified as particularly common comorbidities. The committee agreed that in the absence of evidence on how people living with dementia should have comorbidities managed differently from people without dementia, the key issue was ensuring equivalent access to appropriate services. This was what led to the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				and psychosis, to ensure optimal management of coexisting conditions"	
Alzheimer's Society	Short	3	12	The estimate of the number of people with dementia in the UK should be updated to 850,000 – the figure currently used by many stakeholders including Alzheimer's Society, DH, NHSE, PHE and ARUK.	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years.
Alzheimer's Society	Short	3	16	The number of people newly diagnosed each year should be replaced with a more current figure than 2011. There are 209,600 new cases of dementia a year in the UK (Matthews, F.E et al (2016). A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. Cognitive Function and Ageing Studies (CFAS) Collaboration).	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years.
Alzheimer's Society	Short	6	18-24	This recommendation should include the importance of determining the effect of dementia on **co-morbidities** and their management and vice versa. Around 7 in 10 people with dementia have another long-term health condition and dementia can impact on the person's ability to manage this. Person-centred care should consider the person as a whole, therefore considering co-	Thank you for your comment. The guideline contains a specific review question on the management of comorbidities in people living with dementia, and recommendations on this topic are included in that section of the guideline.

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				morbidities is an essential part of this and it would be useful to recognise this here.	
Alzheimer's Society	Short	7	5	The content of this section is all things that happen after diagnosis and so it is potentially confusing and difficult to follow in practice for this section to precede the 'diagnosis' section of the guidance.	Thank you for your comment. This concern was noted, but it was agreed to keep this section at the start of the document, to give it as high a prominence as possible within the guideline.
Alzheimer's Society	Short	7	10	This point could include reference to supported decision making and advocacy. These are mentioned in section 1.3 on care co-ordination but could be given prominence here.	Thank you for your comment. The committee did not want to duplicate recommendations across the guideline for risk of confusion, and agreed these issues were addressed in section 1.3.
Alzheimer's Society	Short	7	12	This should include provision for review of any such structured document.	Thank you for your comment. The committee noted this suggestion, but agreed that in the absence of any evidence it was not possible provide more detail or guidance than that currently included in the recommendation.
Alzheimer's Society	Short	7	12	This should include provision for involvement of a carer in the compiling of the tool with the person's consent or on a best interests basis in line with the MCA if the person is unable to consent.	Thank you for your comment. The committee noted this suggestion, but agreed that in the absence of any evidence it was not possible provide more detail or guidance than that currently included in the recommendation.
Alzheimer's Society	Short	8	3	In our work we hear from many people who did not receive information after their diagnosis. For	Thank you for your comment. The committee agreed the guideline was very clear that information should be provided

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				our Turning up the volume report some people we interviewed told us they felt like they had been left to fend for themselves, with no offer of help and little hope for assistance in the future. We also found that less than a quarter of the public (22%) who responded to a survey for the report agreed with the statement that they would know where to find care and support if they had dementia. We don't believe that there is enough direction in this point to ensure that information is provided to everyone diagnosed with dementia. The full document (page 150) says 'The committee noted that occasionally people living with dementia are diagnosed as having dementia but are then 'forgotten' by the system.' The full document also says 'The committee agreed that the positive overall findings from the studies on case management provided robust evidence that there should be a single person responsible for coordinating care. Otherwise, it is common for health and social care professionals to assume that other members within the team are coordinating care when they are not.'	to people "at diagnosis", that they should be directed to other services for information and support, that they should be offered follow-up appointments, and that they should know where they can get more information on if their needs change. The committee agreed that, were these recommendations to be fully implemented, they should cover the issues raised. In particular, they noted that since these points should be addressed at diagnosis, it would be the responsibility of the person delivering the diagnosis to ensure the appropriate information was supplied.

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				To avoid people being left without information, the guidelines could provide further direction in specifying who should provide this information, or that provision of information should be documented in a single place, accessible to all people that may be providing care (such as in the care plan), so that it is known whether information has been provided.	
Alzheimer's Society	Short	8	3	As highlighted above information provision is vital and we very much welcome its inclusion in the guidance. However there could be some consideration of not overwhelming people with too much information at the point of diagnosis, and the importance of providing a follow up appointment after diagnosis, and to provide more information at this point. This follow up could be with a Dementia Adviser, GP, or memory clinic staff for example. At the time a diagnosis is given many patients are in a state of shock, and in some cases denial, and in need of time to digest the diagnosis. There is recognition of this in the full document which says 'being diagnosed with	Thank you for your comment. The committee agreed with the importance of their being further opportunities for providing information and support, and the guideline includes a recommendation to "direct people and their family members or carers (as appropriate) to relevant services for information and support" after diagnosis. They also agreed providing carer with information was important, and noted the recommendations on information were phrased as "provide people living with dementia and their family members or carers (as appropriate) …"

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				dementia can be a stressful and traumatic experience' (page 98). Our research for our Turning up the volume report found that a sense of hopelessness and anxiety can occur at diagnosis, particularly associated with a feeling of losing identity. The full document says: 'The committee noted that the evidence demonstrated that most people living with dementia expressed a clear preference for being offered information early, usually soon after diagnosis'. It is important to provide a follow up appointment after diagnosis, to provide more information after the individual has come to terms with the diagnosis. It is also important to provide information to carers at the point of diagnosis.	
Alzheimer's Society	Short	8	3	This list should also include **information that explains how people can participate in research**. People with dementia and people with mild cognitive impairment should be given the option	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all

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				to participate in research at the earliest opportunity. National Institute for Health Research figures (from 2015) show only 5% of people with dementia are involved in research studies. Many people are not routinely offered information on research opportunities or are offered this when it is too late to take part. As government and charity funding for dementia research has doubled, researchers urgently need more people to participate in studies. There is a national ambition for a cure or disease modifying treatment by 2025 which if to be achieved will require increased participation in dementia research, especially involving people in the very early stages of disease. Taking part in research also allows people to learn more about the condition and can help people feel they are contributing towards the development of future treatments. The importance of research to people with dementia is reflected in the new Dementia Statements (which reflect things people with dementia have said are essential to their quality of life), which include 'We have the right to know about and decide if we want to be involved in	stages of the condition) about research studies they could participate in."

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				research that looks at cause, cure and care for dementia and be supported to take part'. There is also evidence of willingness to take part in dementia research – in a YouGov poll for Alzheimer's Research UK (2015), 62% of people said they would be willing to take part in dementia research, but only 19% thought they would know how to volunteer. This could specify the national research participation initiative, Join Dementia Research, developed by the National Institute for Health Research in partnership with Alzheimer Scotland, Alzheimer's Research UK, and Alzheimer's Society.	
Alzheimer's Society	Short	8	3	This list could also include explaining the link between dementia and vascular risk.	Thank you for your comment. The committee noted this was a relevant issue, but agreed it did not come through the evidence identified in the guideline as being as high a priority as the other issues mentioned, and the committee therefore decided not to mention this in the recommendations. The committee noted the topics/items mentioned were not meant

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					to be a full list of everything that should be discussed, merely a minimum list of things that definitely should be.
Alzheimer's Society	Short	8	8	This point could clarify exactly what needs to be said about driving to make this easier to implement in practice.	Thank you for your comment. The committee noted that the exact information that needed to be given about driving would differ between individuals (in particular, based on their subtype diagnosis). They agreed the key practical issue was informing people about their responsibilities to inform the DVLA and their insurer.
Alzheimer's Society	Short	8	18	We welcome that this point says 'ask the person' which implies asking face to face rather than asking via a form. This is important as the individual needs to understand what is being asked around consent to share information, and it is important that if the person is happy for information to be shared with a carer, that this happens, as there are many benefits to this. In current practice, sometimes forms are given to patients asking for consent for sharing information and often the forms are not understood and can be left uncompleted. This point could emphasise the **importance of asking in person**, the importance of the individual understanding what is being asked, and the	Thank you for your comment, and your support for this recommendation. The committee agreed that the important focus here was on specifically asking the person's opinions on these issues, and consent for information sharing if applicable.

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				importance of gaining consent to share information.	
Alzheimer's Society	Short	8	18	This recommendation should make reference to the **new data protection legislation**, to ensure it is fit for purpose with this new legislation and that practitioners know that this guidance adheres to the new legislation, so they can be more confident in following this guideline.	Thank you for your comment. A reference to the new data protection legislation has been added to the list of relevant legislation at the start of the guideline.
Alzheimer's Society	Short	8	23	This needs **clarification on the definition of 'the person's records**', as this could imply a primary care record, a care plan or a social care record. 'Tell all relevant services what the person has decided' also doesn't seem practical – this could be time consuming and could miss some services that aren't known about or that might be used in the future. The decision should be noted in a single record accessible to all professionals across different settings providing care for the individual. This could be the care plan. There should be consistency throughout this guidance in documenting information about the	Thank you for your comment. The committee agreed some confusion has been introduced in this recommendation by the statement to "tell all relevant services what the person has decided", which has now been deleted. The committee noted the importance of having information contained in a single record so it was accessible to multiple services, but agreed that in the absence of evidence, they could not give specific guidance on how this system should be organised.

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				individual's care in a single place that can be accessed by all the various people providing care and support to the individual in different settings.	
Alzheimer's Society	Short	8	25	This should be consistent with point 1.3 in the guidance (page 13, line 22), which recommends providing people with a single named person responsible for coordinating their care and provides information about available services and how to access them (page 13, line 28). Instead of directing people to the relevant services, they **should be directed to their single named care coordinator**.	Thank you for your comment. A cross-reference has been added here to the recommendation on care coordination.
Alzheimer's Society	Short	8	27	We are concerned about the wording of this recommendation and that if used in practice, if a person says they do not want to be contacted again at a later date, they may not receive further support. After diagnosis some people may be in shock and may say they would not like to be contacted again, particularly if they are in denial, however they may change their mind at a later date. It is important that the offer of support is proactive and not reliant on the patient actively seeking	Thank you for your comment. The committee noted this concern, and agreed that there was a significant issue in people being lost to the health and social care system after diagnosis. It was for this reason the guideline included recommendations for follow-up after diagnosis, people being offered future opportunities for contact, and people being given clear instructions about how to get more information and support, should they need it.

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				help, which they may not do before reaching crisis point. This recommendation should be written in line with the full document (page 130) that recommends 'people living with dementia be **offered information and opportunities for discussion on an ongoing basis'**.	
Alzheimer's Society	Short	9	6	**There is a lot of jargon and different terms used in this section**, which we have found to often be confusing to people with dementia. Added to this we have found that people are often given conflicting and sometimes inaccurate information. Therefore, we feel that it is crucial in this section that the importance of accurate, clear and accessible information on advance care planning is given. Also it is crucial that any jargon used is explained, including what planning ahead actually is.	Thank you for your comment. The committee agreed that all these concepts would need to be properly explained for advance care planning to work properly. However, they also noted that most of the terms included here had a specific technical meeting, and therefore it was important to maintain that wording in the recommendations.
Alzheimer's Society	Short	9	7	Lasting power of attorney for property and affairs should be listed as well as health and welfare, as many people will find they need both.	Thank you for your comment. The committee agreed with this suggestion, and this change has been made.

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Alzheimer's Society	Short	9	14	This statement is indicating that the professional will note down the advance statements and decision, which is a fantastic idea for people as this would make it easier for people to do this. If professionals were involved in this way then it may lead to an increase in people planning ahead in this way. However, for this to happen properly and be of real benefit to people the **staff doing this will need to be properly trained**, especially as for an advance decision to be valid there are certain legal requirements that need to be met.	Thank you for your comment. The committee agreed that staff involved in advance care planning would need appropriate training to ensure they fulfil the appropriate legal requirements in the documentation.
Alzheimer's Society	Short	9	16	As a whole the section needs to emphasise **joint working** across specialties and services.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service, rather than decisions being made jointly between primary and secondary care. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has

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					been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Alzheimer's Society	Short	9	16	There is no mention in this section of **diagnosis in care homes** and how this should be done. By only covering diagnosis in specialist settings this could give the impression that people in care homes that develop dementia should be referred to a specialist setting, when for many of these people this is not feasible. Alternatively, it suggests that people who develop dementia in a care home do not need to be diagnosed. People living in care homes should have the same rights as people living in the community, and should have an equal right to a diagnosis. There are many benefits to diagnosing dementia in care homes including:	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their

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				• Helping care home staff understand behaviours and how these should be treated • Prompting a review of medication that may be worsening symptoms • Supporting family members by helping them understand changing behaviours and how they can best support the person • Some care home residents may develop mild or moderate dementia and symptoms which may be helped by pharmacological treatments. • Allowing for advance care planning if not done already.	home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment.”
Alzheimer’s Society	Short	9	18	The full guidelines say ‘the person considering referral should **carry out routine investigations and tests** to rule our reversible causes of cognitive impairment’ but this is not explicit in the short guidelines. The full guidelines (page 99) state that although no data was found to support this, ‘the committee considered this to be general good practice based on their experience and made a	Thank you for your comment. The committee agreed with the suggestion, and agreed that it was appropriate to retain the recommendation from the previous guideline, and therefore “conduct a physical examination and undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline” has been added to the recommendation for initial assessment in non-specialist settings.

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				recommendation to reflect this, and agreed that failing to rule out reversible causes of cognitive decline may lead to over referrals, both wasting resources and causing unnecessary stress to individuals'. This should justify inclusion in the short guidelines. At the moment this is only implicit later in the guidance in the statement 'if reversible causes of decline have been investigated' (page 10, line 12). This is not clear enough and could lead to clinicians not doing these important tests, as stated above, leading to potentially unnecessary stress to individuals and waste of resource. This recommendation needs to include carrying out routine investigations and tests as appropriate to presentation, to rule out reversible causes of cognitive impairment. For example: Assessing the anticholinergic burden of medications Physical examination Blood tests e.g. for blood glucose, thyroid Screening for infections Checking blood pressure	

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				Checking pulse	
Alzheimer's Society	Short	9	18	Taking a history shouldn't just include cognitive and behavioural symptoms but should also consider a **wider range of symptoms, notably psychological (mood changes, apathy, psychoses) and physical changes**. This supports a person-centred approach and is in line with the principles asserted at the start (page 6).	Thank you for your comment. The committee agreed with these suggestions, and therefore the history has been expanded to include "cognitive, behavioural and psychological symptoms" and reference has been included to a physical examination.
Alzheimer's Society	Short	9	21	This is a good addition of including someone who knows the person well in taking a history.	Thank you for your comment and your support for this recommendation.
Alzheimer's Society	Short	9	24	**We are surprised not to see the inclusion of the GPCOG and would like to see this included**. Whilst the full guidelines (page 99, page 101) state that evidence for GPCOG is from a screening study rather than a study in people with suspected dementia, the GPCOG is routinely used in GP practices.	Thank you for your comment. The committee were aware of the use of the GPCOG in practice. However, they noted that the GPCOG has only been tested as a screening test, and no evidence currently exists on the accuracy of the test in a population of people with suspected dementia. The committee noted that studies are likely to find better diagnostic accuracy in an unselected population than one with suspected dementia (as many people in the study will have no cognitive impairment, and therefore will be easily classified by the test), and therefore agreed it was appropriate to

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				The GPCOG also has the benefit of being used with both the patient and a family member. There is also evidence showing that the GPCOG is not influenced by someone's cultural and linguistic background, making it useful in multicultural patient settings (Basic, D., Khoo, A., Conforti, D. et al. (2009) Rowland Universal Dementia Assessment Scale, Mini-Mental State Examination and General Practitioner Assessment of Cognition in a multicultural cohort of community-dwelling older persons with early dementia. Australian Psychologist 2009; 44(1):40-53). The full document also notes that among three cognitive tests, the GPCOG was considered the most cost effective option for the NHS.	recommend only those tests shown to have sufficiently good properties in the relevant population. The evidence in the health economic study which found the GPCOG to be the most cost-effective test was also taken from a screening study, and comparing data on screening for the GPCOG to data from a suspected dementia population for the other tests is likely to bias results in favour of the GPCOG, and therefore the committee agreed the evidence was not sufficient to include the GPCOG on the list of recommended tests.
Alzheimer's Society	Short	9	24	There needs to be reference here to **people without English as a first language or with other communication needs**, and that the standard memory tests may not be appropriate. The full document (page 102) acknowledges that 'some tests (e.g. MoCA) are less robust in certain	Thank you for your comment. The committee agreed there were a range of issues that could affect interpretations of test scores, including language, education, learning disabilities or age. It was for this reason the committee agreed it was not appropriate to set cut-offs to use for the particular tests, but they should instead be considered alongside a broader assessment including a history (including cognitive, behavioural

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				population groups due to cultural differences'. It says for this reason cut offs are not specified, but more than this, the guidelines should include a general reflection on the importance of recognising cultural differences in these tests.	and psychological symptoms), a physical examination and appropriate blood and urine tests to exclude reversible causes of cognitive decline.
Alzheimer's Society	Short	10	5	We welcome this point not to rule out dementia because of a normal score on a cognitive test.	Thank you for your comment and your support for this recommendation
Alzheimer's Society	Short	10	5	This could include specific reference to younger people that may do well on cognitive tests.	Thank you for your comment. The committee agreed it was not appropriate to specify cut-offs for tests because of various factors (including age) that affect response. They also agreed that because there were a large number of factors that could affect response (age, education, first language, learning disabilities), and that therefore it was not appropriate to specify a list of things that should be taken in to account.
Alzheimer's Society	Short	10	16	This point seems to imply that in all cases where rapidly-progressive dementia is **not** suspected, there is no need for referral to a neurological service, but other atypical cases, such as young onset and inherited dementia, could benefit from **referral to neurology** also.	Thank you for your comment. The committee agreed this recommendation referred to a specific circumstance where referral to a neurological service was appropriate, but did not preclude people from referring to those services in other circumstances, if clinically appropriate.
Alzheimer's Society	Short	10	16	This is an example where the guidelines could benefit from reference to **more integrated**	Thank you for your comment. The committee discussed this but noted the studies looked at did not consider joint working,

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				working. A better recommendation would be for joint working with a neurological service.	and therefore it was not possible to make this part of the recommendation.
Alzheimer's Society	Short	10	19	This should highlight that people with a learning disability, particularly those with Down's syndrome, are at a greater risk of developing dementia at a younger age.	Thank you for your comment. The committee agreed with this point, and made the following comments in their discussion of the diagnostic evidence in the full guideline: "The committee agreed that physicians should be aware of the additional challenges of diagnosing dementia in certain vulnerable groups, such as people with learning difficulties and Down's syndrome, and those people with language and sensory impairment, lower educational levels and a low standard of literacy. Whilst the evidence base did not allow them to make specific recommendations for how the diagnostic pathway should be different for these groups of individuals, they agreed that it was important that people from these more difficult to diagnose groups should be assessed by a clinician with specialist skills in those areas, who would be familiar with the difficulties and able to make appropriate adaptations to the process used."
Alzheimer's Society	Short	10	22	This heading refers to diagnosis in specialist services and the previous heading refers to assessment in non-specialist settings. This would seem to imply that diagnosis shouldn't happen in non-specialist primary care settings, however there are examples of this being done, for example in Salford. In some cases, where primary care staff are appropriately trained, and for cases	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that some stakeholders interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and

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				that are more severe, **diagnosis in primary care** can be better for both the patient and the system. One example of diagnosis in primary care (in Gnosall) is outlined here in the [Models of Dementia Assessment and Diagnosis: Indicative Cost Review]() from NHSE.	treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Alzheimer's Society	Short	10	23	**This section as a whole is not clear or logical to follow.** Recommendations 1.2.12-1.2.22 could be moved and put under 1.2.11. We note also that some of the guidance linked to in 1.2.11 contradicts some of the later guidance in 1.2.12-1.2.22. There needs to be more clarity on what tests are being recommended here and in what circumstance.	Thank you for your comment. This section has been restructured to draw a clear distinction between things that should be performed as part of the initial specialist assessment, and additional tests to consider only if it is still not possible to diagnose a subtype after initial assessment. An additional recommendation has now been added ahead of these other tests, to make clear they are not appropriate or necessary for everyone undergoing diagnosis. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."

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				There could also be a general point on using appropriate diagnostic tests responding to the need of the individual, considering age, nature of onset and clinical history, to allow clinical freedom to do the appropriate thing for patient.	
Alzheimer's Society	Short	10	23	The wording should be changed to 'consider' a test of verbal episodic memory, to allow for consideration of non-memory presentations.	Thank you for your comment. The recommendations have been rewritten to make clear this should be a test of verbal episodic memory as part of a wider cognitive test, not that a test of this single domain is sufficient.
Alzheimer's Society	Short	10	25	Structural imaging can also support diagnosis of dementia subtype. This should say 'to rule out reversible causes of cognitive decline **and to support subtype assessment'** The current guidelines reflect this in 'Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis.' Using structured imaging only to rule out other causes of cognitive decline would be a big difference to international practice.	Thank you for your comment. The committee agreed with this suggestion, and the recommendation on structural imaging has been changed to "rule out reversible causes of cognitive decline and to assist with subtype diagnosis"

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Alzheimer's Society	Short	10	25	In line with the above, this recommendation should also be made stronger, to say 'offer' rather than 'consider'. Similarly, the current guidelines say 'structural imaging **should** be used'. There could be an addition to say unless this is likely to cause distress or if the diagnosis is already clear. We are concerned that the softer recommendation of 'consider' may lead to scans not being done to save money, which could lead to missing identifying a structural cause and missing something that may help with management. Most national guidelines suggest that structural neuroimaging is part of routine clinical assessment of dementia.	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."
Alzheimer's Society	Short	11	5	Semantic dementia is a type of primary progressive aphasia (see Gorno-Tempini 2011 source cited) and so the text here should read 'primary progressive aphasia including semantic dementia'.	Thank you for your comment. The committee noted this but agreed the current wording used in the guideline was sufficiently clear to signpost people to the appropriate set of criteria.

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Alzheimer's Society	Short	11	15	**This point needs more clarity** – if the diagnosis is uncertain after what? Also, does this mean if the diagnosis of dementia or the dementia subtype is uncertain? This links to the general lack of clarity of the recommendations in this section. Some consensus guidelines recommend CSF for patients under 65 or in atypical clinical presentations of Alzheimer's disease).(Hort J, O'Brien JT, Gainotti G, et al, on behalf of the EFNS Scientist Panel on Dementia. EFNS guidelines for the diagnosis and management of Alzheimer's disease. Eur J Neurol 2010; 17: 1236–48).	Thank you for your comment. This section of the recommendations has been restructured to make clear that these tests are referring to a situation where: "• it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management"
Alzheimer's Society	Short	11	17	Consideration should also be given as to how it would be implemented in practice by professionals outside of neurology, in whom lumbar puncture is not generally part of routine clinical practice. Such a change may require a change in skillset.	Thank you for your comment. The committee noted there are issues around access to CSF examination in certain areas, but agreed the evidence showed these test could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations.
Alzheimer's Society	Short	11	28	This statement isn't quite accurate – the older a person is the less good the test is for a positive predictive value, however it remains good for a negative predictive value.	Thank you for your comment. The committee agreed with this point, and for clarity the recommendation has been amended to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination."

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Alzheimer's Society	Short	12	3	Whilst it is not appropriate to use Apolipoprotein E genotyping or electroencephalography in the diagnosis of Alzheimer's disease, this point may lead people to not use EEG at all. However in people with epilepsy, and people experiencing seizures, an EEG may be appropriate.	Thank you for your comment. The committee agreed that, for clarity, this recommendation should be modified to "do not use electroencephalography to diagnose Alzheimer's disease." In the absence of evidence, the committee agreed it was not possible to make a more positive recommendation about when it might be used.
Alzheimer's Society	Short	12	24	Whilst the full document states that this recommendation is not in conflict with the dementia CQUIN, now part of the standard contract for hospitals, carrying out cognitive assessments on patients over 75 with an unplanned hospital admission, which could be considered a form of case finding, we believe this could appear to be in conflict with the CQUIN, and should be clarified.	Thank you for your comment, and for pointing out this error. This section of the guideline has been rewritten to make clear that this guideline does not affect the interpretation of the CQUIN: "The committee noted that case finding for dementia was introduced in acute hospitals as part of the Commissioning for Quality and Innovation (CQUIN) 2013/14 guidance, and that the committee's recommendations should be interpreted as applying to situations outside this existing guidance."
Alzheimer's Society	Short	13	13	**This recommendation lacks clarity**. It says to refer a person to a memory service, but they would already be in a memory service for diagnosis. Whilst it is good that the recommendation highlights the importance of a multidisciplinary service, it is unclear what is meant by 'a memory	Thank you for your comment. The committee agreed it was appropriate to reword this recommendation as "ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service." The committee agreed they would have liked to be able to make more specific recommendations on how these service

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				service or equivalent hospital or primary-care-based multidisciplinary dementia service' and what this looks like in practice.	should be organised, but this was not possible based on the evidence available.
Alzheimer's Society	Short	13	16	The wording of 'a choice of flexible access or prescheduled monitoring appointments' is **quite vague** and unclear.	Thank you for your comment. The committee agreed they would have liked to be able to make more specific recommendations on how these service should be organised, but this was not possible based on the evidence available.
Alzheimer's Society	Short	13	22	The word **'integrated'** should feature in this section a lot more. There are different models of care coordination but integration across settings is key.	Thank you for your comment. The guideline contained a specific review question on the integration of health and social care services, but only a limited amount of evidence was identified and the committee agreed it was not possible to make more directive recommendations than those currently included.
Alzheimer's Society	Short	13	23	Although implied, this could benefit from stating that **care coordination should take place as soon as possible**.	Thank you for your comment. To address this, a cross-reference has now been added from the recommendation on information to give at the time of diagnosis, to the recommendation on care coordination.
Alzheimer's Society	Short	13	23	We welcome the recommendation for a single person coordinating care. The full document states 'The committee agreed that the positive overall findings from the studies on case management provided robust evidence that there should be a single person responsible for coordinating care' however this does not state	Thank you for your comment. The committee noted this point, and agreed that in practice this role was sometimes carried out by someone who is not a health or social care practitioner. However, they agreed that since the evidence identified all had people from these roles carrying out the care coordination (specifically either nurses, social workers or occupational therapists) it was appropriate to retain this wording in the recommendation.

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				that there is evidence showing this person should be a 'health or social care professional'. We are concerned by this wording as often the person coordinating care will be a Dementia Adviser / Dementia Support Worker / similar role from the third sector. These roles can be the link between primary and secondary care, the voluntary sector and see people across the whole pathway, and be of great value both to the individual and to health and social care professionals. We would suggest that it is most important that the person coordinating care should be trained with appropriate skills and experience in dementia care and support,; not that they are a health or social care professional. We recommend therefore that this line should state 'Provide people living with dementia with a single named person trained with appropriate skills and experience in dementia care and support, who is responsible for coordinating their care.'	

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Alzheimer's Society	Short	14	3	This bullet point needs more detail to recognise the importance of the presumption of capacity and supporting decision-making in line with the Principles of the Mental Capacity Act. There also needs to be more detail on best interests decision-making for people who do lack capacity, in line with Section 4 of the MCA. This includes amongst other things, consideration of the wishes, feelings, beliefs and values of the person.	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to both the Mental Capacity Act and the Care Act within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
Alzheimer's Society	Short	14	6	We feel that this needs to go one step further, and place onus onto the professional to arrange advocacy if needed and appropriate.	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to the Mental Capacity Act within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
Alzheimer's Society	Short	14	7	This should say 'advocacy services' not 'advocate'	Thank you for your comment; this has been changed as suggested.
Alzheimer's Society	Short	14	7	This needs more clarity on 'if appropriate to the immediate situation'	Thank you for your comment. The committee noted that the circumstance in which involving an IMCA were needed were detailed in the Mental Capacity Act (and the accompanying Code of Practice). The committee agreed that rather than these issues being considered individually within a condition-

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					specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to the Mental Capacity Act within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
Alzheimer's Society	Short	14	9	This should specify there should be one care plan for one person, which should be holistic, not condition or setting specific. This would be in line with the person-centred principles outlined at the start.	Thank you for your comment. This recommendation has been amended to make clear that people developing a care and support plan with a person living with dementia should "ensure it contains information on the management of any comorbidities the person has."
Alzheimer's Society	Short	14	9	This could benefit from referring to the NHSE Dementia: Good Care Planning document which provides further details on care planning. Currently within these recommendations there is not enough clarity on what a care plan is, how it should be used, and its value.	Thank you for your comment. This resource has been linked to as suggested.
Alzheimer's Society	Short	14	9	This could include the importance of people knowing where the care plan is, how to access it, and people knowing that they have them.	Thank you for your comment. The committee agreed with this suggestion, and an additional step has been added to that recommendation to "provide a copy of the plan to the person, or their family members or carers (as appropriate)."

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Alzheimer's Society	Short	14	12	This could include the need to be aware that **a review may be needed sooner than planned for**, and the need to ensure that the individual and their carer are aware that they can request a review sooner too. Dementia is not predictable, and so changes to someone's support needs can change quite quickly and generally not when planned. This is reflected in the full document (page 162) which says 'focus more upon an emergent and flexible approach to reviewing people living with dementia and addressing person-centred need based upon a multidisciplinary co-ordination of care' and (page 161) 'for typical patients, only having routinely scheduled appointments and standard structured assessments may not deal with the reality of situations experienced by people living with dementia. It agreed that reviewing people living with dementia requires a flexible approach and is dependent upon individual needs, rather than reliant upon a prescriptive approach. The committee recognised that a flexible approach would have different implications at each stage of the dementia trajectory. People living with more severe dementia may also be living with multiple	Thank you for your comment. The committee agreed that, in common with many other conditions, there are a whole range of factors that could require a review to take place earlier than scheduled. However, they agreed the key part of this recommendation was around ensuring there is a maximum time scheduled until the care plan will be reviewed, to ensure that people living with dementia are frequently reviewed, and are not lost to the system through a lack of contact.

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				comorbidities, which may require more rapid reviews and more frequent follow up'	
Alzheimer's Society	Short	14	12	This could state that as a minimum the care plan should be reviewed annually (as recommended in the NHSE Dementia Good Care Planning guidance).	Thank you for your comment. The committee discussed whether to set a minimum frequency of review, and 1 year was one of the options discussed. However, they were concerned that this would lead towards an assumption that annual reviews were sufficient in general, whilst for many people the reviews may need to occur more frequently. For this reason, the committee agreed it was appropriate not to specify a frequency of review in the recommendation.
Alzheimer's Society	Short	14	14	This section is good, and it is particularly good to see recognition of a wide range of health and care settings mentioned here, but the statements here are very broad and not prescriptive. Whilst the full document (pg 152) recognises a lack of evidence on how information should be transferred and that local areas may adopt different solutions, we still feel more guidance is needed here for it to have any impact in practice.	Thank you for your comment. The committee noted the concerns raised by a number of stakeholders about the lack of specificity in the recommendations, but agreed that at the current time the evidence did not enable them to be more prescriptive. They noted the guideline does contain a number of recommendations for future research in this area, which will hopefully enable more specific recommendation to be mad in future updates of the guideline.
Alzheimer's Society	Short	14	25	This could include a statement on those with learning and /or physical and sensory disabilities.	Thank you for your comment. The committee agreed with this suggestion and these groups have been added to the recommendation.

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Alzheimer's Society	Short	15	5	This section should include the **importance of healthy lifestyle** - exercise, low alcohol intake, not smoking; or 'what is good for your heart is good for your head'. Whilst the full document says 'The committee noted the absence of studies evaluating nonpharmacological or behavioural interventions for modifying risk factors like poor diet, obesity, alcohol consumption and smoking.' (page 189) we still feel this would be a helpful addition.	Thank you for your comment. No specific evidence was identified to make recommendations on these topics, but the committee agreed a number of these issues are covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Alzheimer's Society	Short	15	5	There is a **lack of psychosocial intervention content**. See BPS, A guide to Psychosocial Interventions in Early Stages of dementia for an example of interventions that may be beneficial, with accompanying evidence. We also note that most of the psychosocial interventions are preceded with 'consider', yet many of the pharmacological interventions are recommended.	Thank you for your comment. The committee agreed it would have been able to provide more detailed targeting of the recommendations for psychosocial interventions, but agreed the evidence was not sufficient for them to be able to do so. They noted a number of recommendations for future research in this area were made, which they hoped would mean these issues can be resolved in future updates of the guideline.
Alzheimer's Society	Short	15	9	The recommendation on CST has softened from the current guidelines, which state 'People with	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and

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				mild-to-moderate dementia of all types **should be given the opportunity to participate in** a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia.' This is surprising as the evidence base for CST has increased since the last guidelines. **Evidence for CST:** For example, a systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions. Several trials within the Cochrane review compared Cognitive Stimulation with an active, social control group, yet the results were consistently in favour of structured group Cognitive Stimulation over a social control (Woods et al, 2012). There are benefits to CST that are not noted in the full document (pg 296). There are other	come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life, but the pooled result of the studies included in the meta-analysis could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool

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				benefits found in some of the studies included in the NICE review: quality of life (Spector et al 2003), mood (Yamanaka et al 2013), activities of daily living (Orrell et al 2014). There are also additional studies not included in the NICE review including Niu et al 2010 which showed benefits to depression and apathy, and Paddick et al 2017 that showed benefits to anxiety and behavioural symptoms; and also a Cochrane systematic review (Woods et al 2012) on 15 RCTs of CST that found evidence of improvements in quality of life and communication. The recent Lancet commission on dementia also states that CST is the psychological approach with the strongest evidence for improving cognition. This evidence is also specific to CST, there isn't evidence to suggest that unspecified elements of CST, as recommended in these new guidelines, would have the same effects. CST is also quite different to reminiscence therapy – CST focuses on the generation of new thoughts, ideas and associations and is believed to engage executive functioning skills and enable new semantic connections to be made; whereas reminiscence therapy focuses on the past.	with the other quality of life measures found in other studies, so this data point was not included. Orrell (2014) reported an improvement in QoL-AD but the pooled result of the meta-analysis could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Olazaran (2010) was included as a systematic review in Appendix O but data was not extracted because Olazaran (2010) did not report details of the individual studies in included in their systematic review. Paddick (2017) has now been included as evidence for CST. The inclusion of this study did not make a meaningful difference to any of the results of the analysis. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

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				Evidence for cost effectiveness of CST: We would suggest that the assumption that there would be no difference in cost of delivery between providing an intervention with a more varied range of components cannot be made without a cost effectiveness analysis. There is strong evidence for the cost effectiveness of manualised CST, in two key papers (Knapp et al, 2006; D'Amico et al, 2015). There are several errors in Appendix J (p.10) which considers the cost of providing CST: It states that band 4 or 6 staff are required to run sessions, when in reality this is often band 2 staff. It states that groups are for 5 people, when key research trials included between 5-10 people in each group and many trusts offer groups for up to ten people. The total cost per session is calculated as £233.19 in appendix J, however the Knapp (2006) paper calculated the cost per session as £90. Using the Knapp cost per session calculation, even with just 5 people in each group, the total cost per patient	

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				per CST course (14 sessions) is £252, compared to NICE's estimate of £652.94. Additionally, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually. There is also widespread support for CST. CST is now a required standard for the Memory Services National Accreditation Programme (MSNAP). Several other reports have endorsed CST since the 2006 guidelines. For example, the World Alzheimer Report (Alzheimer's Disease International), in 2012 and subsequently; have stated that CST should routinely be given to people with early stage dementia.	

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				The impact of this change in the guidelines should be considered. It is likely that many people now are accessing CST because of its inclusion in the previous guidelines. **We would suggest that this wording is reverted to the former wording from 2006.**	
Alzheimer's Society	Short	15	9	This phrasing should be 'offer' rather than 'consider' for **group activities and this should specify that this should be peer support**. Losing independence and confidence in the ability to do what is familiar, in addition to fearing how others will react to the challenges presented by dementia, meant some people we spoke with for our Turning up the volume report described actively avoiding situations which had the potential to cause upset or stress which led to them seeing fewer people and leaving the house less frequently. Sometimes people with dementia feel they are left with little option but to increasingly withdraw from their community as the condition progresses. Indeed, over a third (35%) of people with dementia that we spoke to said they have felt lonely recently, a particular	Thank you for your comment. Following extensive feedback at consultation, these recommendations have been reworked to focus specifically on those interventions with evidence of benefits, namely CST, reminiscence therapy, cognitive rehabilitation and occupational therapy. The new set of recommendations is: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia. Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia." Unfortunately, peer-support was not an area where robust evidence was identified, and therefore the committee did not feel able to include this in the list of recommendations.

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				concern given wider research into the increased likelihood of mortality from isolation (Holt Lunstad et al., 2015). There is evidence on the benefits of peer support here: https://www.housinglin.org.uk/_assets/Resources/Dementia/OtherOrganisation/Peer_support_resource_pack_HIN.pdf This should be a separate point to offering CST.	
Alzheimer's Society	Short	15	21	While true, this feels like odd advice and potentially risks putting people off IPT in general.	Thank you for your comment. A definition has been added to the guideline, and the committee were keen to stress this was a recommendation not to use interpersonal therapy to treat the cognitive symptoms of Alzheimer's disease. If people living with dementia had another condition for which interpersonal therapy were indicated, the committee agreed it would be correct to offer them to people living with dementia in the same way as those without.
Alzheimer's Society	Short	16	1	We would recommend the addition of a section **on when to review pharmacological interventions, what to review and how to assess benefit**. The latter should take into account information from patients and carers and include consideration of: not just improvement in	Thank you for your comment. The guideline did look for evidence on when and how pharmacological interventions for people living with dementia should be reviewed. However, no evidence was identified, and therefore the committee agreed it was most appropriate for this section to cross-refer to the NICE guideline on medicines optimisation.

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				cognition, BPSD and / or function but also slowing of decline, stabilisation. In a neurodegenerative condition improvement (especially sustained improvement) is not the usual outcome.	
Alzheimer's Society	Short	16	19	There is inconsistency here in the recommendation to consider **memantine for anyone taking AChEIs** but not a suggestion of the reverse.	Thank you for your comment. The committee noted this concern, but agreed that since the majority of the evidence was specifically on the addition of memantine to a cholinesterase inhibitor, and cholinesterase inhibitors are the recommended first line treatment for people with mild dementia, the current wording of the recommendation was the most appropriate one. They did, however, note that in practice people were likely to also consider the addition of cholinesterase inhibitors for people who had already started on memantine.
Alzheimer's Society	Short	18	27	Consider making it clearer that these should continue to be offered as clinically indicated for underlying conditions such as diabetes or hypertension.	Thank you for your comment. The committee agreed this point was covered by the part of the recommendation to "not offer the following to slow the progress of Alzheimer's disease." The phrase "specifically to slow the progression of Alzheimer's disease" has now been used to make clear they should still be offered for relevant comorbidities. Treatment of the comorbidity itself would be covered by the alternative recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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Alzheimer's Society	Short	19	6	We welcome this section, which brings a more pragmatic approach to the limited evidence base around the therapeutically challenging area of dementia with Lewy bodies.	Thank you for your comment, and your support for these recommendations.
Alzheimer's Society	Short	20	20	There is some evidence that simple painkillers such as paracetamol could reduce agitation in people with dementia. (Ballard study - https://www.nursingtimes.net/paracetamol-could-reduce-agitation-in-dementia-patients/5032937.article)	Thank you for your comment. The Ballard study published by Husebo et al. (2011) was found by the searches for this evidence review. However, Husebo et al. (2011) was excluded because the paper did not report on the clinical outcomes listed in our PICO for this review question.
Alzheimer's Society	Short	20	21	Consider expanding this list of 'pain, delirium or inappropriate care' to include 'sensory impairment(s), overly noisy environment'	Thank you for your comment. The committee noted it was not possible to provide an exhaustive list of things that may be associated with agitation, and agreed these would be covered under "clinical or environmental causes".
Alzheimer's Society	Short	20	24	'Offer psychosocial and environmental interventions' is broad and vague, and could include specific interventions to offer. Behavioural and psychological symptoms of dementia such as agitation, aggression, changes in communication and apathy affect up to 90% of people with dementia (Feast, Orrell et al. 2016) and there should be more guidance in this area.	Thank you for your comment. The committee agreed it would have been able to provide more detailed targeting of the recommendations for psychosocial and environmental interventions, but agreed the evidence was not sufficient for them to be able to do so. They noted a number of recommendations for future research in this area were made, which they hoped would mean these issues can be resolved in future updates of the guideline.

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				The following could be considered as practical examples: social interaction, meaningful occupation, decluttering and calming the environment, cognitive stimulation, music therapy, reminiscence / life story work, exercise. There is best practice here http://mhoad.slam.nhs.uk/disorders/dementia/alzheimers-disease-2/moderatesevere/community-support/managing-bpsd/) which recommends referral to a specialist in management of BPSD (e.g. clinical psychologist) before considering medication.	
Alzheimer's Society	Short	21	5-6	Consider flagging extreme caution in use of antipsychotics in dementia with Lewy bodies, because of risk of severe adverse reaction.	Thank you for your comment. The committee noted the specific concerns around the risks of antipsychotics in people with dementia associated with Parkinson's disease, and therefore agreed to add an extra recommendation to this section, stating to "be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in NICE guideline on Parkinson's

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					disease. Be aware that interventions may need to be modified for people living with dementia."
Alzheimer's Society	Short	22	7	A 'consider' recommendation of an antidepressant for severe dementia would seem reasonable. Evidence is not strong either way but options in this group are limited.	Thank you for your comment. The committee agreed that in the absence of any evidence, it was not possible to make recommendations on the use of antidepressants in people living with severe dementia.
Alzheimer's Society	Short	22	11	There is reasonable evidence and clinical practice to support use of melatonin for REM sleep behavioural disorder in dementia with Lewy bodies (for example, www.ncbi.nlm.nih.gov/pubmed/20191945/) and a 'consider' recommendation for sleep problems (or RBD) in dementia with Lewy bodies would arguably be justified.	Thank you for your comment. The committee noted this and the fact that the majority of the evidence from the trials was in Alzheimer's disease, and therefore agreed it was appropriate to amend this recommendation to "do not offer melatonin to manage insomnia in people living with Alzheimer's disease." The committee also agreed it was appropriate to add a cross-reference to the Parkinson's disease guideline for the management of non-cognitive symptoms (included RBD) covered there, as no evidence was identified specifically in people with PDD or DLB to allow recommendations to be made in this guideline.
Alzheimer's Society	Short	22	17	There is no mention of **sensory impairment**. Omitting sensory impairment seems an oversight and useful guidance in this area could support the quality of life and abilities of many people with dementia. Having sight or hearing loss makes things even more difficult for the person with dementia who may already be struggling with	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes the recommendations you quote on hearing

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				making sense of the world around them. It can also be difficult to identify sensory impairment that develops in someone with dementia as people may assume the problems are caused by the dementia. According to Age UK, 50 per cent of people aged over 60 will be affected by some type of hearing loss, and according to Sense one in 20 people aged over 75 are likely to be classed as deafblind (with moderate or severe hearing loss as well as moderate or severe sight loss). This suggests these sensory impairments to be highly prevalent in people with dementia. There is evidence that regular check-ups and appropriate interventions can improve sensory impairment and therefore quality of life in people with dementia. The PrOVIDe study found that up-to-date spectacle prescriptions can reduce visual impairment in people with dementia. There is a body of research that has looked at the needs of the BSL Deaf community in terms of diagnosis and support which could be referenced	assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). They also agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years" Finally, the committee agreed that once hearing or visual loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				and signposted to. (e.g. Young et al, 2016 https://www.ncbi.nlm.nih.gov/pubmed/25469427; Ferguson-Coleman et al, 2014 https://www.ncbi.nlm.nih.gov/pubmed/24499410; summarised at https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/deafness.asp). Neuropsychological instruments recommended for making a diagnosis of dementia, are not suitable for BSL Deaf users when translated. There are validated and culturally sensitive instruments that can be used with BSL users, and the guidance should recommend the use of The British Sign Language Cognitive Screening Test (Atkinson et al, 2015, Detecting Cognitive Impairment and Dementia in Deaf People: The British Sign Language Cognitive Screening Test, *Archives of Clinical Neuropsychology*, Volume 30, Issue 7, Pages 694–711, https://doi.org/10.1093/arclin/acv042). This	

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				guidance could be implemented by reference to a clinic at Queens Square that takes national referrals for BSL users with cognitive complaints. http://www.ucl.ac.uk/dcal/clinical; http://www.uclh.nhs.uk/HP/GPNEWS/Pages/CognitivedisordersclinicattheNHNN.aspx Carers need to ask specifically and should remember FEET (Feet, eyes, ears and teeth) and the importance of regular review of these areas.	
Alzheimer's Society	Short	22	17	As mentioned earlier, it could also be useful to mention here the importance of a single holistic person-centred care plan, covering all multi-morbidities.	Thank you for your comment. The recommendation on care and support plans has been modified to include a statement to "ensure it contains information on the management of any comorbidities the person has."
Alzheimer's Society	Short	22	17	Many people with dementia will struggle to self-manage **co-morbidities**, especially as their dementia progresses and linking to other more general guidance is not sufficient. The severity of someone's dementia can have consequences on their ability to manage their other conditions. For example, someone	Thank you for your comment. The committee agreed with the importance of appropriately managing comorbidities in people living with dementia. But noted there was very limited evidence available on how management of these comorbidities should be different in people living with dementia to those without. As a result of this, the committee agreed the main focus should be ensuring people living with dementia get the same access to treatments for comorbidities as those without,

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				managing diabetes has to carry out self-testing and administer insulin at certain times of the day. Because of the dementia, their ability to carry out this task will deteriorate as their memory and cognition worsens, with responsibility eventually falling to a carer. Mismanagement of a health condition can lead to someone falling seriously ill, resulting in an emergency admission to hospital. It can also mean that the progression of the condition is quicker compared to if they didn't have dementia. It is also essential that the comorbidities section makes reference to how to manage vascular conditions such as stroke and heart disease, which are highly prevalent among people with dementia and have specific treatment regimes that need to be carefully adhered to. The following statistics highlight the most prevalent co-morbidities in people with dementia. Studies have shown that: • 41 per cent have high blood pressure • 32 per cent have depression • 27 per cent have heart disease • 18 per cent have had a stroke or transient ischemic attack (mini stroke)	and this is what led to the recommendation to "ensure that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities to people who do not have dementia."

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				• 13 per cent have diabetes Barnett K, et al (2012) Epidemiology of multimorbidity and implications for healthcare, research, and medical education: A cross-sectional study, *Lancet*, 380, 37–43.	
Alzheimer's Society	Short	22	24	Whilst this does refer to people who are unable to self-report pain, this should also highlight that people with dementia frequently don't volunteer when they have pain or discomfort.	Thank you for your comment. The committee agreed with your comment and for this reason made the recommendation to use "a structured observational pain assessment tool alongside self-reported pain and standard clinical assessment."
Alzheimer's Society	Short	23	4	This should detail the stepwise treatment protocol or link to one for clarity and consistency.	Thank you for your comment. The committee noted that the stepwise protocols in the studies were the same as those that would be used for people without dementia, and therefore would be familiar to the relevant healthcare professionals.
Alzheimer's Society	Short	23	15	Research has found that **older adults with dementia are twice as likely to fall as those without dementia (Allan et al, 2009)**. It would be important to acknowledge this. It would also be beneficial to highlight types of dementia that may increase falls risk such as Parkinson's disease dementia and dementia with Lewy bodies.	Thank you for your comment. The committee agreed that people living with dementia are at increased risk of falls, and tis was behind their reasoning to highlight the importance of people getting access to the same evidence based falls prevention interventions as would be offered to people without dementia.

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Alzheimer's Society	Short	24	9-13	For people with dementia it can be difficult to determine when they are "approaching the end of life." More detail to support practitioners with this would be helpful. As the person may lose capacity, conversations with the individual, their family and carers where appropriate should take place as early as possible (as the person may have lost capacity when they are at the end of life). It would be useful to add 'identifying whether the person has made an advance decision to refuse treatment / Lasting Power of Attorney for health and welfare' as these will be relevant if the person does lack capacity.	Thank you for your comment. The committee agreed that it can be difficult to identify when someone with dementia is approaching the end of life, and the guideline contains a research recommendation on "the most effective interventions to support staff to recognise advanced dementia and develop appropriate escalation/end of life plans to facilitate care to remain at home." They also agreed it was important that information on any advance decision made was available to health and social care staff.
Alzheimer's Society	Short	24	1	The full document (page 170) recognises that 'it was often not appropriate for people living with dementia to be treated on general hospital wards' and 'The committee agreed the correct approach was rather to take elements of best care found in specialist units and apply these to all geriatric units, thereby raising the overall standard of care.' No elements of this 'best care' is reflected in the short guidelines.	Thank you for your comment. The committee noted that the large NIHR TEAM trial (comparing ways of organising hospital care), if it had produced more positive results, could have led to a number of strong recommendations being made around how care in hospitals should be organised for people living with dementia, and agreed it was unfortunate that meaningful benefits for people living with dementia were not identified in this study. The committee agreed that, given the results of this study, it was not possible to include any strong and definitive recommendations in this section.

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				The guidelines recognise that admission to hospital should be avoided wherever possible, recognising the evidence that people with dementia who go into hospital are often less physically well and less mentally well when they leave than when they went in. Some hospital admissions are unavoidable though and so it seems an omission not to include guidance on how to improve care for admissions that are unavoidable, to avoid or reduce these negative outcomes. Department of Health figures show that people with dementia in hospital account for around 3.2 million bed days a year, with 25 per cent of hospital beds occupied by people with dementia at any one time. (http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2014-11-05/213473). There is an impact both on the individual and cost of care, if a person's condition deteriorates and they require a longer stay or require discharge to residential care. While screening for delirium at arrival is essential, much more can be done to improve care quality for people with dementia in hospital; specific to meeting the needs of people with dementia, so	

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				not covered by other guidelines. This section should address the following: • Making the environment dementia friendly e.g. good signage, contrasting colours for doors, seating areas in wards • Access to a liaison service or dedicated dementia team that specialises in the assessment and management of dementia or older people's mental health • Families of people with dementia able to stay overnight/outside of visiting hours and help at mealtimes • Catering services in hospitals should be able to provide for the needs of people with dementia, who may not be able to eat full meals at regular times and need finger food meal alternatives and snacks available at any time to ensure they are nourished. • People with dementia and family carers are partners in care Alzheimer's Society Fix Dementia Care Hospitals report outlines some of the poor care people with dementia are receiving in hospitals and huge	

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				variation in quality of care, which highlights the need for recommendations in this area (with data collected from Freedom of Information requests to hospital trusts regarding key indicators of dementia care (falls, length of stay, discharge, emergency readmissions); a Facebook survey of carers and people with dementia regarding their experiences in hospital and an economic analysis of dementia care in hospital using HES data and NHS tariffs to assess the money wasted on excess length of stay, falls and emergency readmissions). We found that: • only 2 per cent of those caring for people with dementia felt that all hospital staff understood the specific needs of people with dementia • thousands of people with dementia are being discharged between the hours of 11pm and 6am each year • people with dementia stay five to seven times longer than other patients over the age of 65 in the worst performing hospitals • £264.2 million was wasted due to poor dementia care in hospitals in 2013/14.	

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Alzheimer's Society	Short	24	5	This section would benefit from an acknowledgement that **people may not be aware that dementia is a life limiting condition** - only 22% of the general public who responded to a survey for our Turning up the volume report thought that dementia is a condition which results in death. The section should also acknowledge the need for appropriate conversation with the person and those supporting them at a time that suits them (for some people it may not be appropriate). This could also benefit from more clarity on what is meant by palliative care and what good palliative, and end of life care, looks like for a person with dementia. It also needs to be integrated within the person's wider care arrangements – at the moment it reads as being offered as a separate add-on.	Thank you for your comment. The committee agreed they would have liked to be able to include more specific recommendations around palliative care in the guideline, but noted they were constrained by the very limited quantitative evidence base in this area. They therefore agreed it was most appropriate to cross-refer in this section to existing NICE guidance and standards on palliative and end of life care, with the particular caveat that a palliative care approach should be used from diagnosis for people living with dementia.
Alzheimer's Society	Short	24	5	(1.10) There is no acknowledgement of other living arrangements, and the merits in checking procedures when it comes to supporting a person	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified from either the qualitative or quantitative reviews for this question, it was not

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				with dementia at the end of life e.g. in a care home.	possible to include any recommendations on this topic in the guideline.
Alzheimer's Society	Short	24	6	The point of diagnosis may not be appropriate to 'offer' someone palliative care as they may be reluctant to have a conversation, so this should be an ongoing process that responds to the person's needs.	Thank you for your comment. The committee agreed with this point, and noted that the phrase "from diagnosis" was used to capture that this should be a continuous process throughout the person's life.
Alzheimer's Society	Short	24	9	Further information is needed for what constitutes an 'anticipatory healthcare planning process'.	Thank you for your comment. A cross-reference has been added from this recommendation to the section on advance care planning to improve the clarity of this recommendation.
Alzheimer's Society	Short	24	14	As the guidelines signposted to here are not dementia-specific**, the section on palliative care in the dementia guidelines needs more detail about the specific needs of people with dementia** when it comes to palliative care and how palliative care can support the individual, rather than just signposting to other guidance. Similarly, the mental capacity guidance is not completed yet and more detail is needed for supporting people with dementia approaching the end of life who may lack capacity.	Thank you for your comment. An evidence review was conducted, looking for evidence on specific palliative care interventions for people living with dementia. However, in the absence of any effective interventions being found, the committee agreed it was most appropriate to cross-refer to the general NICE guidance on palliative care. The NICE guideline on decision-making and mental capacity is due to publish in July 2018.

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Alzheimer's Society	Short	24	23	This statement is quite generic and misses the opportunity to talk directly to the individual about issues which impact them, particularly around comfort feeding. Positive to have this included as previously the notion was if a person was dying then it would be better not to provide drink, but there needs to an element of assessment in this which is not referred to.	Thank you for your comment. The committee noted that a decision-aid is going to be produced to accompany the guideline, covering issues around eating and drinking. The committee agreed this should hopefully address many of the points raised.
Alzheimer's Society	Short	24	25	We still see people with dementia who receive the feed so more information on this point is needed. Alzheimer's Society has a report on end of life which has more information and could be helpful for these purposes.	Thank you for your comment. NICE will be producing a decision-aid on issues relating to feeding that will be published alongside the guideline.
Alzheimer's Society	Short	25	1	It is good to see this point about keeping people with dementia out of hospital. At the same time, this section could be more explicit about which services the hospital should refer to. Suggesting local health and care services that should be considered as an alternative would be beneficial. Stakeholders need the additional guidance on this and the NICE guidelines are an excellent opportunity.	Thank you for your comment. The committee agreed that no evidence was identified on alternative services to refer people living with dementia to if hospital admission is deemed inappropriate, and therefore it was not possible to make recommendations on this topic.

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Alzheimer's Society	Short	25	1	There doesn't seem to be any discussion of different care settings and the decision seems to be based only on "medical needs". At end of life, people can be admitted to hospital in times of crisis but there is no mention of how to address this early, before the decision to admit someone (or even call an ambulance) arises.	Thank you for your comment. The committee agreed that no evidence was identified on alternative services to refer people living with dementia to if hospital admission is deemed inappropriate, and therefore it was not possible to make recommendations on this topic.
Alzheimer's Society	Short	25	10	It is positive to see above factors being taken into account but is the staff member having a conversation with the relevant stakeholders about Lasting Power of Attorney etc. and the protocols that need to be in place to inform decision making about what to do in any health and care setting. There needs to be a wider discussion with family and carers even if there is no LPA. There should be an in-depth conversation about how to take into account any advance care and support plans and what in particular needs to be taken into account. This should not just be a DRI. In some CCGs, there is strict guidance.	Thank you for your comment. The committee noted that the list of factors given here were only examples, and there were many other factors that would need to be taken in to account in individual cases. The specific examples on the list were chosen by the committee as those they agreed were likely to be the most common problems encountered.
Alzheimer's Society	Short	25	14	Family carers should be provided with information to understand what happens when	Thank you for your comment. The committee agreed that providing accurate and timely information was important for

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				they take on a caring role to enable choice. Identifying a circle of support for carers who are able to spread the burden of the caring role and incorporating this into the care plan would make an immense difference to the lives of carers.	carers of people living with dementia, but that in absence of any information on what should be provided and when, it was not possible to make specific recommendations on this topic.
Alzheimer's Society	Short	25	14	Carers often do not know how to register on a GP or Local Authority list as a person's carer – this is immensely important as it helps to flag and recognise their status, allowing the carer more time and resource.	Thank you for your comment. The committee agreed that providing accurate and timely information was important for carers of people living with dementia, but that in absence of any information on what should be provided and when, it was not possible to make specific recommendations on this topic.
Alzheimer's Society	Short	25	14	Over a quarter (27%) of carers say that no one has provided them with advice or support about caring for someone with dementia (Alzheimer's Society Turning up the volume report, 2017). There needs to be a mechanism for recognising carers and signposting them to this support.	Thank you for your comment. The committee agreed that providing accurate and timely information was important for carers of people living with dementia, but that in absence of any information on what should be provided and when, it was not possible to make specific recommendations on this topic.
Alzheimer's Society	Short	25	14	Young carers and vulnerable adults who become carers should be referenced here.	Thank you for your comment. The committee noted that the recommendation included a reference that support should be "tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)."
Alzheimer's Society	Short	25	14	Support and training for carers is positive but this point is quite generic. There is a question	Thank you for your comment. The committee disagreed that this recommendation was generic, and noted there were

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				regarding who would administer the training and at what level (e.g. Tier 1 or Tier 2). The training would also need to be individualised. Training often provides a significant amount of information but for carers this needs to be condensed so it's not an overload.	specific intervention packages (such as the START intervention referenced in the full guideline) that were available to implement this recommendation in a very structured way.
Alzheimer's Society	Short	25	14	Carers should also be given information, at the point of diagnosis.	Thank you for your comment. The committee noted that the recommendations on providing information did include that carer and family members should be provided with information (if appropriate), as well as people living with dementia.
Alzheimer's Society	Short	25	14	Supporting carers should include financial and legal advice	Thank you for your comment. The committee noted that the recommendations on providing information did include that carer and family members should be provided with information (if appropriate), as well as people living with dementia, and this would include financial and legal advice, if appropriate.
Alzheimer's Society	Short	25	16	This could also include prevention, recognition and management of delirium.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in delirium
Alzheimer's Society	Short	25	19	This could be improved by changing this to: 'specialist training in how to provide support and	Thank you for your comment. The committee noted this suggestion, but agreed the current wording of the

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				care, including how to understand and respond to changes in behaviour, that is tailored to diverse groups, and tailored along the dementia pathway'	recommendation most accurately reflect the evidence upon which this recommendation was based.
Alzheimer's Society	Short	26	20-28	We understand that there is other NICE guidance on moving to different care settings, however, these do not focus specifically on dementia. People with dementia experience different issues when moving to different care settings, compared to those that do not have dementia, and so this guidance could be expanded to focus on these issues and consider a dementia perspective on moving.	Thank you for your comment. The guideline did look for evidence on how transitions should be managed for people living with dementia. However, the evidence found for this review question was not sufficient to allow any recommendations to be made, and it was for this reason the guideline chose to make cross-references to the existing NICE guidelines on transitions between care settings, rather than different recommendations being made for this guideline.
Alzheimer's Society	Short	26	2-3	The first two bullets of this section should be swapped around.	Thank you for your comment. This has been changed as suggested.
Alzheimer's Society	Short	26	10	This statement is too broad – does this mean cost effective or effective in the form of the intervention, or both? Group sessions should be tailored to meet the needs of the person and culturally appropriate, e.g. reflecting the needs of the LGBT, BME or travelling community.	Thank you for your comment. The committee agreed the evidence available, from both subgroup analyses of the RCT data and the meta-regression model, showed that on average, group sessions were more effective than individual, telephone or online sessions. However, the committee also agreed both that the group sessions would need to be appropriately tailored to the individuals attending them, and that this format would not be

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					the most suitable for all individuals, due to differences in their circumstances and preferences. They therefore agreed it was appropriate for the recommendation for group sessions to be kept at the weaker "be aware" level, and that the guideline should also recommend support for carers is "provided in a format suitable for them (for example individual or group sessions, or online training and support)", to ensure this is not taken as a blanket statement that group sessions are the most appropriate format for all carers.
Alzheimer's Society	Short	26	15	The carers assessment should mention care act advocacy, and support should be provided to carers to do the assessment. The assessment should have a vision of what to do at point of crisis and reference the dementia journey such as palliative care planning. The assessment should enable capturing of data around behaviours that challenge to provide context where additional support is required.	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified, it was not possible to give recommendations on what the content of a Carer's assessment should be, or how they should be conducted.
Alzheimer's Society	Short	26	19	Overall, the guidance in this section is not very clear. It would be quite difficult to use this guidance to ensure stakeholders are following good practice of transition between care settings. If the guidelines were more detailed, they would provide a better guide for developing a good standard of care at a local level.	Thank you for your comment. The guideline did look for evidence on how transitions should be managed for people living with dementia. However, the evidence found for this review question was not sufficient to allow any recommendations to be made, and it was for this reason the guideline chose to make cross-references to the existing NICE guidelines on transitions between care settings, rather than different recommendations being made for this guideline.

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Alzheimer's Society	Short	26	15 and 28	Just to note that NHS England now prefer the term 'replacement' care to 'respite' care.	Thank you for your comment. Since respite care is still the more commonly used term, it was agreed to be appropriate to maintain that for clarity.
Alzheimer's Society	Short	27	3	Any or all training should be based on or around the Dementia Training Standards (formally known as the Dementia Core Skills Education and Training Framework). The Standards were developed and are supported by many national bodies in health and social care such as Health Education England and Skills for Care. There should be reference to the three 'tiers' in the Standards. Our investigation for our Fix Dementia Care: Homecare report found that 38% of homecare workers do not receive any dementia training and most (71%) do not receive dementia training that is accredited. Only 2% of people affected by dementia say homecare workers 'have enough dementia training'. The report found this lack of appropriate training had consequences including emergency admission to hospital from a failure to identify infections, ineffective safeguarding procedures in place, and care workers refusing to make further visits to someone with dementia as they felt	Thank you for your comment. The committee decided not to refer to the Dementia Core Skills Education and Training Framework document as part of the recommendations themselves, as these needed to be based on the evidence identified from the literature review. However, it was agreed to be appropriate to refer to this document within the list of relevant other guidance at the start of the document, alongside other Department of Health frameworks.

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				unprepared and helpless. This highlights the need for appropriate training.	
Alzheimer's Society	Short	27	3	There should be reference made to a recent piece of work undertaken by Professor Claire Surr at Leeds Beckett University, looking into (and funded by the Department of Health) "What works?" in dementia training. For example training most likely to be effective: • Includes face-to-face delivery using group-based activities and discussion • Is tailored to the staff attending so it is relevant to their role and service setting • Is delivered by an experienced facilitator • Combines theory/knowledge with opportunities to apply learning through practice/practice-based activities • Is of at least three hours duration with longer programmes more likely to be effective	Thank you for your comment. This study did not meet the inclusion criteria for the review question on staff training (which included randomised controlled trials and systematic reviews of randomised controlled trials) and therefore it was not possible to include this work as part of the guideline.
Alzheimer's Society	Short	27	3	There should be a clear link made to the co-existence of dementia with other health	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely

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				conditions e.g. mental health problems, diabetes etc. and for all health and social care staff/multi-disciplinary health teams to receive training on how these conditions co-exist. This holistic approach should allow for a more person centred and considered view of an individual's care and support needs.	delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
Alzheimer's Society	Short	27	3	There should be greater acknowledgement, training (blended learning) and support for the role carers can play whilst also recognising the impact on their own mental wellbeing.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
Alzheimer's Society	Full	General	general	Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications National Dementia Helpline, website and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social	Thank you for taking the time to comment on the guideline.

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				research into the cause, cure and prevention of dementia and the care people receive. We welcome the update to the dementia guidelines and the important opportunity this presents for improving care and support for people with dementia and carers. To inform our response to the draft guidelines, we consulted with over 30 experts including researchers, health and social care practitioners, policymakers, and people with dementia and carers, as well as utilising our own organisational insight and expertise to inform our response.	
Alzheimer's Society	Full	General	general	As a whole the **guidance is quite vague**, without enough detail to implement many of the recommendations in practice. Much of the guidance doesn't seem to account for the reality of practice and capacity, and without additional resource, much of the guidance will be difficult to implement. In many cases it is unclear who the recommendation is for, which could be an additional barrier to translation into practice. It	Thank you for your comment. The committee noted that the recommendations made in the guideline were as specific as was possible from the evidence available. They agreed that a number of the recommendations made would have resource implications, and agreed this made it even more important that those recommendations be based on robust evidence to make clear the potential costs are justified by the benefits. The committee agreed that in a number of areas the evidence did not enable them to be specific about who should carry out recommendations. The evidence on case management involved studies where this was done by social workers, nurses and occupational therapists, and it was not possible to identify

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				also appears that much of the guidance is more useful to commissioners than to practitioners, linked to the point above that more resource is required to deliver much of the guidelines. Additionally the order of some sections, particularly the diagnosis section, is quite confusing and could present a further barrier to following the guidance in practice. Without greater clarity and direction much of the guidance may have little impact on current practice.	which of these was the most appropriate model of care. However, in situations where evidence was available, the committee tried to be as specific as possible in the recommendations made. In other situation, the committee agreed it would be up to local decision makers to decide how best to implement the advice given. Some ordering changes have been made to various sections of the guideline (including that on diagnosis) to try and address the concerns raised around clarity.
Alzheimer's Society	full	General	general	**There seems to be a general retreat from the previous guidelines** where some sections are no longer included, which has left unfortunate gaps. There are some **key omissions of care in certain settings,** in particular care in hospitals, at home, and in care homes. We recognise that there are other guidelines that cover general provision of care in these settings, but believe that the needs of people with dementia require sufficiently different practice to justify specific recommendations within these guidelines.	Thank you for your comment. The committee noted that in many areas the evidence base only covered people in a particular setting (e.g. the majority of the evidence on staff training came from people living in care homes). The committee agreed that wherever possible it was appropriate to try and extrapolate this evidence to the more general population of people living with dementia, as otherwise there was a risk of particular groups or dementia subtypes not being covered, solely because studies happened not to have been done in those populations. They agreed this in places led to a lack of specific recommendations for different settings, but believed this was

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				The lack of guidance on **care homes** means a significant population of people with dementia are being missed. 70% of care home residents are people living with dementia (Prince M, Knapp M et al (2014). Dementia UK: Update, Alzheimer's Society). This is around 280,000 people in the UK. The current guidelines provide some recommendations for care homes (1.1.10 in current guidelines) - including the importance that design of built environments for living in meet the needs of people with dementia, and factors that should be paid attention to including size of units, mix of residents, skill mix of staff, a supportive and therapeutic environment. At a minimum this previous guidance should be reinstated. There is also new evidence in relation to care homes that could be considered. Randomised trial evidence (Ballard et al, 2018 https://www.ncbi.nlm.nih.gov/pubmed/29408901) arising from a large NIHR (WHELD) programme grant has underlined the benefit of person-centred approaches in nursing settings. This study aimed to evaluate the efficacy of a person-centred care and psychosocial intervention incorporating an antipsychotic review, WHELD, on	a more acceptable situation than for whole situations not be covered due to a lack of evidence. The committee also noted that many of the recommendations made (such as those around staff training and managing non-cognitive symptoms) were of direct relevance to care homes, and much of the evidence underpinning these recommendations was based on people living in care homes. The committee noted there is considerable ongoing research around dementia care and how this should be organised in different settings, and agreed that the publication of this evidence should make it possible to make more specific recommendations in future updates of the guideline. The specific study you cite (Ballard 2018) was published after the cut-off date for evidence to include within the guideline. However, this reference has been passed to the NICE surveillance team for consideration in planning future updates of the guideline.

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				QoL, agitation, and antipsychotic use in people with dementia living in nursing homes, and to determine its cost. These findings suggest that the WHELD intervention confers benefits in terms of QoL, agitation, and neuropsychiatric symptoms, albeit with relatively small effect sizes, as well as cost saving in a model that can readily be implemented in nursing homes. The lack of guidance on **home care** means a significant part of the dementia journey is being missed. An estimated 60% of people receiving homecare services have some form of dementia (UKHCA, 2013). This is around 400,000 people in England. Care in hospitals is commented on later.	
Alzheimer's Society	Full	General	general	The guideline scope document says that people with a confirmed diagnosis of **mild cognitive impairment (MCI)** will not be covered by this guideline. However the boundary between dementia and MCI is not always clear cut.	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team

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				People who have MCI are also at an increased risk of going on to develop dementia (around 39% of those diagnosed with MCI in specialist settings and 22% in population studies develop dementia over the subsequent 3 to 10 years compared with 3% of the population without MCI at the same age - Lancet commission). We therefore think it is important that people with MCI are considered within this guideline. As per the current version of the guideline, people with MCI should be offered follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage (1.3.3.3. in current guidelines). It could also be added that a diagnosis of MCI provides an opportunity for making lifestyle changes to reduce the chances of MCI progressing to dementia. The Lancet commission calculated that 21.7% of dementia progression from mild cognitive impairment is potentially preventable by eliminating poor diet, diabetes, and neuropsychiatric symptoms (assuming these are risk factors for, not symptoms of, or the result of, dementia), whilst recognising that more research is needed in this area. MCI also isn't currently covered by any other NICE guidelines.	within NICE for consideration when the topics of future guidelines are discussed.

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Alzheimer's Society	full	General	general	The guidelines have removed mention **of review and treatment of vascular and other modifiable risk factors** in middle aged and older people (for example, smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) and there is no mention at all of risk in these new guidelines. With the Lancet commission on dementia reporting that 30% of cases of dementia are potentially avoidable through modifiable lifestyle factors, it is important that risk factors are recognised within these key dementia guidelines.	Thank you for your comment. This guideline did not contain a review question on the prevention of dementia, or risk factors for the development of dementia, and therefore it was not possible to make recommendations on this topic.
Alzheimer's Society	Full	General	general	There is an omission of the importance of the **physical environment**, which can affect aspects of assessment, management and support in general (i.e. a noisy or poorly lit room during assessment). The environment is only mentioned briefly in managing non-cognitive symptoms (1.7). There is evidence on the environment from the Kings Fund's Enhancing the Healing Environment (EHE) Programme (funded by the Department of Health) and the Association for Dementia Studies at the University of Worcester.	Thank you for your comment. Evidence on modifications of the physical environment was looked for in the section of the guideline on maintaining independence and reducing risk. Only a very limited amount of evidence was identified on this issue, and none that the committee believed was robust enough to be able to use to make recommendations. The particular report you cite was not included as evidence, due to not being published in a peer-reviewed journal. However, the committee did agree this was an important issue, and one that should be considered in future updates of the guideline. The committee also noted that the guideline did make a number of recommendations around staff training, and that

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				Through its work with over 250 care organisations, the EHE Programme has created a solid body of evidence to support the design of environments which promote well-being. Projects have demonstrated that relatively inexpensive interventions, such as changes to lighting, floor coverings and improved way-finding, can have a significant impact. Evaluation has shown that environmental improvements can have a positive effect on reducing falls, violent and aggressive behaviours (as well as improving staff recruitment and retention). The EHE schemes have shown that it is possible to improve the quality and outcomes of care for people with dementia as well as improve staff morale and reduce overall costs by making inexpensive changes to the environment of care.	well-trained staff were likely to be able to respond more promptly and appropriately in situations where aspects of the physical environment need to be modified in order to improve the care and support for people living with dementia.
Alzheimer's Society	Full	General	general	There is an **omission of assistive technology** that can support someone to live well.	Thank you for your comment. Evidence on the effectiveness of assistive technology was specifically looked for as part of the development of the guideline, but no randomised controlled trials were identified. The committee agreed it was therefore not possible to make recommendations on this topic at this time, but did note that there are a number of ongoing trial in this area, such as the ATTILA (Assistive Technology and Telecare to maintain Independent Living At home for people

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					with dementia) study. Therefore, it will hopefully become possible to make recommendations on this in the future when these studies have published.
Alzheimer's Society	full	General	general	There is no mention of **inherited dementia** and referring people for **genetic counselling,** as included in the current guidelines (1.3.1.3 and 1.3.1.4 in current guidelines). People can experience distress if diagnosed with dementia that is likely to have a genetic cause – worried about children they have, or about future reproductive choices.	Thank you for your comment. Based on the feedback received at consultation, the committee agreed it was appropriate to add two new recommendations to the guideline, raising awareness of the genetic causes of a proportion of both frontotemporal dementia and early-onset Alzheimer's disease. They agreed that the evidence was not sufficient to make specific recommendations on how this should be managed, but that, in line with elsewhere in the guideline, they would expect equivalent advice and support be provided to people diagnosed with dementia as those within and other genetic condition.
Alzheimer's Society	full	General	General	The guidelines don't address the issue of **people that have obvious cognitive impairment but don't want a diagnosis**. This can have huge consequences for the individual, can be hugely challenging to families and can present ethical issues too. This can be very challenging for GPs and guidance in this area would be welcomed.	Thank you for your comment. The committee agreed that there was no evidence identified within the guideline that would enable them to make recommendations, but agreed this was a relevant issue. As noted within the committee's discussion of the evidence for the diagnostic section; "the committee commented that it was also important to consider situations where a patient may not want a referral for an assessment/diagnosis, and the potential disadvantageous outcomes that might result from this choice (e.g. problems with obtaining support, care and treatment)."

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Alzheimer's Society	full	General	General	**Discrimination, by reason of a dementia diagnosis**, is not mentioned. The Equality Act is not listed on page 6 as a relevant piece of legislation, although it is referred to on page 8 in the context of provision of information about employment rights.	Thank you for your comment. The committee agreed the Equality Act was a relevant piece of legislation, and this has now been added to the section you mention on page 6.
Alzheimer's Society	full	General	General	There is no **acknowledgement of individuals' psychological, cultural, religious and spiritual needs.** These can play an important part in many aspects of assessment, management and support for people affected by dementia and should be represented in this guidance.	Thank you for your comment. The committee agreed that these were all important issues that should be addressed in care for people living with dementia, and these were all constituent parts of the recommendations on encouraging people to express their own views and opinions, and on tailoring both information and support to the individual. However, the committee agreed that no specific evidence was identified on how care should be modified to best address people's cultural, religious and spiritual needs, and therefore it was not possible to make directive recommendations on how best to manage these issues. The committee noted these were also important issues to consider around the support provide to carers, and that "emotional and spiritual wellbeing" are mentioned in the section on providing support to carers of people living with dementia.
Alzheimer's Society	full	General	General	There is hardly any acknowledgement of **people from BAME communities** regarding assessment, management and support. The only references are in relation to treatment but there should be	Thank you for your comment. The committee agreed there were particular issues around people from ethnic minorities, both in terms of the general difficulties these groups have in

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				appropriate information under diagnosis and making services accessible. It is estimated that there are nearly 25,000 people with dementia from BME communities in England and Wales (2013, APPG on dementia) and there is an expected seven fold increase in dementia in BME communities over the next 30 years, compared with a two fold increase in the white British population, with prevalence in BME communities expected to grow to nearly 56,000 by 2026 and to over 172,000 by 2051 (APPG, 2013). There is substantial evidence that people from BME communities are less likely to receive a diagnosis or are diagnosed at a more advanced stage of illness than white British people (Moriarty, Sharif, and Robinson, 2011).	accessing healthcare, and specific issues in relation to care from dementia. The committee noted that no specific evidence was found to enable recommendations on how care should be tailored to best meet the needs of this group, but agreed the recommendations on making care accessible to as many groups as possible and tailoring information and interventions to the individuals needs and preferences were relevant to this issue, as were the references in the guideline to relevant pieces of legislation, including the Equality Act. The committee also agreed that it was appropriate to draw particular attention to people (including those from BME communities) who are less likely to access services for diagnosis and support. Therefore, an extra bullet point has been added to the recommendation on making services accessible, to cover: "people who are less likely to access health and social care services, such as people from black, Asian and minority ethnic groups."
Alzheimer's Society	full	General	general	Throughout there should be more guidance to support **integration of services**.	Thank you for your comment. The guideline contained a specific review question on the integration of health and social care services, but only a limited amount of evidence was identified and the committee agreed it was not possible to make more directive recommendations than those currently included.

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Alzheimer's Society	full	General	general	We welcome the **'person-centred care'** section preceding the recommendations, but there should be more mention of 'person centred' care throughout the recommendations themselves.	Thank you for your comment. The committee agreed that person-centred care should be a key feature underlying all of the interactions between staff and people living with dementia and their carers. They therefore agreed it was most appropriate to retain this as a standalone section, since including references to this in some recommendations in the guideline could have the incidental effect of making the principles appear less important in those areas where they are not referenced. An exception to this was made for the recommendation on staff training, where the committee agreed that training on person-centred care was sufficiently important that it should be explicitly mentioned.
Alzheimer's Society	Full	98		The full guidelines recognise that 'being diagnosed with dementia can be a stressful and traumatic experience' and **'the importance of guiding people with suspected dementia through the assessment process carefully'** (page 98). This needs to be reflected in a recommendation in the 'Diagnosis' section.	Thank you for your comment. The committee agreed there was not sufficient evidence to make specific recommendations around how the diagnostic process should be organised for people living with dementia. However, they did agree that a key aspect was staff being appropriately trained in how to manage this process. Consequently, they amended one of the recommendations around staff training to make explicit it covered the diagnostic process. Specifically: "Health and social care professionals advising people living with dementia (including those involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations."
Alzheimer's Society	Full	101		The full guidance states that 'physicians should be aware of the additional challenges of diagnosing	Thank you for your comment. The committee agreed with the importance of this issue – hence its inclusion within their

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				dementia in certain vulnerable groups, such as people with learning difficulties and Down's syndrome, and those people with language and sensory impairment, lower educational levels and a low standard of literacy'. It says the evidence base did not allow specific recommendations, but that it was '**agreed that it was important that people from these more difficult to diagnose groups should be assessed by a clinician with specialist skills in those areas**, who would be familiar with the difficulties and able to make appropriate adaptations to the process used'. This is not reflected in the guidelines. We would suggest a recommendation should be added to reflect this. The cross-reference to the NICE guideline on mental health problems in people with learning disabilities (1.2.7) is not sufficient to cover this.	discussion of the evidence. However, in the absence of any evidence as to exactly which people should be diagnosed or managed within a particular services, they agreed this was not something that could be included within the recommendations themselves. The committee also noted that the majority of people with moderate to severe learning disabilities and dementia would be diagnosed and managed with learning disabilities services rather than standard dementia services, and therefore the assessment would be conducted by someone who is a specialist in learning disabilities.
Alzheimer's Society	Full	104		The full document says 'The committee noted that there can be problems with the interpretation of imaging data by non-specialists	Thank you for your comment. The committee noted that the text quoted accurately captured their views on this topic. However, in the absence of any specific evidence on this issue,

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				and commented that where scans are requested by primary care physicians/nonspecialists, specialist input should be obtained to help them interpret scan data. This will facilitate faster, more accurate diagnosis of dementia and reduce unnecessary tests and referrals'. However this is not included in the short guidelines. Given the benefits outlined here of specialists interpreting the scans, this should justify inclusion in the short guidelines.	and the knowledge that there would inevitably be cost implications to such an approach, they agreed it was not something that could be included within the recommendations themselves.
Alzheimer's Society	Full	125	20	The Mental Capacity Act 2005 code of conduct – is a code of 'practice'	Thank you for your comment. This has been changed as suggested.
Alzheimer's Society	Full	131	14	Care needs to be taken in advising people with dementia that they can change any advance decisions, statements or directives they have made in the future. Whilst the evidence indicates this can be a reassuring factor there is also the possibility that capacity may be lost such as to prevent any change.	Thank you for your comment. The committee agreed this was a relevant issue, and as part of any discussion around advance decisions, statements or directives very clear information should be given about under what circumstance a person would no longer be able to make changes, due to a lack of capacity. A cross-reference has now also been added to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018) that provides additional guidance on these issues.

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Alzheimer's Society	Full	151		The full document says 'The committee agreed that the positive overall findings from the studies on case management provided robust evidence that there should be a single person responsible for coordinating care. Otherwise, it is common for health and social care professionals to assume that other members within the team are coordinating care when they are not.' Care coordinators should be notified of people newly diagnosed with dementia to help prevent this.	Thank you for your comment. Whilst the evidence base identified did not specifically look at the issue of when a care coordinator should start working with a person living with dementia, the committee agreed there was no reason (other than a person living with dementia declining this option) for this process to be delayed. As a result of this, the committee agreed not to specify any timepoints in this recommendation, to make clear it applies to all people living with dementia, at any stage off the condition.
Ashford Place	Full	16	45	We are pleased you want to put the person living with the dementia at the centre of the support pathway. This would be strengthened by supporting the development of a service user group who could help you support this model so as not ensure that it is not tokenistic The offer of information for people living with dementia is great but in our experience the service user would prefer face to face contact from a professional who can explain and guide them through their journey, as well as some short written information pieces.	Thank you for your comment. The committee agreed that involving people living with dementia (and their carers) in the design of services was likely to be a positive future development. The also agreed with the points around the importance of a single named professional, and of face to face contact for both the provision of information, and to allow any concerns to be raised and addressed. The committee agreed that the recommendations to "provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care", and to "arrange an initial assessment of the person's needs, which should be face to face if possible" matched with the points raised here.

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				The primary request from our service users is that they have a named professional throughout their journey, not just after diagnosis and not just once a year with a review. Diagnosis is very scary and unlike patients with e.g. cancer they are not given someone who they can rely on and help them navigate through services and support.	
Association for Family Therapy and Systematic Practice in the UK	short	5	24	What "meaningful care" means is open to debate. It would be helpful to define this further – meaningful to whom? And how can meaningfulness be measured or ensured? Perhaps tying this in with the principles of person-centred care might be useful? For example, using the term 'person-centred care' as this is specifically defined, might be more helpful. If 'meaningful care' differs from person-centred care, it is important to know how it differs.	Thank you for your comment. The committee agreed it was appropriate to retain this wording, as it is a reflection of what it is describing in the Prime Minister's Challenge.
Association for Family Therapy and Systematic Practice in the UK	short	6	23-24	We welcome recognition of "the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing."	Thank you for your comment and your support for this section.
Association for Family Therapy and Systematic Practice in the UK	short	7	1-3	The comment "Finally, the principles emphasise the importance of taking account of the needs of carers (whether they are family and friends or paid care-workers) and supporting and enhancing	Thank you for your comment. The format used here is solely chosen to make a demarcation between the points around the person living with dementia, and the point around carers.

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				their input." This is not listed as a bullet point and may lead to it being given lesser importance than the principles of person centred care. We think consideration should be given to this point being presented as a bullet point, too.	
Association for Family Therapy and Systematic Practice in the UK	short	8	15	Refers to offering people information about local support groups. Does this refer to support groups for people with dementia, family members, whole families or carers or all of these groups? Would be helpful to have more definition / prompts.	Thank you for your comment. The committee agreed that all of these groups would be relevant to mention, and it would depend on what services are available in the local area.
Association for Family Therapy and Systematic Practice in the UK	short	15	21-22	This says: Do not offer interpersonal therapies to treat the cognitive symptoms of mild to moderate Alzheimer's disease. We assume that this recommendation does not rule out using a systemic / family therapy approach to families with conflict and distress related to the diagnosis of dementia in a family member. This may be covered by the statement on page 4 lines 20-21 "The guideline does not cover every aspect of dementia care or support, or areas where recommendations would be the same for people with or without dementia." However in our opinion, dementia can add a specific burden in terms of likelihood for family conflict and the resultant distress to both the person living with dementia and their family member. This is an	Thank you for your comment. The committee agreed that your interpretation of this recommendation is correct. The recommendation is solely that interpersonal therapy not be offered to treat "the cognitive symptoms of Alzheimer's disease." If people living with dementia had another condition or problem for which interpersonal therapy were indicated, the committee agreed it would be correct to offer them to people living with dementia in the same way as those without.

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				area where systemic therapists working in older people's services have particular expertise and consideration of this therapeutic avenue might be worth including in the guideline.	
Association for Family Therapy and Systematic Practice in the UK	short	28	11-13	Says: Health and social care professionals advising people living with dementia should be trained in starting and holding difficult and emotionally challenging conversations. This might have considerable training and cost implications.	Thank you for your comment. The committee noted this concern, but agreed the clear evidence that this training was effective in improving the experience of people living with dementia justified its inclusion in the recommendations.
Bangor University	Full	108	30-31	'If Alzheimer's disease is suspected, include a test of verbal episodic memory in the assessment.' This is sound advice, that would be improved by examples of the type of tests that the committee had in mind as being helpful. These might range from the 3 item free recall on the MMSE, the name and address on the ACE-R to sub-tests of the Wechsler Memory Scale. However, we are concerned that readers might gain the impression that a cognitive test in a single domain suffices in a diagnostic assessment. In cases where the diagnosis is not clear cut, a neuropsychological assessment covering the whole range of cognitive functions is needed (to assess global impairment), and in straight-forward cases a wide-ranging scale such as the ACE-R may serve this purpose. Thus	Thank you for your comment. The committee agreed the evidence did not enable them to identify a preferred verbal episodic memory test to recommend. However, to address the concerns about this being undertaken at the expense of more detailed testing, two changes have been made to the recommendations. First, reference has been added to "cognitive testing" as part of the initial specialist assessment, to make clear the verbal episodic memory test should be part of broader cognitive testing. Secondly, a specific recommendation has been added around formal neuropsychological testing for people with an unclear diagnosis: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or

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				this recommendation – the only one regarding cognitive assessment in a specialist setting – runs the risk of being misleading.	• what the correct subtype diagnosis is."
Bangor University	Full	108	4, 14-16	We were surprised not to find any mention of the GP-Cog (Brodaty et al 2002; JAGS), which has the advantage over other scales of having a brief informant questionnaire built in – easier to administer in primary care than IQCODE. For primary care use, I think this scale should be considered.	Thank you for your comment. The committee were aware of the use of the GPCOG in practice. However, they noted that the GPCOG has only been tested as a screening test, and no evidence currently exists on the accuracy of the test in a population of people with suspected dementia. The committee noted that studies are likely to find better diagnostic accuracy in an unselected population than one with suspected dementia (as many people in the study will have no cognitive impairment, and therefore will be easily classified by the test), and therefore agreed it was appropriate to recommend only those tests shown to have sufficiently good properties in the relevant population.
Bangor University	Full	109	9-24	'If the diagnosis is uncertain and Alzheimer's disease is suspected…' ; in this section new diagnostic procedures are being recommended that appear to us to be beyond the capacity of the memory assessment services with which we have worked over many years. We would welcome clarity as to what is meant by 'if the diagnosis is uncertain'; does this mean a) that it is uncertain whether or not the person has a dementia or b) the sub-type of dementia is uncertain? If the	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these test could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all

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				latter, then we wonder what the cost-benefit analysis of sub-type determination is – especially for older age groups, where it is well-established that mixed sub-types are the norm, and where, as the draft guideline states CSF evaluation is less accurate. There needs to be a balance between full investigation and the benefits gained, determined on a case by case basis. In the hard working, accredited memory services we have worked with, one of the factors in extending the period required for a diagnosis to be made has been the waiting time for 'specialist' investigations such as MRI scans. More resources would be needed for timely access to the new investigations recommended here, and we would suggest that these resources might be equally, if not more, valuable used in providing post-diagnostic support for those who are diagnosed.	the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
Bangor University	Full	300	4-6	We have looked at the recommendations, and the underlying rationale, in some detail, because we have participated in many of the largest UK trials of approaches including cognitive stimulation, reminiscence and cognitive rehabilitation. We have also led the Cochrane reviews of cognitive stimulation (2012) and of reminiscence therapy, which is due to be	Thank you for your comment. Please find below a response for each of the papers you cited. Thank you for pointing out the error with the Woods data – this has now been corrected wherever it appeared. Regarding Eritz (2015), there was variability between the different non-pharmacological interventions. Therefore,

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				published early March 2018. We appreciate the huge volume of work that has gone into the reviews and meta-analyses in the draft guidelines, and the complexity of interpreting the world-wide literature. In relation to reminiscence therapy, the Cochrane review has drawn on a similar pool of studies, although some different decisions have been made regarding studies to include in meta-analyses. We noted that (appendix H, p120) Woods 2012/2016 is included in studies using the ADCS-ADL – this is incorrect. We also noted that (appendix H, p124) Eritz et al are included in the individual reminiscence therapy analysis – our reading of this paper suggests that the study did not include any formal reminiscence work with individual patients. Leaving aside any errors or differences in interpretation, our overall results are similar. We found overall a very small effect on cognition (14 studies SMD 0.11; 95%CI 0.00 to 0.23) and no overall effect on quality of life. The smaller number of studies (nine) using the MMSE showed a mean difference of 1.87 points (95%CI 0.54 to 3.20). However, we found a great deal of inconsistency, and as well as the individual v group v joint reminiscence sub-group analyses	interventions were grouped together into categories if they shared the same characteristics. For example, Eritz (2015) evaluated a life history intervention involving semi structured interviews with people living with dementia and/ or a proxy family carer or relative regarding residents' childhood, friends, personality and life events. This life intervention was categorised as reminiscence therapy which also uses life stories to improve psychological well-being. The overall quality of life SMD at follow-up (0.26, 95%CI 0.03 to 0.49) was downgraded for impression because 95% CI crossed 1 line of a defined MID interval. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations,

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				that NICE have undertaken we found that whether the study used a care home population or a community sample made some difference to the results obtained. In care homes, there was an improvement in quality of life (3 studies; SMD 0.46; 95%CI 0.18 to 0.75), but not in community settings. In relation to cognitive stimulation, the effects on cognition are well-established, and there was also – in our view more importantly - an effect on quality of life in our 2012 Cochrane Review. We consider this case has been strengthened by the Orrell et al 2014 maintenance cognitive stimulation study. Examining the meta-analyses of this outcome for cognitive stimulation (appendix H, pp. 102-103), it appears that the mid-point evaluation in this study has been included as 'postintervention' and the final evaluation, at the end of the 6 months of once a week sessions has been included under 'follow up'. We note that the overall quality of life SMD at follow-up is 0.26 (95%CI 0.03 to 0.49), which would appear to be above the pre-determined threshold of 0.2 for a meaningful clinically important difference, and so we would suggest that this provides evidence for the broader effect	a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				of cognitive stimulation, beyond cognition. We have previously shown, of course, that the changes in cognition mediate the changes in quality of life in cognitive stimulation groups (Woods et al; 2006 Aging & Mental Health, 10, 219-226). We note that the improvement specifically on the QoL-AD is 1.87 points, which falls short of the 3 point difference the committee established as the MID for this scale – this is a tough test, reflecting an SMD of around 0.5. In summary, we are suggesting from our examination of the evidence that: a) The committee distinguish between the benefits of interventions for people with mild to moderate dementia living in care homes, compared with those living in the community. b) The committee recognise the effects of cognitive stimulation on quality of life as well as on cognition. It is noteworthy that in the maintenance cognitive stimulation trial (Orrell, 2014), no difference in outcomes between care home and community settings was found, so this is probably an issue largely for reminiscence therapy.	

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				We have read with interest the committee's thinking that has led to recommendation 75. We do not consider that the recommendation to include elements of cognitive stimulation and reminiscence therapy in structured group activities is supported by the evidence, and cannot be justified on the basis that cognitive stimulation includes elements of reminiscence. These are distinct groups of approaches, each with a large body of work beyond RCTs developing understanding of concepts and mechanisms of change. Reminiscence in particular comes in many shapes and forms, with individual life story books probably the most promising aspect for the future. Where cognitive stimulation considers aspects of the person's life story, this is brought into the present and changes over the years highlighted. There is one study that does include a mixture of reality orientation (an early form of cognitive stimulation), reminiscence and physical exercise (Tanaka 2017) that has been included in the NICE meta-analyses as a reminiscence study, but the evidence from this small study does not appear to us strong enough to recommend a mixed treatment approach of this type.	

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				A mixed treatment needs development and evaluation in its own right; we cannot imagine a similar recommendation being made for psychological therapies in other domains, where generally the evidence suggests that following one model produces the best results (even if the choice of model is less crucial). We note that the committee consider it possible that any effects of these interventions is due to effects not specific to the actual treatment modality e.g. simply meeting as a group. We considered this possibility in our 2012 Cochrane review of cognitive stimulation, and were not able to identify different outcomes for those studies with some form of attentional control. We are also concerned regarding the recommendation being restricted to those not already accessing them (structured group activities). If they are currently being offered, this is typically as a result of the 2006 NICE guideline and resulting MSNAP accreditation criteria. Any recommendation regarding future availability of psychosocial intervention groups does not need this restriction.	

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				We also note that the committee consider the interventions discussed here as being 'intensive' (p 299). We note that the interventions both in the REMCARE and maintenance cognitive stimulation trial comprised one session a week, and we would suggest this is hardly intensive in the context of dementia. Early studies for example delivered sessions up to 5 days per week. In conclusion, we would re-frame the recommendation as follows: **"Offer structured group activities, including cognitive stimulation groups and reminiscence groups, to people living with mild to moderate dementia in care homes and cognitive stimulation groups to people living with mild to moderate dementia in community settings."**	
Betsi Cadwaladr University Health Board	Short	3	5	Fronto temporal dementia should be included here	Thank you for your comment. This has been included as suggested.

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Betsi Cadwaladr University Health Board	Short	10	22	Apart from the assessment of verbal episodic memory if a diagnosis of Alzheimer's disease is suspected, there is no mention of the use of cognitive assessment. This is a serious omission. In addition to being an important route to diagnosis and to the identification of subtypes of dementia, cognitive assessment should be able to answer questions that people have about their cognitive abilities and provide them with an account of their strengths and weaknesses (Clinical Psychology in the Early Stage Dementia Care Pathway, The British Psychological Society, 2014).	Thank you for your comment. The committee noted this concern, and agreed the recommendation on initial assessment in specialist settings should be expanded to mention cognitive assessment, specifically: "Diagnose a dementia subtype (if possible) if initial specialist assessment (including a neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out." They also agreed it was appropriate to add a specific mention around neuropsychological testing for people with an unclear diagnosis to this section: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is."
Betsi Cadwaladr University Health Board	Short	12	18	Apart from the assessment of verbal episodic memory if a diagnosis of Alzheimer's disease is suspected, there is no mention of the use of cognitive assessment. This is a serious omission. In addition to being an important route to diagnosis and to the identification of subtypes of dementia, cognitive assessment should be able to answer questions that people have about their cognitive abilities and provide them with an account of their strengths and weaknesses	Thank you for your comment. The committee agreed it was appropriate to make 2 modifications to the recommendations to address this concern. First, a reference to cognitive testing has been added as part of the initial assessment in specialist services. Secondly, an additional recommendation has been

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					added around the use of neuropsychological testing; specifically: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is."
Betsi Cadwaladr University Health Board	Short	29		'Specialist clinicians are those with appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in diagnosing and treating Alzheimer's disease'. This list does not fully reflect a multi-disciplinary approach to assessment, management and support for people with dementia and requires the specific inclusion of Clinical Psychologists and Occupational Therapists, both of whom have essential roles in the delivery of these services.	Thank you for your comment. The committee were keen to point out that this definition solely referred to the question of who should give advice before pharmacological treatment for Alzheimer's disease is started. It was not intended as a more general statement around who would count as a specialist clinician. The final version of the guidance should make this point clearer.
Biogen	Short	7	15	Can the statement be broadened to include staging and causes of disease – even if they are in an earlier stage of the disease continuum (eg prodromal AD)	Thank you for your comment. The committee agreed there were many factors that would influence the information relevant to a person at a given time, and that the terms "circumstances" and "stage of their condition" appropriately

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					captured the important features of how this information should be tailored.
Biogen	Short	9	18	Would it be useful to suggest some criteria for when to suspect dementia? Eg cognitive complaint, care giver feedback	Thank you for your comment. The guideline did not contain a review question on the signs and symptoms that should make someone suspect dementia, and therefore the committee were not able to make any recommendations on this topic.
Biogen	Short	11	15-26	We would highlight the importance of these biomarkers (and additional ones, such as amyloid PET) earlier in the disease continuum, especially with possible DMTs in the future. We wonder if a statement advocating referral to a clinical trial could be added also?	Thank you for your comment. Whilst the committee did not believe it was appropriate to advocate referral to specific clinical studies, they did agree it was appropriate to add a general recommendation to the guideline to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
Biogen	Short	16	1	Could a comment be added to acknowledge ongoing research into AD, including possible future DMTs?	Thank you for your comment. The committee agreed that, in the absence of particular DMTs that could be recommended for research at this time, this was not something that could be considered within the guideline.
Biogen	Full and Short	General	general	General comment : whilst we appreciate that these guidelines are focused on (overt) dementia, we feel that it would be useful to broaden to reflect the course of disease in conditions such as Alzheimer's (AD). In the case of Alzheimer's, there is a spectrum of disease which ranges from preclinical AD, to prodromal (pAD) / mild cognitive impairment (MCI) due to AD, to overt, severe Alzheimer's dementia. For patients with cognitive symptoms (pAD/MCI) the issues faced	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.

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				by them and their relatives will be similar to those of patients with overt dementia – ie need for a diagnosis, need for a care plan (to include potential interventions – lifestyle or pharmaceutical (via trials)) – it would be great if the guidelines could be broadened to include pAD/MCI due to AD. A number of current molecules in development for the treatment of AD are focused on modifying the course of treatment – so called disease modifying therapies (DMTs). It is postulated that these DMTs will have greatest impact when used earlier in the disease spectrum (pAD/MCI due to AD) and therefore it would be useful if these guidelines could include some reference to the disease continuum. In this context, the biomarkers mentioned in the guidance would be of great importance in the earlier disease setting, as could additional biomarkers such as amyloid PET or CSF determination of amyloid pathology. Could the guidelines be adapted to include and to think about potential future therapies?	
Biogen	Full	10	1	Description of dementia should be broadened to include/reflect prodromal/MCI due to AD. It is appreciated that the guidelines are dementia	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make

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				specific, but feel that this document should also include information on earlier forms for the reasons highlighted above.	recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Biogen	Full	10	20	Again, if looking at why this guidance is needed, it would also be important to consider the needs of patients/carers with earlier forms of AD (ie prodromal/MCI).	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Biogen	Full	20	Table 1	Please specify who these MIDs are reflective of (as MID is reflective of where in the disease the patient is). As we move earlier in the disease spectrum, the MID for early stage patients is unlikely to be the same as for later stage patients.	Thank you for your comment; this information has been added.
Biogen	Full	29	35	Please specify some recommended, evidence-based examples of tests as this would be useful for clinicians.	Thank you for your comment. The committee agreed that the evidence did not enable them to identify clear preferences as to which tests should be used, and that because this recommendation is for people in specialist dementia diagnostic settings, they agreed this terminology should be familiar to people undertaking these assessments.
Biogen	Full	30	18	As variation in assays exist, would it be useful to specify minimum standards?	Thank you for your comment. The committee agreed there was not currently evidence to include recommendations in the

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					guideline on this topic, but agreed it was an important implementation issue for local areas to consider.
Biogen	Full	30	18	CSF testing in the UK could prove a challenge, as the number of sites offering the assays are limited.	Thank you for your comment. The committee agreed this was an issue, and noted that this recommendation should affect only a limited number of people who cannot be diagnosed with simpler investigations, and that FDG-PET and perfusion SPECT were mentioned as alternatives in the guideline.
Biogen	Full	30	26	Query including specificity/sensitivity ranges for ages? Does this data exist? This would help to interpret data and for clinicians to decide in what age ranges these tests may not be useful	Thank you for your comment. The committee noted that because the majority of the CSF studies were undertaken in a younger population, there was not good data to help calibrate differences in thresholds by age.
Biogen	Full	31	15	Could this be an opportunity to advocate biomarkers for patients with MCI? To ensure a more accurate diagnosis? And also an opportunity to include some minimum standards for follow up for MCI patients?	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Biogen	Full	44	3-6	We would agree that these are important questions to be addressed	Thank you for your comment.
Biogen	Full	47	1-20	MCI included in analyses but categorised as no dementia. This downplays the importance of prodromal/MCI due to AD in the continuum of disease	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and

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					this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Biogen	Full	73	Section 5.1.4.6	The utility of biomarkers should be expanded to include their value in diagnoses of prodromal AD/MCI due to AD. Currently their value in overt dementia is stated (see earlier comment)	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Biogen	Full	98	Table 5.1.5.1	With regards to MOCA, could they provide the evidence/reference that this test is not popular?	Thank you for your comment. The committee noted that the MOCA did not show any evidence of superior accuracy to the shorter tests recommended, and therefore agreed it was appropriate to recommend those tests that could be completed in a shorter amount of time, if they provided the same value at this stage of the diagnostic process. The full explanation is given in the "evidence to recommendation" section of the diagnostic chapter, and an extract of the relevant section is given below: The committee also noted that more complex (and therefore time-consuming) tests did not appear to be more effective at detecting dementia than shorter and simpler tests, and it was therefore a more efficient use of resources to use these briefer tests within a time-constrained primary care setting."

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British Acupuncture Council	Full	271	13-14	Most of the 18 excluded acupuncture papers (Appendix F) were removed because they were not English language. Given that acupuncture is an integral part of Chinese medicine, that much of the research on it is Chinese, and that all of the RCTs to date on acupuncture and dementia are Chinese this is a major problem if you are aiming to get a good idea of existing research on the subject. None of the other interventions considered is in this situation and it introduces a possible bias to your review.. We appreciate that there would be practical difficulties and expense in including Chinese language papers but this is increasingly the approach taken by Cochrane groups	Thank you for your comment. The exclusion of papers not in English is a consistent approach taken throughout NICE. The committee noted this led to particular problems with the evidence base in certain areas, and hope that greater translation of papers published in other languages to English would enable a greater volume of evidence to be captured in the future.
British Acupuncture Council	Full	295	19-21	For the two included acupuncture trials you calculated a mean difference of 1.88 in favour of acupuncture (vs no acupuncture) for the MMSE outcome (Appendix G). This is above the minimal clinically important difference value used for the guideline (1.4) but it's not statistically significant. Partly this is because of the heterogeneity in the two studies you've chosen and partly because of the small numbers. Both of these problems would have been lessened if Chinese language studies had also been included. In Zhao et al's (2015)	Thank you for your comment. The exclusion of papers not in English was a consistent approach taken throughout the guideline. The committee noted this led to particular problems with the evidence base in certain areas, and hope that greater translation of papers published in other languages to English would enable a greater volume of evidence to be captured in the future.

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				systematic review on acupuncture for Alzheimers the meta-analysis mean differences for the MMSE outcome were: a) Acupuncture vs drugs (n=6 trials): 0.54 (95% CI 0.02–1.07) b) Acupuncture + donepezil vs donepezil (n=3): 2.37 (95% CI 1.53–3.21) c) Acupuncture vs no treatment (n=1): 3.74 (95% CI 1.34–6.14) This suggests that a more complete literature review would have generated clinically and statistically significant results	
British Acupuncture Council	Full	298		Despite the above we can understand why you could not recommend acupuncture. Although both the recent (English language but drawing on English and Chinese databases) systematic reviews on this topic (Zhao 2015, and Cao 2013) found clinically significant benefits for acupuncture we would have to class the evidence as weak positive or unclear due to its low quality. This situation will change: Chinese trials are increasingly of better quality and more of them are being published in English (at least one more since your literature search). We would suggest that there is enough preliminary evidence for a	Thank you for your comment. The committee agreed that if higher quality research was published in the future showing clinical benefits of acupuncture, this would need to be considered in future updates of the guideline. The committee noted the suggestion for additional research in this area and would welcome additional English language publications, but agreed that there were currently higher priorities for future research in dementia that should be recommended.

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				research recommendation: there is a complete shortage of clinical trial data for a UK, or UK comparable setting.	
British Association for Psychopharmacology	Short		1.13	It might be helpful to refer to the core competencies for dementia care enshrined in the Health Education England documentation. https://www.hee.nhs.uk/sites/default/files/documents/Care%20Navigation%20Competency%20Framework_FINAL.pdf	Thank you for your comment. The committee noted the existence of this (and other) HEE framework documents that could be useful in dementia, but agreed it would not be appropriate to pick out 1 or 2 of these to refer to over and above other advice on training and competencies.
British Association for Psychopharmacology	Short		1.1.11	It is open to debate as to when is the right time to offer advice on advance care planning and guidance. I think perhaps the word "timely" rather than "early" would be better as most practitioners would agree that it can sometimes be too early to provide information on advance care planning e.g. at the first clinic appointment.	Thank you for your comment. The committee discussed this issue and agreed there was an important balance between early opportunities to discuss topics such as advanced care planning, and not introducing at an inappropriate stage. The committee stressed that early did not necessarily mean at the first opportunity or first appointment. However, they did also note the evidence showed staff were often reluctant to initiate these discussions, and people often wanted to have these conversation before they are currently offered them. They therefore agreed "early" was the appropriate word to use, and noted that since the recommendation was phrased as "offer", there would be nothing to stop an individual deciding it was earlier than they wanted to start these conversations, and that it would then be appropriate to offer additional opportunities to discuss at a later date.

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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British Association for Psychopharmacology	Short		1.1.2	I think the use of the term "simplify" text is somewhat patronising in that it suggests that people with dementia need things produced in a simple way – in many ways this is the antithesis to person centred care and I am sure the committee will find, if they are minded, a better and less patronising word for this.	Thank you for your comment. The committee discussed this wording and agreed that the current wording is clear and unambiguous, and should therefore be retained. They were in agreement that the use of clear and simple text was not patronising, but a basic part of good information provision that could and should often be applied more widely across the healthcare system.
British Association for Psychopharmacology	Short		1.2.11	I would have thought reference to the generally approved diagnostic criteria such as the International Classification of Diseases (ICD) might be more useful for clinicians rather than going into the very specialist diagnostic criteria, which are often used for research.	Thank you for your comment. The committee noted that the current ICD classifications are somewhat out of date, and therefore it was appropriate to refer to more modern criteria. However, they agreed it may well be appropriate to refer to the ICD10 classification, once that is finalised.
British Association for Psychopharmacology	Short		1.2.12	Going straight to detailed Cerebrospinal Fluid (CSF) examination or a PET scan seems clinically very inappropriate and the remarkable statement that "if one does not work try the other one" will, in untutored hands, cause a great deal of unnecessary upset for patients and their families. Someone reading this might think that a person in their mid-eighties who has mild loss of memory and in whom the diagnosis of Alzheimer's disease or mild cognitive impairment is uncertain should have a CSF examination and, if this does not give a diagnosis should then have a PET scan, I would	Thank you for your comment. The committee noted that the 'consider' recommendations for CSF examination and imaging came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF and imaging earlier in the diagnostic pathway, and to counter that conception agreed it

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				have thought some sort of phrase covering this would be important and I suspect that the use of the work "consider" gives this much more traction than is justified. To have the same number of pages talking in great detail about brain scans as it does for the section on person centred care, gives the wrong impression.	was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed this should address any concerns about the guideline advocating a sudden expansion in the use of complex diagnostic tests, or their use in determining if someone has dementia at all, rather than to support subtyping.
British Association for Psychopharmacology	Short		1.2.2	Probably one of the commonest diagnostic tests is the GP Cog and it would be appropriate to mention this. The committee make reference to case finding and PHE's screening committee have said, quite rightly, that screening is not appropriate and yet, three of the six tests suggest that it is a screen. Also, it may be that practitioners are not used the three of the six tests and the test your memory is a self-administered rather than a clinician administered test.	Thank you for your comment. The committee were aware of the use of the GPCOG in practice. However, they noted that the GPCOG has only been tested as a screening test, and no evidence currently exists on the accuracy of the test in a population of people with suspected dementia. The committee noted that studies are likely to find better diagnostic accuracy in an unselected population than one with suspected dementia (as many people in the study will have no cognitive impairment, and therefore will be easily classified by the test), and therefore agreed it was appropriate to recommend only those tests shown to have sufficiently good properties in the relevant population.

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					The committee noted that although there were differences between the six tests recommended (whether or not they were initially designed as screening tests, self-administered versus clinician-administered) they all showed sufficiently good diagnostic accuracy to be useful tools in guiding referral decisions in primary care.
British Association for Psychopharmacology	Short		1.4	It is very helpful to have clear guidance on the things not to give - reference to aromatherapy would be helpful.	Thank you for your comment. The committee agreed it was appropriate to make "do not offer" recommendations in areas where there was no evidence of benefit from interventions. For aromatherapy, whilst the evidence base was limited, there was some evidence of potential benefits on agitation in people with severe dementia. The committee agreed this evidence was not sufficient to make a positive recommendation, but also that it was not appropriate to make a negative recommendation when there is some evidence there may be potential benefits.
British Association for Psychopharmacology	Short		1.2.2 3	It is important to note that national initiatives for raising awareness of dementia care	Thank you for your comment. The committee noted that this recommendation focused solely on case finding in a population with no clinical suspicion of dementia, and agreed that generally raising awareness of dementia among health and social care professionals was a fundamentally different and important issue. The committee were also aware of specific policy initiatives (such as the dementia CQUIN) and it has been made clear within the guideline that this recommendation is not meant to affect the interpretation of that pre-existing policy.

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British Association for Psychopharmacology	Short		1.2.27	Using some less traditional language of "refer" "and multidisciplinary" phrases feels outdated and taking advice from dementia advisors who can be based at primary care seems to be appropriate. Reference should be made to the current review of the Mental Health Act and the implications that will have in terms of capacity would be important.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment." A cross-reference has now also been added to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018), which the committee agreed was the appropriate place for issues around the Mental Health Act to be considered.

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British Association for Psychopharmacology	Short		1.2.6	I think it is an important point to make that not everybody with suspected dementia needs to be referred to a specialist dementia diagnostic service. There are very good examples where the diagnosis can be made in primary care by a GP who knows the person well. For example, an elderly person who has been a long-time resident of a care home who has developed some cognitive impairment in whom the GP has done all the various tests is a situation where it would be clinically inappropriate for that person to be removed and taken to a memory service and subjected to an MRI scan. I have sent examples of this to Harry Allen some time ago. This would be counter to good clinical practice. Many colleagues in Primary Care are able to make a diagnosis and can use the advice of support of specialist memory services without a formal referral being made – perhaps it is the word "refer" that could be amended to reflect the breaking down of barriers between primary and secondary care which is to the benefit of people with dementia and their families.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
British Association for Psychopharmacology	Short		1.3.6	I would have thought some reference for marginalised group would be appropriate.	Thank you for your comment. The committee agreed there were particular issues around a number of marginalised groups, both in terms of the general difficulties these groups

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					have in accessing healthcare, and specific issues in relation to care from dementia. The committee noted that no specific evidence was found to enable recommendations on how care should be tailored to best meet the needs of this group, but agreed the recommendations on making care accessible to as many groups as possible and tailoring information and interventions to the individuals needs and preferences were relevant to this issue, as were the references in the guideline to relevant pieces of legislation, including the Equality Act. The committee agreed that it was not appropriate to try and write an exhaustive list of all the groups who special attention would be needed for, as this risked making it seem that any group not mentioned did not have these needs, but noted that all groups covered by the Equality Act would necessarily have to be considered to see if additional or modified support was required.
British Association for Psychopharmacology	Short		1.5.4	It is a great advance to say that one of the anti-Alzheimer drugs can be prescribed by people other than specialists.	Thank you for your comment and your support for this recommendation.
British Association for Psychopharmacology	Short		1.2.8	Many people reading the guidance will not know what a verbal episodic memory test is – giving an example would be helpful.	Thank you for your comment. The committee agreed it was appropriate to keep the phrase "verbal episodic memory" as the most specific and accurate term available, but that the evidence was not sufficient to be able to recommend one test over the others. However, they did agree it was appropriate to

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					add a definition of this to the guideline to ensure there was no misunderstanding of what was meant.
British Association for Psychopharmacology	Short		1.2.9	In previous NICE guidance it has been suggested that a brain scan is not necessarily in established disease and reflecting this here would be useful.	Thank you for your comment. The committee agreed with this suggestion and an additional note has been added to the recommendation to "be aware that structural imaging is not always needed, if dementia is well established and the subtype diagnosis is clear."
British Association for Psychopharmacology	Short		1.4.7	A definition of interpersonal therapies would be useful as there is some evidence that psychotherapy can help people with early Alzheimer's disease.	Thank you for your comment. A definition has been added to the guideline, and the committee were keen to stress this was a recommendation not to use interpersonal therapy to treat the cognitive symptoms of Alzheimer's disease. If people living with dementia had another condition for which interpersonal therapy were indicated, the committee agreed it would be correct to offer them to people living with dementia in the same way as those without.
British Association for Psychopharmacology	Short	General	General	I would like to congratulate NICE and the committee for all their hard word into producing such an excellent guideline.	Thank you for your comment and your support for the guideline.
British Association for Psychopharmacology	Short	3-5		In the background it might be worth mentioning the numbers of people diagnosed with dementia and it seems a shame to simply infer this from a publication now 6 years old that dealt primarily with antipsychotic prescribing. The last figures from NHS Digital is that in December 2017 there were 456,739 people on GP registers as having a formal diagnosis of dementia, of whom 441,782	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years. Specifically: "Finally, in December 2017, there were 456,739 people on GP registers with a formal diagnosis on dementia, up from approximately 290,000 people in 2009/10, with the majority of this difference accounted for by an increase in diagnosis rates."

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				were over the age of 65. The estimated prevalence in that age group of 647,013 gives a national diagnosis rate of 68.3%. This compares to 2009/10 where there were some 290,000 people on the register with an estimated diagnosis rate of around 40%. It would be good to reflect this to, I think, recognise the huge amount of work that has gone in to dementia from everyone around the country, not least members of the committee.	
British Association for Psychopharmacology	Short	3		A lot is talked about staff training – I think many people would regard this as a paternalistic and rather outdated way of describing "learning and education". It might be worth a note of explanation with regard to the devolved nations. Scotland, Northern Ireland and Wales have their own dementia plans and although the Prime Minister's Challenge 2020 is on behalf of the Prime Minister of the UK, and is certainly used as guidance for the devolved nations, it might be helpful to clarify this.	Thank you for your comment. The committee agreed to amend the heading of this section to training and education to address this point, but believed it was important to retain the word training as a key part of the recommendations. In common with all NICE guidance, decisions about whether and how to apply these recommendations in the developed regions are matters to be decided locally, as the guidelines are written solely for England.

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				Also, NICE Guidelines are used nationally and internationally, but there other guidelines used in the devolved nations that might be appropriate to make reference to this.	
British Association for Psychopharmacology	Short	6		The section on person centred care is very welcome and extremely important. As the committee knows the Alzheimer's Society / Dementia Action Alliance have produced a set of "We" statements which are an update of the original "I" statements and reference to these might be useful. The majority of practitioners are aware of these and they simply articulate good practice and recognise the rights and responsibilities of individuals.	Thank you for your comment, and for this information.
British Association for Psychopharmacology	Short	10	12	There should be some indication that infections should be examined for as a potential cause of cognitive decline that is independent to delirium. i.e. just excluding infections that are associated with delirium ignores the important finding that infections can contribute to cause cognitive decline without causing a delirium. Likewise they also contribute to behavioural and psychological symptoms. We are concerned that infections will only seem of importance in dementis in situations where it is causing delirium but would otherwise be ignored as non contributory.	Thank you for your comment. The committee noted this point, but agreed it was not possible to include an exhaustive list of all dementia mimics in the guideline, and this was not as significant an issue as the ones (such as delirium and depression) that are specifically mentioned in the recommendations.

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British Association for Psychopharmacology	Short	10	16	The term rapidly progressive dementia should be clearly defined. i.e. what time frame is considered rapid. We are concerned that rapid might be misconstrued to mean only dementias that develop over less than a week.	Thank you for your comment. The committee discussed this issue and agreed the presentation of rapidly progressive dementia was sufficiently clear it would be highly unlikely to cause confusion for GPs.
British Association for Psychopharmacology	Short	10	25	The advice for the use of structural imaging would benefit from a more structured approach and the use of structural scan considered when a rapidly progressive dementia is present should be changed to mandatory unless there are clinical contraindictions .It should be also mandatory in patients at high risk of treatable pathology e.g. under the age of 65 years or where there are doubts about the diagnosis. We are concerned that the current guidance is opening the door to poor clinical practice.	Thank you for your comment. The committee agreed this recommendation could have been phrased more clearly, and has now been changed to "offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis. Be aware that structural imaging is not always needed, if dementia is well established and the subtype diagnosis is clear." This is more in line with the recommendation from the previous version of the guideline, which many stakeholders raised as being appropriate to retain.
British Association for Psychopharmacology	Short	11	15-7	The emphasis on the use of PET scans and cerebrospinal fluid access over MRI scans seems to be divorced from clinical reality. It should be emphasised that these specialist investigations should only follow an MRI scan. I am concerned that clinicians seeing this list of idealistic preferences over what is currently available (i.e..CT or MRI scans) in the NHS will undermine any confidence in these guidelines overall.	Thank you for your comment. The committee noted that the 'consider' recommendations for CSF examination and imaging came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF and imaging earlier in the diagnostic pathway, and to counter that conception agreed it

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					was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed this should address any concerns about the guideline advocating a sudden expansion in the use of complex diagnostic tests, or their use in determining if someone has dementia at all, rather than to support subtyping.
British Association for Psychopharmacology	Short	11	28	The use of CSF over the age of 80 is almost certainly of no value. In anything other than a research setting.	Thank you for your comment. The committee agreed that the utility of CSF testing was lower in older people, and this was what led them to make a recommendation to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination."
British Association for Psychopharmacology	Short	12	20	CT head scans should also be used where MRI scans are contraindicated.	Thank you for your comment. This recommendation has been amended to follow this suggestion.
British Association for Psychopharmacology	Short	17	3	I think it would be appropriate to specifically mention old age psychiatrists as they are probably the commonest prescribers.	Thank you for your comment. The committee agreed that old age psychiatrists are likely to be the most common prescribers, but agreed it was appropriate to be more general in the recommendation to avoid giving the impression that other subtypes of psychiatry (such as learning disabilities psychiatrists) were not appropriate prescribers.

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British Association for Psychopharmacology	Full		1.10	I welcome the section on palliative care.	Thank you for your comment and your support for these recommendations.
British Association for Psychopharmacology	Full		1.1.11	Advanced care planning discussions do involve a lot of time if done properly. This would have some implications in terms of time at clinics. This will also have implications if there is a need for this at regular care review.	Thank you for your comment. This element of the guideline formalises what the committee believes is current practice, and therefore should not consume significant additional resources.
British Association for Psychopharmacology	Full		1.2.4	In non specialist settings the concept of functional assessment is very important but I doubt whether in primary care it would be possible or even necessary to use IQCODE or FAQ. This would add time to the average GP consultation – which would not be welcome. The AD8 is a very useful validated questionnaire which can help decide on the need for onward referral to expert opinion. It has been well validated	Thank you for your comment. The committee disagreed with this point, and noted that because neither of these instruments need the GP present to complete, there should no additional time needed for them to be included. As documented in the evidence to recommendation section for this question, "the committee commented that the IQCODE (Informant Questionnaire on Cognitive Decline in the Elderly) and FAQ had the advantage of being self-administered tests. It could therefore be completed in the waiting room by the informant. This could free up time in the appointment for the GP to listen to the patient and informant, potentially reducing the number of appointments needed to reach an initial diagnosis and saving money for the NHS." The committee also noted that although the AD8 has been validated as a screening test for dementia, only one study was identified in a population of people with suspected dementia, and this did not find the AD8 to have as high a diagnostic accuracy as the instruments recommended in the guideline.

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British Association for Psychopharmacology	Full		1.2.6	Good to mention anticholinergic burden	Thank you for your comment and your support for this recommendation.
British Association for Psychopharmacology	Full		1.5.3	These comments concerning memantine addition are very welcome	Thank you for your comment and your support for this recommendation.
British Association for Psychopharmacology	Full		1.5.4	"For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor, primary care prescribers may start treatment with memantine without taking advice from a specialist clinician". These comments are particularly welcome	Thank you for your comment and your support for this recommendation.
British Association for Psychopharmacology	Full		1.2.9	"Consider structural imaging to rule out reversible causes of cognitive decline". I feel that this is not strong enough. For a brain disorder structural imaging of the brain is very important. Perhaps "it is good practice or normal practice to perform structural brain imaging. Patients and carers expect a scan and in some centres the only way to be able to get a FDG-PET scan is to have a structural scan first.	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."
British Association for Psychopharmacology	Full		1.8.8	The reference to use of mirabegron is welcome. In clinical practice there is a lot of urinary frequency induced by cholinesterase inhibitors.This can lead to a lot of anti muscarinic prescription. Many clinicians are unaware of this	Thank you for your comment. The committee agreed with the importance of raising awareness of mirabegron as a treatment option in this population. However, since this recommendation comes from a NICE technology appraisal, it is not possible to do more than add a cross-reference to that appraisal within the

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				side effect. This side effect could be emphasised more in the guideline as it is so common and it would help with patient management.	guideline, as the wording of the recommendations themselves cannot be changed. The committee also noted that there were side-effects associated with cholinesterase inhibitors, but agreed that concerns around anti-muscarinic prescription were covered by the recommendation to "consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives".
British Association for Psychopharmacology	Full		1.7.10 and 1.7.11	This is a very difficult area. It is often very hard to judge depression in even mild moderate dementia. These statements reflect the evidence although is it absolutely clear that psychological treatments help mild to moderate depression and anxiety in people with mild to moderate dementia? In clinical practice specially with moderate dementia this does not seem to be easy to deliver.	Thank you for your comment. The committee agreed with all of these points, and that future research was necessary to try and address these issues. They therefore made the following research recommendation: "What are the most effective psychological treatments for managing depression or anxiety in people living with dementia at each stage of the condition?"
British Association for Psychopharmacology	Full		1.10.8 and 1.10.9	This section is very welcome. I do feel that better promotion of this type of information would lead to less inappropriate hospital admission and extreme intervention for patients with advanced dementia who are dying	Thank you for your comment and your support for these recommendations.
British Association for Psychopharmacology	Full	General	general	Might the committee consider saying that signing up to initiatives such as "Join Dementia Research" (https://www.joindementiaresearch.nihr.ac.uk/)	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of opportunities to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all

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				would be a good way to encourage people into reseach.	stages of the condition) about research studies they could participate in."
British Association for Psychopharmacology	Full	General	General	In summary the new guidelines, in my opinion, are helpful and improve upon the previous guidelines and the committee are to be commended on their hard work in bringing this together.	Thank you for your comment and your support for the guideline.
British Association for Psychopharmacology	Full	General	General	Crucial to any dementia work-up and subtyping is the physical and neurological examination – this is not mentioned in the guidelines. This is particularly important in individuals with early onset, suspected vascular aetiologies, parkinsonism and atypical presentations.	Thank you for your comment. The committee noted this concern and agreed it was appropriate to add in references to a physical examination as part of the initial assessment in primary care (recommendation 1.2.1), and a neurological examination as part of the initial assessment in specialist diagnostic services (recommendation 1.2.9).
British Association for Psychopharmacology	Full	General	General	Sleep apnoea – symptoms of which can masquerade as dementia or indeed can be associated with dementia is not mentioned.	Thank you for your comment. The committee agreed that sleep apnoea can be a dementia mimic. However, they agreed it was not possible to include an exhaustive list of all dementia mimics in the guideline, and this was not as significant an issue as the ones (such as delirium and depression) that are specifically mentioned in the recommendations.
British Association for Psychopharmacology	Full	General	General	Can it be made more explicit the reasons why amyloid PET imaging should not be considered as part of the diagnostic work-up?	Thank you for your comment. The committee agreed that the evidence base for amyloid PET imaging was not yet sufficient to make specific recommendations on its use within the guideline. However, the committee agreed it was an important area for future study, and therefore made a research

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					recommendation on the diagnostic accuracy on amyloid PET imaging. Specifically: "Does amyloid PET imaging provide additional diagnostic value, and is it cost effective, for the diagnosis of Alzheimer's disease and other dementias when compared with standard diagnostic procedures?" We have added some additional information on the committee's reasoning for this decision to the relevant section of the full guideline (the "other considerations" part of the table in section 5.1.5).
British Association for Psychopharmacology	Full	General	General	Whilst I appreciate that the current document is very much focussed on dementia management what is notable is the lack of focus on pre-dementia states, including for example mild cognitive impairment. This is surprising given the greater focus on potentially earlier diagnosis and that mild cognitive impairment is frequently encountered in diagnostic settings including in primary care and specialist services. Differentiating MCI from frank dementia is not discussed or elaborated on nor how services should manage, stratify and follow-up MCI cases most at risk of conversion to dementia.	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been passed to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
British Association for Psychopharmacology	Full	General	General	Despite making recommendations on areas for research there is no mention of how we might facilitate getting more people with dementia into	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a

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				research and clinical trials. Given the huge political impetus to deliver improved dementia research in the UK, it would be important that this is recognised in the document. In particular accessing research studies/clinical trials remains a major challenge in dementia. Connecting people with dementia with well established networks (DeNDRoN) and case registers (e.g. Join Dementia Research) could be mentioned.	recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
British Association for Psychopharmacology	Full	General	General	Atypical, familial or young onset cases should always be referred onto specialist services for further assessment.	Thank you for your comment. The committee agreed that no evidence was identified that enabled them to make specific recommendations around these issues, but did agree that the more unusual the presentation, the greater the importance of involving specialist services early.
British Association for Psychopharmacology	Full	General	general	The guidelines at the moment are quite Alzheimer's centric. I appreciate this is important given that AD epidemiologically is the dominant neurodegenerative dementia in the UK. However, this approach is perhaps to the detriment of the coverage of other dementias (e.g. DLB, FTD, vascular etc.) in the guidelines.	Thank you for your comment. The evidence searches conducted for the guideline looked for evidence on all subtypes of dementia, but more evidence was found on Alzheimer's disease than other subtypes for a number of the questions. In some situations the committee agreed that it was appropriate to extrapolate the evidence found for dementia subtypes including Alzheimer's disease to make recommendations for all people living with dementia, rather than just those with the specific subtypes in the research studies included in the evidence review however this was not always possible.

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British Association for Psychopharmacology	Full	General	General	Despite detailed analysis of the utility of core diagnostic symptoms of DLB (as derived from the consensus criteria as presented in Section 5.1.4.16 for example) the diagnostic utility of 2 or more of visual hallucinations, parkinsonism and REM sleep behaviour disorder in the diagnosis of Lewy body related dementias is not mentioned in the recommendations section (4.1). In addition, REM sleep behaviour symptoms can antedate the occurrence of Lewy body diseases (e.g. Parkinson's disease, DLB) by many years; the occurrence of this symptom in the presence of mild cognitive impairment significantly raises the probability that these individuals will convert to DLB.	Thank you for your comment. Whilst the guideline recommendations do not explicitly refer to these diagnostic symptoms, the recommendations do contain a reference to the International consensus criteria for dementia with Lewy bodies, which these symptoms form a part of. The committee agreed it was more appropriate to reference these validated criteria than to make recommendations around specific individual symptoms.
British Association for Psychopharmacology	Full	General	General	It can be particularly challenging to differentiate DLB from delirium given attentional difficulties, fluctuations, arousal problems and hallucinations occur in both conditions. This may need to be mentioned. See, for example, http://www.jamda.com/article/S1525-8610(16)30292-4/abstract for a further discussion on this topic.	Thank you for your comment. The guideline contained a specific review question on effective tools to differentiate dementia from delirium, and dementia with Lewy bodies was included within that recommendation. The committee made recommendations for specific tests that may be useful to differentiate dementia from delirium.

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British Association for Psychopharmacology	Full	Research recommendations		One major issue is related to development of agitation which is very common. These patients are usually on donepezil. One of the most common side effects of donepezil is agitation. The question in practice is whether the donepezil is contributing to the agitation and whether donepezil should be reduced or stopped or whether memantine should be added. The DOMINO study provided some information on more advanced dementia in relation to whether to stop donepezil or combine with memantine or add memantine. However it did not answer the question: for people taking donepezil who have agitation what are the best options eg reduce donepezil, stop donepezil, change to memantine or add memantine or other options???	Thank you for your comment. The committee agreed this was an issue. However, they also agreed that it would be difficult to conduct high quality research in this area due to problems recruiting a sufficiently large population with levels of agitation that would enable randomisation to answer this question. The committee therefore agreed that this was not a high priority for future research.
British Association for Psychopharmacology	Full	10		The only definition in the guideline is very poor/incorrect! If this intended as just a lay 'definition', then a proper definition should be given later which it isn't. I recommend NIA/AA	Thank you for your comment. The committee noted the guideline contains links to diagnostics criteria for specific subtypes of dementia, and that the included was a suitable 'lay' definition for the introduction to the guideline. Some edits have been made to this definition to improve the accuracy and clarity
British Association for Psychopharmacology	Full	29		Summary of Recommendations – This is the only bit most people will read so needs to be written with this in mind! My comments primarily refer to summary with links to body review. The sub-	Thank you for your comment. This is an issue that should only occur with the consultation version of the guideline. When the guideline is published it will appear on the website with all the headings included with the recommendations.

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				headings need to be included in the summary, in addition to the body text of the review or it becomes a bit confusing with just the numbered points.	
British Association for Psychopharmacology	Full	29	10-17 and 35-36	Section 4.1.2 advises on the use of variety of brief cognitive instruments. These certainly are suitable for primary care / non-specialist setting. It would be important, however, to make this explicit to avoid confusion over what tests might be advocated for use in specialist dementia diagnostic services. For example is the verbal episodic memory assessment (4.1.8, line 35-36) something which is conducted at the latter? The details of which tests are applied in what settings are evident elsewhere in the document but I think the majority of readers will look only at the summary of recommendations section.	Thank you for your comment. The final version of the guideline draws a clear distinction between tests to be used in the initial assessment in primary care, and tests that may be useful in specialist services. In particular, a reference to formal neuropsychological testing has been added to the specialist service setting: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is" Additionally, a definition of verbal episodic memory has been added to the short version of the guideline.
British Association for Psychopharmacology	Full	29	10-17	Choice of tests is fine, but should it say something about limitations? All of these will have validity issues if patient doesn't have good English. This is mentioned superficially in page 102 of the diagnostics section, which very few will read. This is a major problem in cities like Birmingham.	Thank you for your comment. The committee agreed there were a range of issues that could affect interpretations of test scores, including language, education, learning disabilities or age. It was for this reason the committee agreed it was not appropriate to set cut-offs to use for the particular tests, but they should instead be considered alongside a broader assessment including a history (including cognitive, behavioural and psychological symptoms), a physical examination and

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					appropriate blood and urine tests to exclude reversible causes of cognitive decline.
British Association for Psychopharmacology	Full	29	24-28	Section 4.1.5 advises that reversible causes of cognitive decline have been investigated. This may be suitable for delirium or medication derived problems, but often reversible causes can only be determined after specialist assessment and investigation (e.g. normal pressure hydrocephalus, space occupying lesions, vasculitis).	Thank you for your comment. The committee agree with this point, and this is the reason for the difference in language between the primary care section (where reversible causes of cognitive decline only need to be investigated before someone is referred) and the secondary care section (where reversible causes need to be ruled out before a subtype diagnosis is made).
British Association for Psychopharmacology	Full	29	20-23	Perhaps suggest these may be preferred to a cognitive test if English is not good	Thank you for your comment. The committee noted there was no evidence to enable them to make specific recommendations around people without good English proficiency, but noted that for these people, consideration should be given both to appropriate test to use, and how the results of those tests should be interpreted.
British Association for Psychopharmacology	Full	29	29-31	GP won't have a clue about rapidly progressive dementia – need for more detail	Thank you for your comment. The committee discussed this issue and agreed the presentation of rapidly progressive dementia was sufficiently clear it would be highly unlikely to cause confusion for GPs.
British Association for Psychopharmacology	Full	29	41-43	Add 'best contemporary'	Thank you for your comment. The committee noted that these criteria listed were likely to become out of date as time progresses, and therefore noted the recommendation only phrased them as examples of criteria that could be used, rather than recommending them as preferred criteria.

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British Association for Psychopharmacology	Full	29	35-36	Bit vague – 'test of learning and recall' would be better	Thank you for your comment. The committee agreed it was appropriate to keep the phrase "verbal episodic memory" as the most specific and accurate term available. However, they did agree it was appropriate to add a definition of this to the guideline to ensure there was no misunderstanding of what was meant.
British Association for Psychopharmacology	Full	29	37-38	This is interesting. Whilst I am no fan of scan all, this is too vague in my view.	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."
British Association for Psychopharmacology	Full	29	35-36	It is be important to bear in mind that many DLB patients are misdiagnosed as AD initially. Some of this stems from the fact that patients are not assessed adequately from the physical perspective (see earlier comment) and thus, for example, subtle signs of parkinsonism are not detected. There may also be a failure to ask about sleep symptoms (e.g. REM sleep behaviour symptoms as noted above) or a lack of explicit enquiry about visual hallucinations or cognitive fluctuations (core symptoms of DLB). Furthermore in section 5.1.6 – quite rightly the guidelines indicate that "If Alzheimer's disease is	Thank you for your comment. The committee agreed that it had made recommendations for all tests for identifying dementia subtypes on which there was robust evidence available. However, they did note the specific concern raised about signs of parkinsonism not being detected, and agreed it was appropriate to add reference to "an appropriate neurological examination" as part of the initial assessment in specialist services.

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				suspected, include a test of verbal episodic memory in the assessment." However whilst many DLB patients experience memory deficits they may have problems in other domains – for example, often having disproportionate deficits in visuo-spatial and visuo-perceptual function. These aspects are not addressed specifically in the guidelines.	
British Association for Psychopharmacology	Full	29	24	Should this link to delirium guideline?	Thank you for your comment. The guideline does include a cross-reference to the delirium guideline for both the prevention and treatment of delirium.
British Association for Psychopharmacology	Full	30	13-25	Having left any sort of structural imaging optional in 9, this perhaps needs expanding/clarifying. Lab ranges may be an issue. How many UK labs have established reliable ranges?	Thank you for your comment. The committee agreed these were important issues, but no evidence was identified that allowed them to make recommendations.
British Association for Psychopharmacology	Full	30	13-23	It is laudable that for diagnosing uncertain cases of AD there is a recommendation that we should examine the CSF or use FDG-PET. However pragmatically how available will CSF sampling be given that typical memory clinic services are in mental health trusts (and thus lack appropriate infrastructure to do testing) and led by health professionals not skilled in lumbar puncture? There would need to be a significant shift in mind-	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these tests could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all

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				set and investment needed to deliver this and/or FDG-PET (the latter which is also not widely available). In addition amyloid PET imaging (which is licensed) for example may be more accessible in certain services than getting CSF. The default back to SPECT HMPAO/perfusion imaging with its suboptimal sensitivity/specificity in AD seems is somewhat unsatisfactory (given higher sens/spec for other the imaging modalities).	the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed that the evidence base for amyloid PET imaging was not yet sufficient to make specific recommendations on its use within the guideline. However, the committee agreed it was an important area for future study, and therefore made a research recommendation on the diagnostic accuracy on amyloid PET imaging. Specifically: "Does amyloid PET imaging provide additional diagnostic value, and is it cost effective, for the diagnosis of Alzheimer's disease and other dementias when compared with standard diagnostic procedures?"
British Association for Psychopharmacology	Full	30	34-35	Fine, but if local nuclear med can't do DAT then MIBG this will be unreliable. What about polysomnography – not obviously mentioned and it's in revised criteria?	Thank you for your comment. The committee agreed that DAT scans and scintigraphy were the two tests with clear evidence of high diagnostic accuracy, and therefore these were the two it was appropriate to refer to in the recommendations.

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British Association for Psychopharmacology	Full	30	42-43	Not sure I agree with this as stated. Sure, a normal MRI (Kipps 0/1) wouldn't put me off but if the functional imaging was also within normal limits then the FTD diagnosis is certainly in question (possible not probable at best). This is particularly important as normal MRI and normal functioning imaging may indicate a treatable phenocopy	Thank you for your comment. The committee noted that a combination of multiple negative test results would certainly lead to questioning a working diagnosis, but noted that this recommendation was focused on not over interpreting the results of individual imaging tests.
British Association for Psychopharmacology	Full	30	44-45	Bit vague	Thank you for your comment. The committee agreed this recommendation was as specific as it was possible to be given the evidence available.
British Association for Psychopharmacology	Full	30	30-31	4.1.15 – recommends that EEG should not be used for the diagnosis AD. However as worded some may take this implicitly that EEG should not be used at all for dementia when actually it may have a place for atypical presentations (e.g. seizures / encephalopathy).	Thank you for your comment. The committee agreed that, for clarity, this recommendation should be modified to "do not use electroencephalography to diagnose Alzheimer's disease."
British Association for Psychopharmacology	Full	31	3-6	Link to delirium guideline	Thank you for your comment. The guideline does include a cross-reference to the delirium guideline for both the prevention and treatment of delirium.
British Association for Psychopharmacology	Full	31	13-14	Recommendation 4.1.26 "Only conduct case finding for suspected dementia as part of a clinical trial 13 that also provides an intervention to people diagnosed with dementia." I think some	Thank you for your comment. The committee agreed with this suggestion and a definition of case finding has been added to the guideline.

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				description early on is needed by what is meant by case-finding.	
British Association for Psychopharmacology	Full	34	18-37	Interesting. Not much relevant evidence here. Aupperle with CDR improving at 2 years sound very dodgy! Letting anybody prescribe will likely result in people staying on drugs with no individual evidence of efficacy. Agree longer term people in non-specialist care will stop earlier. This will have interesting implications for service structures if widely implemented. Considers dementia treatment generally but really DLB prescribing and monitoring should be restricted to specialists in my view. Why recommend changes if evidenced base for them is poor?	Thank you for your comment. The general feedback from stakeholders around allowing the prescription of cholinesterase inhibitors and memantine and primary care has been positive. However, the committee agrees that evidence does not yet exist as to whether it is safe for treatment to be initiated in primary care for other subtypes of dementia, and therefore the committee did not extend these recommendations to other dementia types, such as DLB.
British Association for Psychopharmacology	Full	34	38-44	In my view it should be with best tolerated oral drug – fortunately currently coincides with price	Thank you for your comment. These recommendations come from a part of NICE technology appraisal 217 that was not updated as part of this guideline, and therefore it was not possible to make changes to the recommendation.
British Association for Psychopharmacology	Full	34	8-11	Statement needs to include evidence after last technology assessment. Having old recommendation preserved in tablet of stone in a new guideline is very silly. Should include severe AD	Thank you for your comment. These recommendations come from a part of NICE technology appraisal 217 that was not updated as part of this guideline, and therefore it was not possible to make changes to the recommendation. The guideline does however include a recommendation to "offer memantine in addition to a cholinesterase inhibitor if

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					they have severe disease", which the committee noted should cover the area of concern.
British Association for Psychopharmacology	Full	34	45-48	Severity is now a non-issue – so irrelevant. Does raise highlight ethnicity issue though for the first time	Thank you for your comment. These recommendations come from a part of NICE technology appraisal 217 that was not updated as part of this guideline, and therefore it was not possible to make changes to the recommendation.
British Association for Psychopharmacology	Full	35	4-21	This is still fine	Thank you for your comment.
British Association for Psychopharmacology	Full	35	30-32	See comment 16	Thank you for your comment. The general feedback from stakeholders around allowing the prescription of cholinesterase inhibitors and memantine in primary care has been positive. However, the committee agrees that evidence does not yet exist as to whether it is safe for treatment to be initiated in primary care for other subtypes of dementia, and therefore the committee did not extend these recommendations to other dementia types, such as DLB.
British Association for Psychopharmacology	Full	35	41-43	More generally whilst readers are directed to the NICE Parkinson's guideline (NG71) with regard to the pharmacological management of Parkinson's disease with dementia, there is no elaboration in the guidelines on the management of non-cognitive symptoms in DLB. Whilst there are symptom overlaps with Alzheimer's disease, a number of symptoms are specific and troubling to people with DLB such as, for example, REM sleep	Thank you for your comment. The guideline did look for evidence on management of non-cognitive symptoms in DLB, but only limited evidence was identified, so the committee did not feel able to make recommendations. They therefore agreed it was appropriate to add an additional reference to the Parkinson's disease guideline to cover the management of non-cognitive symptoms, with a caveat around the need to potentially modify interventions for people with PDD and DLB.

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				behaviour disorder (as noted above), autonomic symptoms, drooling and parkinsonism and management of these are not specifically covered for DLB in the NICE Parkinson's guideline.	
British Association for Psychopharmacology	Full	35	22-23	Agree – a bit inconsistent with technology appraisal stuff above though	Thank you for your comment. This recommendation was an update of the recommendation from TA217 on when treatment should be stopped, and therefore there is no inconsistency, as the appraisal recommendation will be stood down upon publication of this guideline.
British Association for Psychopharmacology	Full	35	33-34	Agree. Should we be giving any advice on stopping ACHEI in LB patients? In my experience there is a significant risk of rebound, i.e. they get worse than they would likely have been if drug is withdrawn	Thank you for your comment. This guideline did not contain a question on stopping rules for cholinesterase inhibitors in people with DLB, and therefore it was not possible to make any recommendations on this topic.
British Association for Psychopharmacology	Full	35	35-36	Galantamine has worse tolerability than the other 2 in AD at effective doses??	**Thank you for your comment. The evidence base for galantamine in DLB and PDD is considerably less than for donepezil or rivastigmine, and it was for this reason the committee agreed it should be the third choice cholinesterase inhibitor in this group.**
British Association for Psychopharmacology	Full	35	39-40	Interesting advice – not sure of logic	Thank you for your comment. The committee noted the point estimates for the effectiveness of memantine were similar to those for cholinesterase inhibitors, although there was considerably more uncertainty, and therefore agreed it was appropriate to make a weak recommendation for its use in cases were cholinesterase inhibitors cannot be used.

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British Association for Psychopharmacology	Full	36	38-41	I think there needs to be a distinction between AD and other forms of dementia where drug risk issues are higher (e.g. DLB). No real distinction drawn either between different types of psychopathology or typical v atypical antipsychotics. All atypicals are not alike – no reliable evidence that quetiapine effective based on several trials. In fact whole section below on pharmacological BPSD management is very limited – needs more detail. In my view an evidence based statement could be made for SSRIs and possibly for ACHEIs and memantine	Thank you for your comment. The committee noted the majority of the evidence available for these drugs was from Alzheimer's disease, and therefore it was not possible to make specific recommendation for other subtypes. The committee also agreed that the evidence came from a sufficient number of different drugs that it was reasonable to make an overarching recommendation around antipsychotics. The committee agreed that there was a lack of detail in some of the recommendations made, but noted that this was a result of the limited evidence base in the area, including around SSRIs, cholinesterase inhibitors and memantine for the management of non-cognitive symptoms. The committee did note the specific concerns around the risks of antipsychotics in people with dementia associated with Parkinson's disease, and therefore agreed to add an extra bullet point to recommendation 1.7.3, stating that "for people with dementia with Lewy bodies or Parkinson's disease dementia, be aware these medicines can worsen the motor features of the condition, and in some cases can causes severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in NICE guideline on Parkinson's disease. Be aware that interventions may need to be modified for people living with dementia."
British Association for Psychopharmacology	Full	36	3-4	True but not exactly helpful. Next item (71, lines 5-6) is fine on its own	Thank you for your comment. The committee noted that there are a number of commonly prescribed medicines that clinicians are often unaware are associated with increased

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					anticholinergic burden, and therefore felt this was a useful awareness making recommendation to make.
British Association for Psychopharmacology	Full	36	25-26	Agree – no mention yet of Souvenaid. We don't prescribe them, but should we have a position on recommending or not?	Thank you for your comment. The committee agreed that at the current time there was no evidence of clinically meaningful benefits from souvenaid, and therefore it was appropriate that no positive recommendations be made for its use.
British Association for Psychopharmacology	Full	36	40-41	Neuroleptic sensitivity in DLB is not mentioned despite significant risks associated with the prescription of these medications in Lewy body dementias. In particular the current advice in the guidelines suggest antipsychotics can be offered to dementia patients (4.1.84) who experience hallucinations and agitation; this advice may be detrimental if that individual has underlying DLB.	Thank you for your comment. The committee noted the specific concerns around the risks of antipsychotics in people with dementia associated with Parkinson's disease, and therefore agreed to add an extra recommendation to this section, stating to "be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in NICE guideline on Parkinson's disease. Be aware that interventions may need to be modified for people living with dementia."
British Association for Psychopharmacology	Full	37	11-12	What is meant by mood stabilizer? No RCTs of lithium, CMZ unproven, but a clear evidence that valproate is harmful. Needs more detail, particularly in headline statement.	Thank you for your comment. The committee agreed it was appropriate to be more specific in the recommendation, and therefore it has been restricted to valproate rather than all mood stabilisers. Specifically, "do not offer valproate to manage agitation or aggression in people living with dementia, unless it is indicated for another condition."

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British Association for Psychopharmacology	Full	37	21-22	The guidance advises against the use of melatonin in dementia. Whilst I appreciate there is a lack of trials for melatonin in DLB and PDD (evidence base in idiopathic REM sleep behaviour disorder), this agent is frequently used, with good effect, in these populations for treatment of REM sleep behaviour symptoms.	Thank you for your comment. The committee noted this and the fact that the majority of the evidence from the trials was in Alzheimer's disease, and therefore agreed it was appropriate to amend this recommendation to "do not offer melatonin to manage insomnia in people living with Alzheimer's disease." The committee also agreed it was appropriate to add a cross-reference to the Parkinson's disease guideline for the management of non-cognitive symptoms (included RBD) covered there, as no evidence was identified specifically in people with PDD or DLB to allow recommendations to be made in this guideline.
British Geriatrics Society	Short and Full	22	n/a	Specific reference on management of REM sleep behaviour disorder in DLB/PDD would be beneficial or reference to an alternative guideline.	Thank you for your comment. The committee noted that only very limited evidence was found on managing non-cognitive symptoms in people with Parkinson's disease dementia or dementia with Lewy bodies, and therefore agreed it was appropriate to cross-refer to the advice in the NICE Parkinson's disease guideline. However, the committee noted these interventions may need to be modified to be appropriate for a population of people living with dementia, and agreed it was important to highlight this within the recommendation.
British Geriatrics Society	Short and Full	102 in Full		Consider carefully what is in the short guide versus the longer guide eg advice on carrying out investigative diagnostic tests sequentially rather than in parallel would be helpful in the short	Thank you for your comment. The committee discussed this and agreed the way the recommendations were presented in the guideline represented a clear sequential pathway.

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				guide	
British Geriatrics Society	Short	16-17		We welcome the recognition that specialists may be psychiatrists, neurologists, geriatricians, GP.	Thank you for your comment and your support for this recommendation.
British Geriatrics Society	Short	9 -10	Line 24 onward	It may be helpful to indicate the cognitive tests recommended have in part been selected with reference to the efficiency as used in primary care. This should be made clear in the short guide	Thank you for your comment. NICE's recommendations themselves do not routinely contain information on why they were made, but the committee noted that these were all tests that have been validated in, and are appropriate to, use in primary care.
British Geriatrics Society	Short	12	25	The section on case finding. Some reference should be made to the national dementia FAIR assessment in secondary care, it could be misinterpreted in the short version as saying there is no value to this. Clearly this is not the case as elaborated upon in the long version.	Thank you for your comment. A definition of case finding has been added to the guideline to address this confusion.
British Geriatrics Society	Short	13	12-21	Some advice on who should have memory clinic follow-up would be beneficial, especially as practice for the sub-types of dementia varies eg people with vascular dementia often receive no specialist follow-up or support.	Thank you for your comment. The committee agreed there was insufficient evidence available for them to be able to make recommendations on the most appropriate methods of follow-up for particular subsets of people living with dementia.
British Geriatrics Society	Short	14	14	1.3.4 short version- a specific example with reference to information sharing that must be mention is sharing between mental	Thank you for your comment. The committee noted that this was merely a set of examples and not an exhaustive list, but agreed that mental health trusts are an important group as well.

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British Geriatrics Society	Short	14	14	The section on care transitions could usefully consider the role of unified DNACPR forms	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified, it was not possible to include these issues within the recommendations made.
British Geriatrics Society	Short	14	18	Care co-ordination- a specific mention that the plan should be shared would be vital.	Thank you for your comment. The committee agreed with this point, and the importance of care and support plans being appropriately shared. The committee noted the guideline contains a recommendation to "Ensure that relevant information is shared and recorded in the person's care and support plan."
British Geriatrics Society	Short	18	27	The section on modifiable risk factors for AD. The effect only on cognition was considered. However these risk factors may have other benefits in terms of preventing physical disability which may be more difficult to manage for a person in dementia. The remit seems a little limited. It certainly merits mention in the short guide that treatment of diabetes etc is helpful for management of co-morbidity	Thank you for your comment. The committee agreed this point was covered by the part of the recommendation to "not offer the following to slow the progress of Alzheimer's disease." The phrase "specifically to slow the progression of Alzheimer's disease" has now been used to make clear they should still be offered for relevant comorbidities. Treatment of the comorbidity itself would be covered by the alternative recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
British Geriatrics Society	Short	22	10	The section on BPSD/sleep-I think in the summary recommendation it would be helpful to recommend that at present trazodone is not recommended, this is a medication seen used a	Thank you for your comment. The committee noted there was positive evidence on trazadone from the only small trial currently published, and therefore agreed there was neither sufficiently strong evidence for it to be recommended, not

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				lot in practice.	sufficient evidence of a lack of efficacy for a 'do not' recommendation to be made.
British Geriatrics Society	Short	25	14	Specific reference to carer training in delirium should be made.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in delirium
British Geriatrics Society	Short	30	n/a	A recommendation about how care providers evidence staff training and standards to be achieved may be beneficial.	Thank you for your comment. The points listed here are merely suggestions for how recommendations could be implemented, and local areas would need to make their own decisions about how best to convert the guideline in to practice.
British Geriatrics Society	Full	48	9	A good quality study has evaluated the 4AT for dementia screening in the acute hospital. See: O'Sullivan D, Brady N, Manning E, O'Shea E, O'Grady S, O 'Regan N, Timmons S. Age Ageing. Validation of the 6-Item Cognitive Impairment Test and the 4AT test for combined delirium and dementia screening in older Emergency Department attendees. 2018 Jan 1;47(1):61-68. 4AT is very widely used in the UK for hospital delirium screening.	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The

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					committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.
British Geriatrics Society	Full	105		The committee base the consideration for further invasive diagnostic tests to subgroup dementia diagnosis on a young population. It is noted that this is 10 years younger than the average age of those attending memory clinic. The committee do not consider that large percentage of people presenting with dementia (often in association with frailty) via the general hospital acute services, geriatric medicine day hospital or hospital at home services (age range approx 80-100). This population rarely features in research studies and therefore it is difficult to draw conclusions, but a pragmatic recommendation about the use of imaging (probably structural imaging to rule out treatable cause) and biomarker analysis (suggest only in those who will benefit from the greater diagnostic accuracy afforded by this investigation) would be useful.	Thank you for your comment. The committee agreed that there are always issue in extrapolating research evidence beyond the very tightly defined populations usually recruited to studies, and attempted to draw more general conclusions from this evidence wherever possible. The committee agreed the appropriate way to cover the population of people in whom additional more invasive testing may not be justified was to add an additional recommendation ahead of the section on subtype diagnosis. Specifically: ""Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
British Geriatrics Society	Full	108		Recommendation on the cognitive tests to use for diagnosis and also around follow-up would be	Thank you for your comment. The committee agreed that the recommendations included in the guideline were as specific as was possible to make from the evidence available,

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				beneficial.	
British Geriatrics Society	Full	111	1	Most delirium occurs in patients with dementia. Therefore, it is likely that most delirium test diagnostic accuracy studies have included many patients with dementia – in some studies, the majority of patients will also have dementia. In such studies, the dementia may not have been ascertained. However, that does not change the diagnostic accuracy of the delirium tool. It is noted that this point is made in 18.1.5. This area of work (studies on delirium vs dementia) is small and more studies are needed. Currently, therefore, it is important to adopt a pragmatic approach which has the goal of detecting delirium in a way that is effective and usable in routine care involving validated brief delirium screening and using validated dementia assessments Unfortunately the long CAM will rarely be used in clinical practice, because it is too long and requires considerable special training (a day – staff do not have time to do this, esp with many	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.

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				staff frequently rotating through different units). The short CAM takes 10 minutes to do and requires training. Debate continues as to whether the CAM (long or short) is practical – this is why it has not become routinely used in the real world despite it being published in 2000 and being recommended in many prior UK guidelines since. In summary: it is critical (a) that delirium is detected, regardless of whether the patient has dementia or not, and (b) to recommend methods of detecting delirium that can and will be used in routine clinical practice. The 4AT is a delirium screening tool which may be useful in this area. .	
British Geriatrics Society	Full	119		About 2/3 of delirium occurs in people with dementia. Because delirium is a strong marker for dementia, it should be recommended that older people with delirium who are not known to have a diagnosis of dementia should then be considered for dementia assessment at some point – some research supports a 3 month interval (Jackson TA, MacLullich AM, Gladman JR, Lord JM, Sheehan B. Diagnostic test accuracy of informant-based tools to diagnose dementia in older hospital patients with delirium: a	Thank you for your comment. The committee discussed this issue, and agreed that whilst assessing for dementia after an accurate episode of delirium was sensible, there was a particular issue that currently there is no evidence to suggest when an assessment for dementia should be carried out. It was for this reason that the committee made a research recommendation on this topic: "In people with treated delirium who no longer meet the DSM-5 criteria, but who have persistent cognitive deficits, when is the most appropriate time to carry out an assessment for dementia?"

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				prospective cohort study. Age Ageing. 2016 Jul;45(4):505-11.). This does need more research, but given that undiagnosed dementia is common in older patients with delirium, the point here has to be that dementia assessment should be strongly considered once the delirium has resolved	
British HIV Association	short	16	26	Regarding the use of memantine and AChE drugs, we are concerned that this recommendation may result in adverse drug interactions with antiretroviral drugs. Tenofovir DF increases levels of memantine by decreasing renal clearance and should be used with caution. Ritonavir will increase the level or effect of donepezil by affecting hepatic/intestinal enzyme CYP3A4. Ritonavir will increase the level or effect of galantamine by affecting hepatic/intestinal enzyme CYP2D6.	Thank you for your comment. No evidence was identified during the update of this guideline on the use of memantine or cholinesterase inhibitors for people taking antiretroviral drugs, and the committee therefore agreed it was not possible to make recommendations on this topic.
British Psychological Society	Short	7	10 and 18	Question 3: Guidance in Wales (1,000 Lives; Good Work framework) makes clear the need to offer the option of a dementia assessment in Welsh. We would like to see guidance on communication and provision of accessible information making clear the duty to consider particular language needs and preferences, which we know will affect	Thank you for your comment. NICE guidance is produced for the English NHS, and as such the committee agreed the most appropriate way to address these issues was with a reference to the NHS Accessible Information Standard, which includes a section about providing information in languages other than English.

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				the ability to conduct an appropriate and valid assessment.	
British Psychological Society	SH	General	general	**References** British Psychological Society (2014) *'A Guide to Psychosocial interventions in early stage dementia' which includes both CST and Reminiscence and the evidence for them*. Capotosto, E., Belacchi, C., Gardini, S., Faggian, S., Piras, F., Mantoan, V., Salvalaio, E., Pradelli, S., Borella, E. (2017). Cognitive Stimulation Therapy in the Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry, **32**, 331-340 D'Amico, F., Rehill, A., Knapp, M., Aguirre, E., Donovan, H., Hoare, Z., Hoe, J., Russell, I., Spector, A., Streater, A., Whitaker, C., Woods, R.T., Orrell, M. (2015) Maintenance cognitive stimulation therapy: an economic evaluation within a randomised controlled trial. *Journal of the American Medical Directors Association,* **16(1)**, 63-70.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				Holle, D., Halek, M., Holle, B., Pinkert, C. (2016), Individualized formulation-led interventions for analysing and managing challenging Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., Orrell, M. (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *British Journal of Psychiatry*, **188**, 574-580. Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J.M., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H.H., Muñiz, R. (2010). Non-pharmacological therapies in Alzheimer's disease: A systematic review of efficacy. Dementia and Geriatric Cognitive Disorders, **32**, 161-178 NHS Education for Scotland website (2018) *Enhancing understanding of the causes of stress and distress in dementia,* http://www.nes.scot.nhs.uk/search.aspx?q=Stress+and+distress+in+dementia Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R.T., Streater, A., Donovan, H., Hoe, J., Russell, I., (2014) Maintenance cognitive	Please find below a response for each of the papers you cited. Spector (2006) is a book and NICE does not include books as evidence when producing guidelines. Orrell (2014), Spector (2003), Yamanaka (2013) have been already included as evidence for CST. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Lai (2010) is actually Olazaran (2010) which was included as a systematic review in Appendix O but data was not extracted because Olazaran (2010) did not report details of the individual studies in included in their systematic review. Holle (2016) would have been excluded because the paper is not a systematic review but an integrative review. Woods (2005) was not included in Appendix O because there was a more recent systematic review on the same topic. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

				stimulation therapy (CST) for dementia: single-blind, multicentre, pragmatic randomized controlled trial. *British Journal of Psychiatry,* **204**, 1-8. Paddick, S.M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., & Mushi, D. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, ***29*(6)**, 979-989. Spector, A., Thorgrimsen, L., Woods, B., et al (2003) Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. British Journal of Psychiatry, **183**, 248-254 Spector, A., Thorgrimsen, L., Woods, B., Orrell, M. (2006) Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy (CST) to people with dementia. Hawker Publications, UK. Woods, B., Aguirre, E., Spector, A., Orrell, M. (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia.	

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				Cochrane Database of Systematic Reviews, **15**, CD005562. Woods B., Spector A.E., Jones C.A., Orrell M. & Davies S.P. (2005).Reminiscence therapy for dementia. Cochrane Database of Systematic reviews 2005, Issue 2. Art. No. CD001120 and Orrell M., Aguirre E., Spector A., Hoare Z., Streater A., Woods B. et al (2014). Maintenance Cognitive Stimulation Therapy (MCST) for dementia: A single-blind, multi-centre, randomised controlled trial of Maintenance CST vs CST for dementia. *British Journal of Psychiatry,* **204(6)**, 454-461 Yamanaka, K., Kawano, Y., Noguchi, D., Nakaaki, S., Watanabe, N., Amano, T., Spector, A. (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, **17**, 579-586.	

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British Psychological Society	SH	8	18	The Society is concerned that this guidance implies that these questions do not need to be asked or documented at the start of the assessment process. A person's right to be involved in discussions and decision making is specified in *Recommendations* and it should therefore be made clear that this applies also to information about a dementia assessment and the need to obtain informed consent for this process, (as a small minority of people choose not to proceed or don't want a diagnosis). This is clearly stated in the standards assessed by the MSNAP memory services accreditation process.	Thank you for your comment. The committee's discussion of the evidence around diagnosis gives their thoughts on this issue: "Being diagnosed with dementia can be a stressful and traumatic experience. The committee recognised this and noted the importance of guiding people with suspected dementia through the assessment process carefully. In particular, it is essential that information is provided throughout the diagnostic process and continued informed consent is obtained for investigations that may be particularly stressful (e.g. imaging and lumbar puncture for cerebrospinal fluid (CSF) biomarker tests). The committee commented that it was also important to consider situations where a patient may not want a referral for an assessment/diagnosis, and the potential disadvantageous outcomes that might result from this choice (e.g. problems with obtaining support, care and treatment)." The committee agreed it was not appropriate to include this in the recommendations, as issues around information and informed consent apply in any interaction between staff and patients/carers, and therefore to mention in one specific situation risked giving the impression these issues were less important at other points in the pathway.

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British Psychological Society	SH	9	18	The Society is concerned that the recommendations do not include the need to ensure the person consents to the assessment itself or to check that the person consents to obtaining a history from others. Removing the recommendation for pre-diagnostic counselling from the 2006 guidance could be seen to imply that a pre-assessment conversation, which is geared around obtaining informed consent, is no longer seen as relevant.	Thank you for your comment. The committee's discussion of the evidence around diagnosis gives their thoughts on this issue: "Being diagnosed with dementia can be a stressful and traumatic experience. The committee recognised this and noted the importance of guiding people with suspected dementia through the assessment process carefully. In particular, it is essential that information is provided throughout the diagnostic process and continued informed consent is obtained for investigations that may be particularly stressful (e.g. imaging and lumbar puncture for cerebrospinal fluid (CSF) biomarker tests). The committee commented that it was also important to consider situations where a patient may not want a referral for an assessment/diagnosis, and the potential disadvantageous outcomes that might result from this choice (e.g. problems with obtaining support, care and treatment)." The committee agreed it was not appropriate to include this in the recommendations, as issues around information and informed consent apply in any interaction between staff and patients/carers, and therefore to mention in one specific situation risked giving the impression these issues were less important at other points in the pathway.
British Psychological Society	SH	9	23	The NICE guidelines, 2006, advised that a neuropsychological assessment be conducted	Thank you for your comment. The committee noted this concern, and agreed it was appropriate to include a recommendation around neuropsychological testing as part of

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				when a diagnosis is mild or questionable but it appears that this has been removed from the current guideline. Cognitive testing in the current guideline refers only to brief cognitive screens and a test of verbal episodic memory in suspected Alzheimer's disease. These measures of cognition are not sufficient for a diagnosis. No recommendations are given regarding the utility of a full neuropsychological assessment to acquire a baseline level of function, assess change or clarify a dementia subtype. The 2006 guidelines noted that Hentschel and colleagues (2005) provide evidence that a neuropsychological assessment adds to the basic neuropsychiatric evaluation, with the initial diagnosis being changed in a significant number of cases. This occurs mainly at the borderline between 'no dementia' and 'dementia'. Without access to comprehensive neuropsychological assessment there is the risk that rates of misdiagnosis will increase. This is highly distressing for patients and their family members and may deny access to treatment and support options. The Society is concerned about the lack of reference to neuropsychological assessment recommendations throughout the current	the diagnostic process in specialist settings. Therefore, the following recommendation was added to the guideline: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is." The committee also noted that there was no evidence that would enable it to make recommendations on which specific tests should be used as part of this process, and that this would often be different between different neuropsychologists.

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				guidelines. This may have a direct clinical impact on care pathways and the services that patients can expect to receive. In addition NICE guidelines are often used to benchmark services against and provide evidence to commissioners regarding what services should be available within a dementia setting. Neuropsychological assessment is required: • To aid diagnosis when an initial assessment (medical review, clinical interview, cognitive screen, scans) is inconclusive. • To aid differential diagnosis • When the case is complex with multiple co-morbidities including significant mental health history, complex physical health problems, head injury, substance misuse for example. • To establish a baseline, against which change can be measured over time. • To assess the effectiveness of an intervention • To contribute to care planning and cognitive rehabilitation	

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				Given the range of applications for a neuropsychological assessment we are very concerned that this is not acknowledged in the current recommendations. NB no mention is given to the key role of neuropsychological assessment in potential cases of Young Onset Dementia, in which most cases could be deemed not clinically obvious and are often complex. This is despite the full guidance (page 370, Section 17, Line 6) noting that young onset dementia will often be of a less typical syndrome, consequently it is much more likely to require a neuropsychological assessment.	
British Psychological Society	SH	9	24	The cognitive screening measures noted in the current guideline are very brief and only appropriate for use as initial screens in primary care. The ACE-III and other comprehensive cognitive screening tools such as CAMCOG, ADAS-cog, MEAMS and the RBANS are not included. The 2006 NICE guideline noted the utility of these more comprehensive cognitive screening tools to be used to determine a baseline, to assess change, to assist in differential diagnosis and to inform management of cases. The 2006 guideline	Thank you for your comment. The committee noted that the cognitive tests mentioned were only recommended for use as part of the initial assessment in non-specialist settings. The committee noted the evidence did not enable them to identify the most appropriate tests to use as part of assessment in specialist services, but agree it was appropriate to include a reference to cognitive testing as part of the initial specialist assessment, as well as an additional recommendation on neuropsychological testing: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment

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				also recognised their utility as an initial part of a full neuropsychological assessment, usually conducted by a clinical psychologist. The ACE-III is routinely used across secondary mental health settings and neurology. Use of a more comprehensive cognitive screen forms part of a stepped care model of assessment for the presentation of cognitive symptoms. Primary care typically administers a brief screen with secondary care using a more comprehensive tool such as ACE-III as one part of the process, which may lead on to a full neuropsychological assessment if required. Various members of multidisciplinary teams including nursing, psychiatry and neurology are able to access an online training programme regarding ACE-III administration as well as supervision by a Clinical Psychologist regarding interpretation as required. To remove these comprehensive cognitive screens from the NICE guideline undermines their clinical validity. It also has the potential to increase assessors' reliance on the briefer measures which yield less clinical information and are not sufficient to lead to a diagnosis in many cases. No information is provided in the current	• whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is."

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				guideline to indicate why the more comprehensive cognitive screens have been omitted.	
British Psychological Society	SH	10	11	The recommendations note that a referral to a specialist dementia diagnostic service should be made following a clinical history and brief cognitive screen. Most young people presenting with a suspected dementia will not go on to actually receive that diagnosis. This population are more likely to be experiencing cognitive symptoms due to mental or physical health problems, medication, head injury, alcohol or substance use for example. Consequently comprehensive assessment for this population should include neuropsychological assessment when appropriate, scans, bloods and full clinical interview with the patient and a significant other, prior to consideration of referral to a specialist dementia service or older people's CMHT.	Thank you for your comment. The committee agreed with the need to rule out other possible presentations before referring to a specialist dementia diagnostic service, and therefore the recommendations on initial assessment in non-specialist settings have been expanded to include "conduct a physical examination, undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline, and use cognitive testing."
British Psychological Society	SH	10	14	The total cost per session is calculated as £233.19. The Knapp (2006) paper calculated the cost per session as £90. The Knapp (2009) paper may be an overestimate, if, as noted above, lower staff salary and travel costs are taken into account. Using the Knapp cost per session calculation, even with just 5 people in each group,	Thank you for your comment. Economic models produced by NICE are based on the best available evidence along with the committee's judgement about the quality and applicability of that evidence to current practice across the whole of the NHS. Our analysis uses up to date costing for staff, and unlike the Knapp (2006) analysis, assumed that the researchers were not

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				the total cost per patient per CST course (14 sessions) is £252, compared to NICE's estimate of £652.94.	skilled in delivering CST and therefore incurred training costs. Furthermore, our analysis assumed that there were external venue costs, and costs associated with the transportation of patients to receive CST. These assumptions were ratified by the guideline committee for use in our economic analysis.
British Psychological Society	SH	10	10,11	The Society would advise that further consideration is given to the assumptions in the cost analysis. Please note groups are generally led by Band 4's (rather than Band 6's); many groups will have a maximum of 8 participants; they are often run from base so there is no staff travel time; participants are generally expected to fund their own travel costs.	Thank you for your comment. We recognise that there is variation between different trusts and organisation, and therefore the guideline committee was consulted with regards to the number and seniority of staff that would be required to run a CST session.
British Psychological Society	SH	10	23	The Society is concerned that a test of verbal episodic memory is the only cognitive assessment recommended as needed in diagnosing possible Alzheimer's disease, as this seems to imply that this is the only cognitive domain that may be affected. The diagnostic criteria for Alzheimer's specify impairment in two or more domains. Also, detailed neuropsychological assessment may be required to differentiate an Alzheimer's presentation from other clinical presentations.	Thank you for your comment. The committee made 2 modifications to address these concerns. First, a reference to "cognitive testing" was added to the recommendation on initial assessment in specialist settings. Secondly, an additional recommendation was added around referral for neuropsychological testing; specifically: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is."

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British Psychological Society	SH	10	27	The guidance on diagnosis of different subtypes implies that this is possible without detailed cognitive assessment. It is extremely difficult to reliably diagnose a dementia subtype and rule out causes such as depression, which in some instances requires detailed neuropsychological assessment.	Thank you for your comment. The committee agreed it was appropriate to make 2 modifications to the recommendations to address this concern. First, a reference to cognitive testing has been added as part of the initial assessment in specialist services. Secondly, an additional recommendation has been added around the use of neuropsychological testing; specifically: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is."
British Psychological Society	SH	13	11	Question 4: We note that guidance is given on telling the difference between delirium and dementia. However, guidance on telling the difference between depression and dementia or MCI and dementia is not included. A significant proportion of referrals for dementia assessment will be of people who have memory difficulties associated with depression, anxiety or stress as well as people with MCI.	Thank you for your comment. Evidence on people with a prior diagnosis of either depression or MCI was looked for in the section of the guideline on diagnosing dementia, but no evidence was identified which enabled the committee to make recommendations on this topic.
British Psychological Society	SH	13	13	Question 3: Consistent with person-centred literature on dementia and studies of the diagnostic process (Aminzadeh et al, 2007), service users emphasise the importance of	Thank you for your comment. The committee agreed with these concerns, and the importance of staff conducting these conversations appropriately. To address this, the committee agreed it was appropriate to amend one of the

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				psychosocial factors, including how the diagnosis is shared and the support that is needed afterwards. Doing this insensitively can cause distress. We are concerned that the lack of reference to considering psychosocial factors in how a diagnosis is shared or in relation to review implies that this is not relevant. A person-centred approach would place these factors at the centre of the process. There seems to be an inconsistency here in emphasising a person-centred approach but providing guidance only on diagnostic tools in relation to assessment and diagnosis.	recommendations around staff training to clarify the importance of this issue. Specifically: "Health and social care professionals advising people living with dementia (including those involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations"
British Psychological Society	SH	15	5	The Society is concerned that recommendations on interventions to promote cognition, independence and wellbeing seem to imply that only cognitive stimulation, cognitive rehabilitation and activities are worth considering. The Society's 2014 guidance on psychosocial interventions in dementia outlines the evidence base for a wide range of possible interventions, including specialist psychological therapies (BPS, 2014). While acknowledging that the evidence base is limited, and may not meet NICE criteria, it should be recognised that there is a growing evidence base for psychological therapies and	Thank you for your comment. The committee noted a wide range of potential interventions were considered within the guideline, but that robust evidence of benefit was only found for CST, reminiscence therapy, cognitive rehabilitation and occupational therapy, so these were the only interventions the committee felt able to make recommendations on. They agreed that further research on other potential interventions would be valuable, and agreed it was appropriate to add a research recommendation on the most effective psychological interventions to support cognition, functional ability and wellbeing in people living with dementia.

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				these should be considered, as laid out in e.g. Matrics Cymru (2017), which provides guidance on evidence based psychological therapies and dementia. In our memory assessment and young onset dementia services we offer specialist psychological therapies to people living with dementia and their care partners where needed in recognition of the fact that they frequently struggle to access generic mental health services, which struggle to adapt to their particular needs.	
British Psychological Society	SH	15	9,10, 11	The Society believes that this recommendation shows a significant shift in language from the previous NICE guidelines, despite further evidence since 2006 for the effectiveness of Cognitive Stimulation Therapy (CST). Also, there is no evidence to suggest that "elements" of cognitive stimulation and reminiscence therapy are effective. The vast majority of positive evidence is for structured CST, following a manualised approach. The wording in the draft guidelines seems to be based on a misunderstanding and misinterpretation of the evidence base for CST.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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					recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
British Psychological Society	SH	17	10	With regard to the transition of some prescribing in dementia transferring to primary care, we believe that it is unclear whether drug monitoring will also move to primary care settings or continue to be provided by secondary mental health teams.	Thank you for your comment. The committee agreed that with the prescribing of these drugs moving to primary care, the monitoring would also move to primary care.
British Psychological Society	SH	20	21	The 2006 NICE guidelines detailed what an assessment of non-cognitive symptoms and distressed behaviour should entail and how individualised care plans should be used (page 21). It appears that all of this information has been removed to be replaced with a short recommendation that psychosocial and environmental interventions should be offered to reduce distress. National guidelines are often used to measure services against and ensure that services are delivering quality care in line with the	Thank you for your comment. The committee noted this concern, and agreed it was appropriate to add a reference to structured assessments at the start of the section on managing distress. Specifically: "Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to: • explore possible reasons for the person's distress and • check for and address clinical or environmental causes (for example pain, delirium or inappropriate care)."

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				guidelines. Losing this detail regarding psychosocial assessment and interventions increases the risk that the emphasis on such approaches will be diluted. Given the risks associated with medication to reduce non cognitive symptoms and distress in people with dementia, emphasis on psychosocial assessment and interventions should be increased in the current guidelines, not significantly reduced. NHS Education Scotland (NES) have devised and rolled out a national training programme called 'Managing Stress and Distress in Dementia'. This is based on The Newcastle Model and teaches attendees how to use psychosocial assessment and interventions to manage stress and distressed behaviours in people with dementia. (NES website, 2018)	
British Psychological Society	SH	20	24	The Society is concerned that this guidance implies that psychosocial and environmental interventions can be offered in the absence of any structured, guiding assessment. A multi-disciplinary approach to assessment of agitation, aggression and distress, allows a biopsychosocial formulation of the person's presenting difficulties	Thank you for your comment. The committee noted this concern about the lack of reference to assessment in the recommendation, and agreed it was appropriate to reformulate this as a recommendation as "before starting non-pharmacological or pharmacological treatment for distress in

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				to be developed, which can then guide appropriate psychosocial interventions. We believe that the importance of guiding interventions by an integrated perspective (often termed a formulation) needs to be included in this chapter due to the introduction in recent years of formulation-led interventions. (Holle, D. et al, 2015).	people living with dementia, conduct a structured assessment to: • explore possible reasons for the person's distress and • check for and address clinical or environmental causes (for example pain, delirium or inappropriate care)."
British Psychological Society	SH	277	37	This section considers the economic analysis of CST, but uses a base case model, rather than published health economic studies. There have been 2 key papers published considering the cost effectiveness of manualised CST (Knapp et al, 2006 which considered CST; D'Amico et al, 2015 which considered maintenance CST). Both are listed in the references in Appendix J, but only D'Amico et al (2015) has been considered in the evidence. These papers show strong evidence for the cost effectiveness of manualised CST and it is important for the Knapp paper to be used, rather than a base case model. These papers look at the cost of the delivery, as well as the changes in use of health and social care services for those in receipt of the intervention.	Thank you for your comment. The Knapp (2006) paper was not a cost-utility study and therefore did was not consistent with the reference case. As a result, it is inaccurate to state that this analysis showed that CST is cost effective, as no threshold value has been established for the effectiveness instruments used against which gains could be assessed. The D'Amico (2015) paper however, was a cost-utility study and was eligible for inclusion as part of the economic review. Please note that the effectiveness evidence used in Knapp (2006) was based on Spector (2003), and has been considered by this guideline by the way of inclusion in our quantitative synthesis of parameters for the model developed by NICE.

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				Furthermore, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually.	
British Psychological Society	SH	296	5	The Society has concerns about the following statement, "No evidence of benefit was found on outcomes other than cognition (for CST)". Several studies have shown statistically significant improvements on outcomes in addition to cognition, namely quality of life (Spector et al, 2003; Capotosto et al., 2017; Paddick et al., 2017; Orrell et al., 2014); mood (Yamanaka et al., 2013; Niu et al., 2010); behavioural symptoms (Paddick et al., 2017); activities of daily living (Orrell et al., 2014).	Thank you for your comment. Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life but the pooled result of all the studies included in the meta-analysis could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool

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				A Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects as well as showing evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis.	with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the pooled result of the meta-analysis could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST. Notwithstanding the above, the committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in

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					equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
British Psychological Society	SH	296	5	The Society has concerns regarding the following statement, "The committee… noted it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity". This statement is not supported by the evidence, which shows that manualised CST is much more effective than other interventions, including Reminiscence. A systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions. Several trials within the Cochrane review compared Cognitive Stimulation with an active, social control group, and the findings were consistently in favour of structured group Cognitive Stimulation over a social control (Woods et al, 2012).	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
British Psychological Society	SH	296	5	The Society has concerns regarding the following statement, "They noted that in practice the two interventions are not mutually exclusive, with cognitive stimulation and reminiscence both forming part of the activities included within those groups". While the committee are correct that CST does incorporate some aspects of reminiscence, the statement is inaccurate with regards to CST (2006). One of the key focuses of CST is on generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills and enable new semantic connections to be made. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence).	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
British Psychological Society	SH	296	5	The Society has concerns regarding the following statement, "The committee agreed the most appropriate recommendation was for people to be provided with access to structured group activities, with cognitive stimulation and reminiscence both forming part of the activities included within those groups. This was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model". There is a far stronger evidence base for CST than for reminiscence. Additionally, the evidence is for CST when used as a manualised intervention. There is no evidence for any benefits if just elements of the programme are used, and there is no evidence in general for structured group activities.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				The current wording risks creating ambiguity and it is likely to be interpreted that any type of structured group is sufficient, leading to a lack of clinical governance, and a lack of adherence to any sort of standardisation. The conclusion in the report that "this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according to important key principles which fit with the underlying theoretical models. We would encourage NICE to argue for more adherence to protocol and evidence base, rather than less.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
British Psychological Society	SH	300	4	The Society has concerns regarding the following statement, "Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them". CST, unlike AChEs	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The

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				and memantine, is suitable for all different types of dementia. It also shows improvement on measures such as quality of life and mood, as well as cognition. There is a risk that the wording "consider" will imply this is not an important recommendation. Additionally, "who are not already accessing them" may imply any sort of group activity will suffice. The Society recommends that the wording is changed to be more similar to the 2006 guidelines *"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia"*. As no recommendations were made for pre- and peri-diagnostic counselling and support for people with dementia and their families (evidence statement 13.1.4 full guidelines, p.263, line 14), or for post diagnostic interventions (evidence statement 13.1.6 full guidelines, p.266, line 2), there is a danger that those with dementia	committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				will be offered only medication, and it will be even harder for people to access non-pharmacological interventions.	
Care and Repair England	Summary	General	General	Whilst the title includes management and support for people with dementia and their carers the recommendations seem to be much more focused more on diagnosis, assessment and conditions management and does not give enough focus to long term post diagnosis support. We would have liked to see a greater focus on support for daily living for the person with dementia and their carers including opportunities for a review of this support. Given that there are also quality standards in existence in relation to this it might be helpful to make further reference to this in the text. At present the dementia guidance, quality standards and links between these are a bit unclear.	Thank you for your comment. The committee noted that evidence on diagnosis, assessment and support were all looked for as part of the guideline, and the recommendations made reflected those areas were robust evidence on effectiveness and cost-effectiveness was available. The committee also noted that that quality standard on dementia may be updated after the publication of this guideline.
Care and Repair England	Summary	Page 1	Box	The guideline covers - this should also include **housing professionals** who also support people with dementia	Thank you for your comment. This has been added as suggested.
Care and Repair England	Summary	Page 3	Line 27	While the introduction talks about the importance of coordinating care between different services (a key feature to support people with dementia and their carers) there is little in	Thank you for your comment. The committee noted the guideline contained a specific review question on how health and social care should be integrated, but the absence of robust evidence made it difficult for them to make strong

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				the guideline that addresses this aspect though there is much more on the training aspects and support for carers. We note that the named person is the opportunity to facilitate this coordination, but we would like to see this section expanded a little even if it might be by reference to other NICE guidelines on the coordination of care and support.	recommendations. They agreed the key recommendation in the guideline in this regard was for a single named person coordinating care, and implementation of this should lead to better coordination between services.
Care and Repair England	Summary	Page 4	Line 4 - 5	It is important that people with dementia can get the **housing** as well as the care and support needed	Thank you for your comment. Additional text has been added to the section on who the guideline is relevant for, to include "housing associations, private and voluntary organisations contracted by the NHS or social services to provide care for people living with dementia."
Care and Repair England	Summary	Page 8	Line 6 to 7	Should add **housing professionals** and add a section to this list which refers to the suitability of their housing since this should be a part of the assessment. We suggest the following – an assessment of their housing suitability and any plans to make the home more suitable.	Thank you for your comment. The committee noted this concern, but agreed that in the absence of evidence it was not possible to include this reference in the recommendations.
Care and Repair England	Summary	Page 9	Line 11	We are pleased to see a reference to considering a person's preference for their 'place of care' and 'place of death'. We feel it would be better to talk about where people live so perhaps say a preference for where they want to live and die – rather than their place of care and death. After	Thank you for your comment. The committee noted this suggestion, but agreed that the included terms had a technical meaning that was well understood, and were therefore appropriate to retain within the guideline.

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				all, in many cases this will be the person's own home. Who calls their own home a place for care?	
Care and Repair England	Summary	Page 27	Line 4 and 13	We would like to add **housing support staff** as well as care staff many of whom support people with dementia and would also benefit from training. Indeed, in this section where it talks of health and care staff we would like to add housing staff at every reference point.	Thank you for your comment. The committee noted the evidence identified focused on care and support staff, so agreed it was appropriate to retain this wording in the recommendation. However, the committee agreed this training would also be relevant to other groups involved in providing support or services for people living with dementia.
Central and North West London NHS Trust	Full	General	General	A specialist in dementia treatment at CNWL has reviewed the guidelines. The main feedback is an observation that cognitive stimulation therapy appears to have been downgraded in the guidance as an important part of treatment.	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST and the recommendation has therefore been amended to an 'offer'. Specifically, "offer group cognitive stimulation therapy to people living with mild to moderate dementia".
Cochrane Dementia and Cognitive Improvement Group	Full and short	General	general	As worded, the recommendations concerning memantine (1.5.2 and 1.5.3) use are unnecessarily complicated and confusing for clinical practice. We agree that the evidence now supports coadministration of memantine and cholinesterase inhibitors. However, memantine monotherapy also has high quality evidence of a small effect. If a patient with moderate AD is neither already taking a ChEI, nor	Thank you for your comment. The committee appreciated this concern, but noted the guideline was not updating these recommendations on treatment from NICE technology appraisal 217, and therefore it was not possible to make changes to these recommendations. They noted the guideline now contained a clear treatment pathway. Cholinesterase inhibitors for people with mild dementia, consideration of co-prescription in moderate dementia, and offering co-prescription in severe dementia.

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				has been shown to be intolerant of ChEIs, is memantine an option? If not, why not? **The retention of the original 'for those who are intolerant' option (1.5.2) is unnecessary, confusing and does not accord with the evidence base. We think it should be omitted.** Also, recommendations 1.5.2 and 1.5.3 are confusing with respect to severe AD: recommendation 1.5.3 is to 'offer memantine in addition to an AChE inhibitor if they have severe disease', however, recommendation 1.5.2. does not recommend a ChEI for severe disease, only memantine. If a patient presents with severe AD should they be offered a ChEI?	
Cochrane Dementia and Cognitive Improvement Group	Appendix H		H7.4.2	<u>Meta-analysis & network 1 meta-analysis results.</u> There is a numerical error for the Vercelletto study in the forest plot for Neuropsychiatric Inventory (NPI): The first column (mean NPI score for Verceletto) should read 1.9 rather than 19. This change means that memantine looks	Thank you for your comment, and for pointing out this error. This has now been corrected throughout the documents it appeared in. The committee discussed the corrected evidence and noted that there remained no evidence of benefit with memantine in any domain for people with frontotemporal dementia, and

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				much less likely to have an adverse effect on behaviour. We agree that evidence is of low/very low certainty. We also recognise that it is not realistic to expect further memantine trials in FTD, not least because evidence from autopsy confirmed cohorts is that the specificity of the diagnosis of frontotemporal dementia is poor: often, patients with 'clinical FTD' have AD. **In light of the correction, the diagnostic difficulty and the safety profile of memantine, we think it would be more appropriate simply to omit the strong 'do not use memantine in FTD' recommendation (1.5.14).** Or perhaps it should read **Do not offer AChE inhibitors to people with frontotemporal dementia. Only consider memantine for people with frontotemporal dementia if they have suspected comorbid AD.**	therefore agreed it was appropriate to maintain the 'do not offer' recommendation in the guideline. The committee noted the concerns about misdiagnosis in frontotemporal dementia, but agreed the appropriate response was to try and improve the accuracy of diagnosis, rather than treat people with a drug (with known side effects) to cover the risk they may have been misdiagnosed.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	general	general	No mention of covert medication administration and the need for a policy to be in place. This happens commonly and We recommend it should be mentioned. Also clearer guidance on de-	Thank you for your comment. The committee agreed these were all relevant issues for consideration, but that in the absence of any evidence being identified, it was not possible to make recommendations on these topics.

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				prescribing in advanced stages of dementia and link with the medicine optimisation policy.	However, the committee did agree it was appropriate to add a cross-reference to the NICE guideline on "managing medicines for adults receiving social care in the community", which does include recommendations around covert administration of medicines.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	16	19-24	The statement is not clear whether memantine should be considered in all ACHEI users or only where there is a lack of response to ACHEI. It would help to have criteria to guide when the memantine should be added in. We are concerned that prescribers in primary care may not have the experience to know when to add it in and needs more guidance. I think this will be challenging to implement because it is assuming that people are seen when they progress from mild to moderate or moderate to severe stages. This may not always be the case.	Thank you for your comment. The committee noted the guideline contains recommendations from both NICE technology appraisal 217 and new recommendations from the guideline. They agreed though that the guideline did contain a clear pathway, with people with mild dementia being offered a cholinesterase inhibitor, consideration if co-prescription in people with moderate dementia, and finally offering co-prescription in people with severe dementia.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	20	9-13	Strengthen the recommendation to minimise – ie remove 'consider'. Also previous guidance suggested that a full medication review should be carried out prior to referral for cognitive assessment. This need to be clearer to ensure that people with medication related cognitive decline are managed as quickly as possible.	Thank you for your comment. The committee discussed this but agreed that since currently the evidence on actively reducing anticholinergic burden as an intervention was minimal, it was appropriate to maintain this as a 'consider' recommendation. The committee noted that a research recommendation was also included within the guideline on this issue, and that future research in this area would hopefully enable future updates of the guideline to make stronger recommendations.

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College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	20	14	The AEC anticholinergic effect on cognition is another validated tool which is in the All Wales guidance for classification of anticholinergic medication which has looked specifically at effect on cognition and possibly more relevant to use in people with suspected dementia. There is also an online tool www.medichec.com which we think could be mentioned.	Thank you for your comment. The committee noted the existence of this new and potentially improved tool, but were not aware that it had yet been validated in the same way as the other tools included in the review. As a result, the committee agreed it was best to retain the reference to the ABS, but that this was presented solely as an example, and that the use of more modern validated scales would be appropriate when they are available.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	21	8	Need clarity on whose responsibility it is to review the antipsychotic. Need to strengthen the need to document a clear plan and monitoring. National guidance on this area is very poor. The way that this guideline refers the reader to NICE medicines optimisation is not that helpful on this specific topic.	Thank you for your comment. The committee agreed that it was for local areas to implement their own policies around antipsychotic prescribing and monitoring. They noted the key things to emerge from the evidence these recommendations were based on was the need for frequent review, and for treatment to be discontinued if there is not a clear and ongoing benefit from it.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	22	11	Sleep disorders- melatonin mentioned but no advice on zopiclone and other hypnotics. Need to state to avoid all use of sedative and if absolutely necessary to have a time limited prescription.	Thank you for your comment. The committee noted this concern, but agreed there was not sufficient evidence on other pharmacological treatments to be able to make recommendations (either positive or negative), and agreed that an absence of alternatives was not a reason to promote the use of a drug (melatonin) where there is evidence of a lack of efficacy.
College of Mental Health Pharmacy, endorsed by The	Short	23	24	Surely need to mention non drug treatment – whether incontinence a result of AChE and needs review. Also consider that many patients may not comply with assessment and symptomatic	Thank you for your comment. The committee also noted that there were side-effects associated with cholinesterase inhibitors, but agreed that concerns around anti-muscarinic prescription were covered by the recommendation to

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Royal Pharmaceutical Society				treatment may be needed. We consider that it would be worth stating not to use anticholinergic drugs for management of urinary incontinence in dementia before the sentence on mirabegron.	"consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives".
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	25	17	Include education and advice on managing medication in carer support. Many may not know what medication is for and the fact that pharmacist can provide medication review to rationalise medication	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in managing medicines
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Short	27	13	As above but to include training on the effects of medication in people with dementia to care providers	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
College of Mental Health Pharmacy, endorsed by The Royal Pharmaceutical Society	Full	31	3	We consider that in practice, CAM is not a very useful tool for screening for delirium because it is rather vague in scoring against symptoms. In practice this screening is often carried out by junior medical staff or triage nurses. We note that this is in the NICE delirium guidance but it is being superseded in some areas by the 4AT – this may be a useful tool to consider. We are not aware of	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included

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				any studies that compare CAM versus 4AT but 4AT is mentioned positively in the study referenced below: https://academic.oup.com/ageing/article/43/4/496/2812210	recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.
College of Optometrists	Full	General	General	The College is concerned by the use of the phrase 'sensory impairment' as it is too vague and may prove confusing. We suggest that this terminology is replaced with 'vision and hearing impairment'. This is particularly relevant to this document as sensory interventions are often referring to one impairment or the other.	Thank you for your comment. For clarity, this has now been changed to "sensory impairment (such as sight or hearing loss)"
College of Optometrists	Full	31	22 – 46	Dementia and sight loss develop independently, but both dementia and the main causes of sight loss are age-related. The ageing population trends	Thank you for your comment. The committee considered these issues, and the high rates of comorbid visual loss in people living with dementia, and agreed it was appropriate to make a

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				mean that more people will have both together. Dementia alone has a significant impact on quality of life, and visual impairment in older people can lead to functional impairment, which may adversely affect quality of life even further. (*Trigg R1, Skevington SM, Jones RW (2007),How can we best assess the quality of life of people with dementia? the Bath Assessment of Subjective Quality of Life in Dementia (BASQID). Gerontologist. 2007 Dec;47(6):789-97)*. The ability of a person with dementia to cope with visual impairment is also reduced, which means the effects of both concurrently can be much more severe on activities of daily living and cognitive performance. *(McKeefry D, Bartlett R (2010) Improving Vision and Eye Health Care to People with Dementia. London: Thomas Pocklington Trust)* Detecting and correcting impaired vision and refractive error can improve quality of life and reduce related co-morbidities among the dementia population. The Prevalence of Visual Impairment in People with Dementia (PrOVIDe) study (2016) (*Bowen, M., Edgar, D. F.et al, Health Services and Delivery Research, 4(21), pp. 1–200. doi: 10.3310/hsdr04210*) shows that finding and	recommendation on eye tests similar to that on audiology assessments for people living with dementia included in the NICE guideline on hearing loss. Specifically: "Encourage people living with dementia to have eye tests every 2 years. Consider referring people who cannot organise appointments themselves." The committee noted there was no evidence identified that enabled them to make specific recommendations the management of visual loss in people living with dementia, but agreed this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				correcting impaired vision in the dementia population is often not as difficult as many believe. Optometrists have the skills, equipment and expertise to perform a comprehensive eye examination on most people with dementia. At dementia diagnosis stage, correcting the impaired vision with up-to date spectacles or referring for cataract surgery could have a significant positive impact on a dementia patients' ability to live life independently for longer. For recommendation 29 under Providing Information, we strongly urge that information on vision and dementia is included. For recommendation 31, to ask when the patient last had an eye examination, and to suggest an eye examination by an optometrist.	
College of Optometrists	Full	389	31	The PrOVIDe study demonstrated that 1/3 of dementia patients also have visual impairment, which is a known factor in increased falls risk. This is already included in the falls NICE guidance (NG161) but due to the increased prevalence of visual morbidity in this group, special provision should be made. We recommend that special	Thank you for your comment. The committee noted this evidence and concern, but agreed that in the absence of specific evidence on how this should be managed differently in people living with dementia, this should be covered by a cross-reference to the NICE falls guideline, and by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care

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				attention is given to visual assessment and rehabilitation for patients with dementia suffering falls and that they have a thoroughly vision check as part of their post-fall assessment.	services for comorbidities to people who do not have dementia." They also agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years"
College of Optometrists	Full	394	21	The Prevalence of Visual Impairment in People with Dementia (PrOVIDe) study (*Bowen, M., Edgar, D. F.et al, (2016) Health Services and Delivery Research, 4(21), pp. 1–200. doi: 10.3310/hsdr04210*) recently demonstrated an increased level of visual impairment among people with dementia, compared to the non-dementia population. 1/3 of the dementia population also have some form of visual impairment. We are concerned that no reference has been made to visual impairment or uncorrected refractive error – as even the latter can reduce quality of life in a person with dementia (*Trigg R1, Skevington SM, Jones RW (2007),How can we best assess the quality of life of people with dementia? the Bath Assessment of*	Thank you for your comment. The committee noted this evidence and agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years", in line with the recommendations for hearing tests for people living with dementia in the NICE guideline on hearing loss. The committee agreed that once someone was identified as having visual impairment, they should then be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				Subjective Quality of Life in Dementia (BASQID). Gerontologist. 2007 Dec;47(6):789-97).	
Compassion in Dying	Short	9	4	We recommend deleting the first word of this sentence, "Offer", and replacing it with a more proactive word such as "Encourage". Compassion in Dying undertook work to engage with minority communities who have lower awareness of their rights to plan ahead and more difficulty accessing information about their health and care than the wider population. We learned that developing alternative ways to enable people to express their wishes, such as providing people with a way to visually express their views so that they can be translated into written format was particularly valuable. The programme demonstrated that for some of the most isolated groups there is a huge value in reaching out and enabling them to have a conversation and record their end of life wishes. After creating a visual advance statement, one Somali woman said through an interpreter that "it is important for her because if she goes to	Thank you for your comment. The committee appreciated the thought behind this suggestion, but noted that 'offer' was the standard terminology used throughout NICE guidelines, and agreed it was appropriate to maintain this wording for consistency with other NICE guidelines. The committee agreed with the importance of alternative communication techniques, and noted the guideline contained a recommendation to "if needed, use additional or modified ways of communicating (for example visual aids or simplified text)", and that staff should be given training in "adapting communication styles." The committee agreed there was a particular issue around people with fluctuating capacity, and this fed in to the recommendation to offer people "ongoing opportunities" to engage in the process of advance care planning.

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				hospital and is unable to speak, instead of the doctors saying 'who is she, where is she from', she now has a book which describes everything about her. For her she has made that easy and easier for the clinicians as well." In relation to the draft NICE guidelines, carers and healthcare professionals should be aware that a person with dementia's capacity can fluctuate depending on the time and the decision that needs to be made. This means thinking creatively about the particular times and settings where it is best to support the person with dementia to understand and engage in decisions about their care. A tailored approach to advance care planning with each individual is necessary to overcome the issue of fluctuating capacity, and will prompt ongoing conversations about advance care planning, particularly for those who may be reluctant. The word 'encourage' better encompasses this tailored approach to advance care planning and avoids a purely 'tick box' system.	

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Compassion in Dying	Short	9	6	We welcome the recommendations on advance care planning and the acknowledgment that it is important for people with dementia to be involved in decisions about their care. . We recommend that the *specific* benefits of planning ahead for those with dementia and their carers are outlined in this section. The issue of fluctuating capacity should be addressed clearly; dementia will cause a person's capacity to fluctuate and some may lose all capacity to make decisions about their treatment and care, leaving it up to healthcare professionals and carers to make decisions on their behalf. Planning ahead is therefore particularly important for people with dementia to ensure their carers and healthcare team know their wishes for care if they can no longer communicate them. This should be explained to the person with dementia, so that not participating in advance care planning is just as informed a choice as participating in advance care planning.	Thank you for your comment and your support for this recommendation. The committee agreed that all of these points were relevant as part of an advance care planning discussion, but they represented too much detail to be included within the guideline recommendations themselves.
Compassion in Dying	Short	9	11	There is scope in the guidelines to add a bullet point or sentence encouraging healthcare professionals to make referrals to other	Thank you for your comment. The committee agreed that these discussions could involve reference to external sources of information or support, if appropriate, but that the evidence

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				organisations for further support. For example, both the healthcare professional and/or the patient could contact charities such as Compassion in Dying to receive specific guidance on how to fill out an advance decision to refuse treatment or advance statements, order forms or publications from us, or speak to our Specialist Information and Support Nurse.	available did not allow them to include this point within the recommendations themselves.
Compassion in Dying	Short	9	14	We agree that people should be offered the chance to review and change any advance statements and decisions they have made. It should be clear in this section that people should be given this opportunity not only at each care review, but also whenever new symptoms and/or new treatment options are discussed. New symptoms and new treatment options may prompt an individual to change their mind about their care plan, such as refusing certain life-sustaining treatments. It is vital that healthcare professionals properly explain any new symptoms or treatments so they can make informed decisions about their advance care plan.	Thank you for your comment. The committee noted and agreed with the points raised around the review of care and support plans. They noted that any significant change in the person's circumstances or management should lead to a care review, and therefore would be covered under the recommendation to "at each care review, offer people the chance to review and change any advance statements and decisions they have made."

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				Compassion in Dying carried out research, which is the basis of our publication What now? Questions to ask after a terminal diagnosis, a practical toolkit to ensure people ask the right questions, get the information they need and make the right healthcare decisions for them. We talked to more than 600 people living with a terminal illness or caring for someone at the end of life. We asked them how they accessed information, who they spoke to about their options, and crucially, what they wished they'd known at the time. The people we spoke to said that when they asked the right questions about their illness, it helped them to make informed decisions. This meant they were able to have the care and treatment that was right for them, and to live well in the time they had left. One person said: "I wasn't prepared for how quickly my husband went downhill and I think if someone had told him earlier on about what may happen we might have been more prepared to ask about what choices he had for his care."	

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				Another said: "My first treatment drug produced terrible side effects that put me in hospital for three weeks and took six months to recover from. I wish I had known enough to put my foot down and insist my then oncologist either reduced dose or changed the medication. At the time I was new to all of it and could have done with a source of informed support in achieving this." Healthcare professionals should give the person all the information they need to make a decision about treatment, and should also explain the advantages and disadvantages of each treatment option, including any potential risks and side-effects. People with dementia should be given the chance to amend their advance care plan with their new symptoms or treatment options in mind.	
Dementia Industry Group	Short	General	General	The dementia industry group (DIG) is a life sciences industry collaborative group supporting the UK to lead in the field of dementia treatment and research. Our vision is to improve outcomes in dementia by ensuring optimal access and uptake of innovative technologies and treatments	Thank you for taking the time to comment on the guideline. Individual comments have been responded to where they appear.

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				for eligible patients as well as ensuring the health and care system is geared to provide the best support for people living with dementia. The dementia industry group currently comprises Biogen, Eisai, Janssen, MSD and Otsuka. The group is advised by Alzheimer's Research UK, MHRA and supported by Mednet. NICE attend the steering group meetings. DIG welcomes the opportunity to respond to this consultation. Our members are involved in the research and development of treatments for Alzheimer's Dementia. Our feedback focuses on the following areas : • Laying the foundations for the early detection of Alzheimer's disease • Identification and understanding of Cognitive, behavioural and functional symptoms • Increasing understanding of dementia and the diseases that cause it amongst healthcare professionals • The importance of NICE clinical guidelines keeping pace with clinical developments in dementia and Alzheimer's disease • The diagnosis of dementia and Alzheimer's disease	

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Dementia Industry Group	Short	General	General	It is estimated that between 5 and 20 per cent of people aged over 65 have MCI. It is not a type of dementia, but a person with MCI is more likely to go on to develop dementia. A lot of research has focused on trying to identify which people with MCI will go on to develop dementia. If this could be predicted, it would mean people could be offered a range of support and treatment earlier in the development of dementia. DIG would recommend that due attention is paid to the detection, care and research into Mild Cognitive Impairment within these guidelines.	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been passed to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Dementia Industry Group	Short	General	General	**Behavioural and functional symptoms:** the full guideline sets out clearly the challenges of diagnosing and treating these symptoms, recognising the qualitative and quantitative burden on individuals, families and health and social care systems. We note that this information and guidance is not incorporated into the short guideline to an extent that would be helpful for professionals. We feel the short guideline does not provide adequate information on definitions, support for detection, diagnosis and care for behavioural and functional symptoms.	Thank you for your comment. The committee agreed that the recommendations included in the short guideline were as specific as possible given the evidence available, and noted that a number of recommendations for future research had been made in areas with a lack of evidence. The committee noted that a number of different terminologies were used to describe non-cognitive symptoms for people living with dementia, but agreed the current wording in the guideline should be clear and familiar to most people working in the area.

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				Recommendation: In reference to symptoms we would recommend the use the terms **cognitive, behavioural and functional.**	
Dementia Industry Group	Short	4	7	DIG welcomes the recognition that new methods for diagnosing and assessing dementia have been developed. Both amyloid imaging techniques and cerebrospinal fluid examination represent reliable methods for diagnosing dementia and Alzheimer's disease. New developments in diagnosing Alzheimer's disease continue to be made, some of these maybe blood tests others could be sensitive digital cognitive tests. For example, researchers presenting findings at the Alzheimer's Association International Conference 2017 demonstrated that a blood test could indicate the presence of amyloid in the brain indicative of Alzheimer's pathology. These developments, along with ongoing innovations in clinical practice and technology, mean that the National Health Service must ensure that it takes opportunities to combine new methods for diagnosing and assessing dementia and Alzheimer's disease with existing clinical practice to enhance the reliability of diagnostic criteria.	Thank you for your comment. The committee agrees with the importance of evaluating the accuracy and effectiveness of newer diagnostic tests, and notes that future updates of the guideline should take account of any new evidence published in these areas.

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Dementia Industry Group	Short	7	14	DIG supports providing people with dementia, their family members or carers (as appropriate) with oral and written information on topics such as their legal rights and responsibilities, their right to reasonable adjustments (in line with the Equality Act 2010) and how to access local support groups and advocacy services. However, we recommend that, at the point of diagnosis and during the course of the illness, people should be asked if they are interested in taking part in research and healthcare professionals should share information on research activities with people diagnosed with dementia, their family members and carers. We would also recommend that people at risk of developing dementia are asked if they are interested in taking part in research. Research is vital to improving the outcomes of people diagnosed with dementia in the UK and there is significant public appetite to participate in dementia research. A poll conducted by *YouGov* on behalf of Alzheimer's Research UK in 2015, found that almost two thirds (62%) of respondents would be willing to take part in dementia research, but more than four out of five people (81%) would not know how to volunteer.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				Recent years have seen progress in supporting people to access dementia research. Between 2012 and 2015, Government funding for dementia research doubled, to over £60m a year. Launched in 2014, Join Dementia Research (JDR) has played an important role in encouraging more people diagnosed with dementia to take part in research. To enhance recruitment to clinical trials in the UK it is vital that GPs, community pharmacies and memory clinics both ask people diagnosed with dementia and those at risk of developing dementia if they would like to participate in research and provide information on opportunities to do so.	
Dementia Industry Group	Short	9	4	DIG welcomes advance care planning to offer early and ongoing opportunities for people living with dementia and people involved in their care to discuss the benefits of planning ahead and their values regarding their future care. As noted above, we contend that people living with and at risk of developing dementia should discuss their interest in participating in dementia research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
Dementia Industry Group	Short	9	24	DIG welcomes the recommendation to use a validated cognitive instrument when using	Thank you for your comment. The committee noted that the MOCA did not show any evidence of superior accuracy to the

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				cognitive testing. However, DIG believes this list should either be exhaustive (e.g. it currently omits the Montreal Cognitive Assessment (MOCA)) or not include specific examples of cognitive tests. NHS staff should be fully trained to diagnose dementia using the appropriate cognitive tests in a timely and appropriate manner. In addition, new research diagnostic criteria, including the National Institute of Neurological Disorders and Stroke– Alzheimer's Disease and Related Disorders Association (NINCDS–ADRDA) criteria, the National Institute on Aging–Alzheimer's Association (NIA–AA) criteria, and the revised criteria of the International Working Group (IWG-2) offer the potential to combine cognitive assessment with biomarkers. These approaches have the advantage not only of introducing biomarkers (discussed below) but also provide criteria for the diagnosis of prodromal Alzheimer's disease, on the basis of symptoms and biomarkers or even on the basis of biomarkers alone. While these tests are not yet used in clinical practice, DIG supports efforts focused on developing new methods to diagnose	shorter tests recommended, and therefore agreed it was appropriate to recommend those tests that could be completed in a shorter amount of time, if they provided the same value at this stage of the diagnostic process. The full explanation is given in the "evidence to recommendation" section of the diagnostic chapter, and an extract of the relevant section is given below: "The committee also noted that more complex (and therefore time-consuming) tests did not appear to be more effective at detecting dementia than shorter and simpler tests, and it was therefore a more efficient use of resources to use these briefer tests within a time-constrained primary care setting." The committee noted that there was considerable ongoing work around updated diagnostic criteria for various dementia subtypes, and that it would be appropriate to consider those newer criteria in future updates of the guideline.

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				dementia at an earlier stage of the disease. This is vital because future treatments are likely to deliver the greatest benefit to patients when initiated at the early stages of the disease and a diagnosis provides people with dementia with an opportunity to plan for their future care needs. To support the early diagnosis of dementia, we suggest that NICE recommends that the diagnosis of dementia is integrated and aligned with Public Health England's *NHS Health Check* programme on dementia and clinicians are supported to understand the very early signs and symptoms of dementia and Alzheimer's disease.	
Dementia Industry Group	Short	11	15	DIG welcomes the inclusion of examining cerebrospinal fluid, FDG-PET and perfusion SPECT as methods of diagnosing dementia. However, DIG contends that these methods should be promoted in suspected cases in combination with cognitive assessment rather than solely if the diagnosis of dementia is uncertain. Wider use of biomarkers can reduce misdiagnosis of dementia and Alzheimer's disease. Diagnosing dementia is complex with most clinical diagnoses	Thank you for your comment and your support for these recommendations. The committee fully agreed that all the information available on an individual should be considered when making a diagnosis, and that individual test results should never be considered in isolation. The committee noted the guideline does contain reference to a number of sets of clinical criteria that can be used to assist the diagnostic process. The committee agreed diagnostic uncertainty would refer to a situation where all the previous steps of the diagnostic pathway have been conducted and

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				made at the dementia stage. However, people with a clinical diagnosis of Alzheimer's disease, when followed to post mortem, do not always exhibit pathology associated with dementia and Alzheimer's disease. It has been suggested that around 20% of people may have been misclassified during their life. Alzheimer's disease is a progressive neurodegenerative disease that can manifest years before symptoms occur. At present, the standard methods for diagnosis of dementia are focused on diagnosing dementia between the mild and severe stage. Current testing practice doesn't support the early and timely diagnosis of dementia. As such, it is vital that biomarkers are used in combination with cognitive tests to support the diagnosis of dementia during the earlier stages of the disease, when future treatments are likely to have the greatest impact. DIG would welcome clarity on what is meant clinically when a diagnosis is not certain of Alzheimer's disease. This paragraph seems to conflate Alzheimer's disease with Alzheimer's dementia and DIG would suggest a broader discussion around the distinction between	these criteria considered, and it is still not possible to make a confident diagnosis of a dementia subtype.

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				diagnosing Alzheimer's dementia and Alzheimer's disease.	
Dementia Industry Group	Short	11	28	Although analysis of Alzheimer's Disease Neuroimaging Initiative (ADNI) data showed that the diagnostic accuracy of the tau/Aß42 ratio was higher in the younger (<75 years) than in the older (>75 years) age group due to reduced specificity in older people, DIG notes that using a combination of biomarkers, may still show satisfactory sensitivity and specificity in older people. We therefore recommend that a combination of biomarkers maybe useful tests at all ages.	Thank you for your comment. The committee agreed there was no clear age threshold above which biomarkers should not be used. However, they noted the evidence did show that the utility of CSF testing was lower in older people, and this was what led them to make a recommendation to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination".
Dementia Industry Group	Short	12	24	DIG notes that the guideline states that case finding for suspected dementia should only be undertaken as part of a clinical trial that provides an intervention to people diagnosed with dementia. While case finding for suspected dementia will not always be appropriate, DIG believes that people with dementia should be able to access diagnostic services. There are over 850,000 people currently living with dementia in the UK, many of whom who have not had a formal diagnosis of their condition. Alzheimer's	Thank you for your comment. The committee agreed about the importance of access to an accurate and early diagnosis, but agreed this was different from implementing a system of active case finding, which would need to have clear evidence of benefits to justify the costs of such an approach, which could otherwise be used to provide care for people with diagnosed dementia.

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				Research UK estimate that the dementia diagnosis rate in the UK was 69% in 2015/16, with significant variation across the UK, which means that many people are unable to access post-diagnostic support and care to better support people living with dementia and help them learn to live well with dementia. Healthcare professionals should be supported to diagnose suspected dementia and identify the early signs and symptoms of the condition to ensure that people can access care and support. There may also be opportunities to align NHS Health Checks with new methods of diagnosis to ensure that those at a high risk of developing dementia are closely monitored for the very early signs of the condition.	
Dementia Industry Group	Short	13	19	**Review after diagnosis:** DIG believe that in addition to the recommendation, there are cognitive, behavioural and functional symptoms for dementia and Alzheimer's Dementia and it is important to make these explicit as part of post diagnosis review. NICE CG42, "*Dementia: supporting people with dementia and their carers in health and social care*" makes this clear by	Thank you for your comment. The committee agreed that, in the absence of evidence, it was not possible to include a recommendation along these lines in the section of the guideline on post-diagnostic review. However, references to a structured assessment are included in both the section on developing care and support plans, and the section on managing non-cognitive symptoms in people living with dementia.

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				stating: "A behavioural and functional analysis should be conducted by health and social care professionals with specific skills, in conjunction with carers and care workers, and an individually tailored care plan should be developed to address the issues." DIG would ask that functional and behavioural needs are referred to explicitly in this section to facilitate care planning.	
Dementia Industry Group	Short	20	20	1.7 Managing non-cognitive symptoms. Agitation, aggression and distress: Given the evidence and challenges set out in the full guidance, DIG suggest that this section could provide clearer and more helpful guidance for professionals on detection and diagnosis, and the need for ongoing review as part of a patient's care plan. DIG would suggest expanding this section to include where and how patients may present; who might be involved in the diagnosis and treatment decision; and include examples of non-pharmacological interventions. DIG would suggest a consistency of language (noting terminology	Thank you for your comment. The committee discussed whether it was possible to make more detailed and specific recommendations in this section, but agreed that the recommendations were as specific as possible given the evidence available. The committee also noted that that quality standard on dementia may be updated after the publication of this guideline.

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				above) and references to delirium. We note that there may be some merit in keeping consistency with the NICE Q30 and in the Dementia flow chart: https://pathways.nice.org.uk/pathways/dementia#content=view-index&path=view%3A/pathways/dementia/dementia-interventions.xml	
Dementia Industry Group	Short	25	8	DIG would advise that in the interests of consistency, when citing examples under which balanced assessments are undertaken which address current medical needs with the additional harms patients may face in hospital; as well as Delirium; agitation, aggression and distress should be mentioned.	Thank you for your comment. The committee noted this point, and agreed it was captured under the bullet points on disorientation, increased morbidity and the effects of being in an impersonal or institutional environment.
Dementia Industry Group	Short	27	3	Recent years have seen remarkable progress in increasing awareness and understanding of dementia amongst the public and healthcare professionals. Nevertheless, it is essential that healthcare professionals have an understanding of the pathology of dementia and Alzheimer's disease. The findings from a 2016/17 pilot project on dementia risk reduction, run in partnership	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.

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				between Public Health England (PHE), the Alzheimer's Society and Alzheimer's Research UK, have shown varying levels of knowledge among healthcare professionals.[i] Some were knowledgeable, having worked with the elderly, while others had specialist experience of dementia or have previously undertaken training on the topic. However, others had limited knowledge on the topic and, similarto the general public, were surprised that lifestyle factors and changes to behaviours could reduce the risks of developing dementia. To enhance understanding of Alzheimer's disease and support the earlier diagnosis of the condition, DIG recommends that care and support providers should train healthcare professionals in the pathology of Alzheimer's disease, in addition to the signs and symptoms of the condition, to improve awareness of the very subtle changes associated with early Alzheimer's disease. This pathway should capture the journey from asymptomatic risk, MCI, early, moderate and severe dementia. In addition, DIG recommends that relevant NHS personnel should receive training on how and	

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				when to use cognitive assessments and other methods of diagnosis including FDG-PET and CSF.	
Dementia Industry Group	Short	27	7	1.13 Staff Training: DIG support the recommendation for care and support providers to provide all staff with training in person-centred and outcome-focused care for people living with dementia. When looking at areas to include, we would ask that the line stating "understanding the signs and symptoms of dementia" is expanded to "understanding the signs and cognitive, behavioural and functional symptoms of dementia'.	Thank you for your comment. The committee noted this suggestion, but agreed to retain the current wording in the guideline as the clearest way to convey the relevant point, that all relevant signs and symptoms of dementia should be included in training.
Dementia Industry Group	Short	31	6	DIG welcomes the decision of the guideline committee to include a number of recommendations for research. DIG suggests that an additional research recommendation should be included on preparing for the early detection of dementia, including the use of new technologies and cognitive assessment. In 2015 the National Screening Committee concluded that it was not appropriate to introduce screening for dementia, highlighting the lack of biomarkers to identify those with, or at risk of, dementia, and the absence of effective	Thank you for your comment. The committee agreed that the earlier detection of dementia was a relevant topic for future research, but agreed it was not as high a priority as the other recommendations included in the guideline. In particular, they noted that it was not currently clear which tools or tests should be prioritised for future research, and only when this became clearer would it be possible to make practical recommendations for future research.

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				early treatment for the condition. Nevertheless, it is imperative that the NHS is prepared to support detection and early diagnosis, keeping pace with developments in diagnostic technology. As noted above, early detection of pathological changes in the brain is already a component in clinical trials of new treatments for Alzheimer's disease. The NHS should consider opportunities to better link risk factor identification to clinical trial recruitment, so that more people can participate in initiatives such as Join Dementia Research.	
Dementia Industry Group	Full	208	23 and 24	DIG recognise that costs related to informal care can be hard to quantify. However, for a condition such as dementia, which relies so significantly on informal carers, to not adequately consider these costs could result in an under-representation of the scale of the problem. We recommend further research to understand how wider cost impacts, including informal care costs, could be measured and the impact this could have on assessing cost-effectiveness for interventions for dementia.	Thank you for your comment. Although we recognise that costs related to informal care are significant, the NICE reference case does not include informal care costs not borne by the NHS.

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				The total cost of dementia is over £26bn. The majority of dementia costs per year are due to informal care at £11.6bn (44.2%), with social care costing £10.3bn (39.0%) and healthcare costs £4.3bn (16.4%).	
Dementia Pathways Community Interest Company	Short	General	General	We feel that a greater emphasis should be placed in the guideline on access to 'Respite Care' and the benefits for family carers of respite care that is well handled.	Thank you for your comment. The committee noted the RCT evidence base for respite care in dementia was not strong (containing only 3 small studies), and therefore agreed it was not possible to make stronger recommendations on this topic in the guideline.
Dementia Pathways Community Interest Company	Short	General	General	The guideline includes is recognition of the special needs and difficulties of younger people who develop dementia and their families, and of people with learning difficulties. There really should be something about people who have limited English and/or live within cultural situations which make understanding and management of dementia more difficult.	Thank you for your comment. The committee noted and agreed these were real concerns, but agreed that in the absence of any evidence they were not able to make recommendation on how best service should be tailored to be most accessible to these groups.
Dementia Pathways Community Interest Company	Short	3	23	Having established the importance of dementia in terms of the number of people affected and its impact on individuals, families and statutory services, page 3 asserts: *'Providing care and support (for people with dementia) is very complex'*. Professor David Jolley, a special adviser to Dementia Pathfinders, expressed the view that "This gives notice of an atmosphere of awe and	Thank you for your comment. This section is merely a general introduction to the guideline, and should not be interpreted as representing the considered view of the committee after having reviewed all the relevant evidence.

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				furrowed brows, which seems to me to exaggerate the facts, almost to excuse failings in what is essentially a simple paradigm: people need help – the help required should be tailored to the individual, be flexible and change over time as needs change. Help will be needed throughout the remainder of life, and family and other carers may require support and therapy even beyond death of the individual".	
Dementia Pathways Community Interest Company	Short	4	3	Page four emphasises the financial implication of individual cases, but most particularly the costs arising within health and social care services. The impression is that the burden of these costs weighs more heavily than the impact on the lived experiences of individuals and their families. From this, a transition to information about new, complex and expensive techniques which require examination of cerebrospinal fluid, fits uneasily. These techniques have been demonstrated but to hint that they can reasonably add to good clinical practice seems less than wise.	Thank you for your comment. NICE's remit is to consider the balance between costs and effects of the interventions it considers. As such, the recommendations made were ones the committee were confident would be an effective and cost-effective use of resources.
Dementia Pathways Community Interest Company	Short	5 6	15 – 29	Reference is made to key relevant legislation since the 2006 NICE Guidance on Dementia. However, there is no mention of the Law	Thank you for your comment. The committee agreed the most appropriate way to address these issues was to cross-refer to the NICE guideline on decision-making and mental capacity

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			1 - 11	Commission's report on DoLS, though this is clearly very relevant to the future of dementia care: www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/	(which is due to be published in July 2018), and this link has now been added to the final guideline.
Dementia Pathways Community Interest Company	Short	7	15 - 17	Information is vital, however people with dementia and families can often be overloaded with information. The emphasis on 'relevant to their circumstances and the stage of their condition' is crucial. This recommendation is challenging in practice because dementia does not progress in a linear fashion and many of the pathway models are complex and involve multiple professionals and agencies.	Thank you for your comment. The committee agreed there can be challenges in appropriately tailoring information for people living with dementia because of the complexity of the condition, but also noted that providing appropriate information was crucial to ensuring people are appropriately informed and able to participate in decisions about their care.
Dementia Pathways Community Interest Company	Short	7	8 -9	Involving people living with dementia in decisions about their care is vital. We would recommend a truly co-productive approach, with professionals and people with dementia and family carers working in partnership to weigh up options and make informed decisions about care. Dementia Pathfinders worked with people with young onset dementia and their families on a DH funded workforce project looking at providing training for the social care workforce on meeting the needs of people living with young onset dementia and their families. This project entailed a co-productive 'listening exercise' which resulted in a	Thank you for your comment. NICE would welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies

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				publication in which people living with young onset dementia and their families spoke about their experiences of seeking a diagnosis, post-diagnosis support and their need for particular services. This is an example of people living with dementia can be encouraged to articulate their needs and influence care provision and the design and delivery of training for heath and care professionals. We would be willing to contribute this experience and an electronic or hardcopy version of the publication 'Approaching an unthinkable future: understanding the support needs of people living with young onset dementia' (2015) to the NICE shared learning database. Contact Barbara Stephens Barbara.stephens@dementiapathfinders.org	
Dementia Pathways Community Interest Company	Short	7	10 - 11	For commissioners and service providers to do this well, there is a need improved understanding of people's lived experiences and communication challenges. We would suggest that there is a cost implication to ensure that professionals in relevant roles are provided with communications skills training,	Thank you for your comment. The committee agreed there would be costs associated with providing staff with training in communication skills, but agreed this would be an appropriate use of resources that would improve the care and support provided to people living with dementia.
Dementia Pathways Community Interest Company	Short	7	12-13	A greater use of structured tools would be a welcome development. Training would be	Thank you for your comment and your support for this recommendation.

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				required to ensure that relevant professionals are equipped to use these tools effectively.	
Dementia Pathways Community Interest Company	Short	9	3 - 15	The section on Advance Care Planning calls for *'early and ongoing opportunities for people living with dementia and people involved with their care'* to complete and iteratively review such plans. We regard this guidance as ethically and pragmatically desirable, however would caution that the fulfilment of this guidance is logistically unobtainable for most people living with dementia without major revision of current services.	Thank you for your comment. The committee noted this concern, but agreed that appropriate opportunities to engage in advance care planning were key to ensuring the rights of people living with dementia are respected throughout their lives.
Dementia Pathways Community Interest Company	Short	13 14	22 - 28 1 - 13	A single named health or social care professional who is responsible for co-ordinating the care of individuals with a diagnosis of dementia would improve their experiences immensely and would encourage the practice of engaging family carers as partners in care. This is a welcome recommendation, which, for decades, has been one of the most widely articulated pleas of family carers (referenced in the Dementia Strategy 2009 and even as long ago as the consultation that informed the inception of Admiral Nurses in the late 1980s). However, a simple model, applicable for all people with a diagnosis of dementia, living	Thank you for your comment and your support for this recommendation. The committee agreed that the recommendations made were as specific as possible given the currently available evidence. However, they agreed there were still important questions to answer about the best way this should be organised in practice, and this led them to make a number of research recommendations on this topic, including "what is the effectiveness of high-intensity case management compared with usual care?" and "what are the most effective methods of care planning for people who do not have regular contact with an informal carer?"

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				in any part of the country, has, to date, eluded health and care services. Robust guidance from NICE, and the revision of DoLS suggested by the Law Commission (which is relevant to this issue) might make it more possible for this recommendation to be realised.	
Dementia Pathways Community Interest Company	Short	15	5 - 15	The non-pharmacological interventions are not given sufficient weight in the draft guideline, when considered in the context of totality of care, treatment and support which individuals with dementia and their carers can benefit from through their journeys with dementia. Disappointingly there is no mention of therapeutic and creative interventions based on the arts. Extraordinary gains in health enhancement, wellbeing and quality of life for people living with dementia resulting from programmes involving music, dance, poetry, painting and other arts interventions. These approaches warrant inclusion in the NICE dementia guideline. Dementia Pathfinders has co-developed and delivered an innovative programme for people living with dementia in care homes called 'Dance for Life', the pilot for which was independently evaluated. Dementia	Thank you for your comment. Evidence was looked for across a wide range of non-pharmacological intervention, including arts based interventions such as those specified. The committee agreed that in the absence of robust evidence of the effectiveness and cost-effectiveness of these interventions, and in view of the high cost of delivering them to a large population of people living with dementia, that they could not justify including specific mention of these interventions within the guideline. However, they did note the guideline contained a number of recommendations around personalised activities, such as: "Offer a range of activities to promote wellbeing that are tailored to the person's preferences" For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest." They agreed that all these would be relevant interventions to consider under these recommendations, assuming they matched to the person's individual preferences.

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				Pathfinders, as a partner of the charity Dance for Life UK www.danceforlifeuk.org would be willing to submit out experiences of developing and delivering this programme for people with dementia in care homes and the community, plus we would be happy to provide a copy of the published evaluation report in hardcopy and/or electronic format. Contact Barbara.stephens@dementiapathfinders.org Dementia Pathfinders is also involved with 'Music for Life' a music improvisation programme delivered in care homes and community settings for people living with dementia. Again, we would be happy to contribute our experiences in collaboration with our partners Wigmore Hall Learning.	
Dementia Pathways Community Interest Company	Short	15	9 - 11	The wording of the guideline for cognitive stimulation therapy and reminiscence therapy has been diluted. 'Consider providing ….' as a form of words is a weak steer and may create a lack of clarity about the nature of specific intervention programmes; potentially, also compromising quality and integrity. Our view, also, is that the range of benefits of CST and other interventions to promote cognition,	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this

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				independence and wellbeing are under-stated in the guideline. For example, research on CST shows significant improvements for people living with dementia in quality of life and activities of daily living. The health gains that result from non-pharmacological interventions are being increasingly recognised and the wealth of qualitative data, as well as data for quantitative outcomes, for a much wider range of interventions should be taken into account. ·	into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Dementia Pathways Community Interest Company	Short	22	17 - 23	The importance of general health and the presence of comorbidities is properly addressed and welcomed.	Thank you for your comment and your support for this recommendation.
Dementia Pathways Community Interest Company	Short	22 23	24 – 27 1 - 10	We welcome the detailed guidance about assessing and managing pain.	Thank you for your comment and your support for these recommendations.
Dementia Pathways Community Interest Company	Short	24 25	25 – 27 1 - 10	Palliative Care is rightly given prominence in the guideline: '*From diagnosis offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.*' Again we are faced with the requirement to identify individuals with dementia early and to follow them up competently throughout the following years to death and	Thank you for your comment and your support for this recommendation.

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				beyond. We very much agree that this is necessary. We know it is what should be done. The challenge is to make it happen for everyone. There are many systemic barriers plus resource issues and training needs for staff across different disciplines.	
Dementia Pathways Community Interest Company	Short	25 26	14 – 29 1 - 18	We strongly support the recommendation that family carers should be offered an extensive range of education, information and support. These measures are known to be well received and helpful; indeed, supporting carers to look after relatives with dementia can prevent hospital admission and delay or even avoid long-term placement in care home settings. We support the empowerment of family carers, alongside the empowerment of people living with dementia. As citizens and patients of the NHS, every effort should be made to ensure that people with dementia and family carers have their voices heard and their respective needs addressed. We would encourage consideration of the full range of care options for all people living with dementia, based on needs, but also choices; and explicit recognition that, at times, there is a conflict of need between the person with	Thank you for your comment and your support for this recommendation. The committee noted there was robust evidence that the carer interventions included in the guideline were both effective and cost-effective, and therefore agreed it was appropriate to recommend they be offered to all people living with dementia. They noted this may involve an expansion of the carer support services available, but agreed the evidence showed this would be a worthwhile use of resources.

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				dementia and the primary family carer. There are resource and training implications for this guideline to be implemented fulsomely and with integrity. We question how provision of training for family carers will be resourced and whether the range of services for family carers highlighted in the draft guideline will be prioritised at a time when resources are stretched. We hope that the strength of these recommendations will have influence.	
Dementia Pathways Community Interest Company	Short	27 28	3 – 29 1 - 13	A national training programme delivered well would provide a solid foundation on which to build a more professional workforce. However, there must be a mechanism for monitoring and evaluating the success of the training and for continuous improvement. People from across the care spectrum should be able to access training at a level that inspires them to focus purposefully on their caring. Reference should be made to the 'Dementia Core Skills Education & Training Framework' published by Skills for Health, Skills for Care and Health Education England in 2015, which was created as a resource to underpin commissioning decisions.	Thank you for your comment. The committee decided not to refer to the Dementia Core Skills Education and Training Framework document as part of the recommendations themselves, as these needed to be based on the evidence identified from the literature review. However, it was agreed to be appropriate to refer to this document within the list of relevant other guidance at the start of the document, alongside other Department of Health frameworks.

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Dementia Pathways Community Interest Company	Short	31	9 - 20	Regarding "case management" and the question of its cost effectiveness - already Admiral Nurses, Community Support Co-ordinators and numerous other case manager models are proving their worth and we need to learn from these innovations.	Thank you for your comment. The committee agreed with this point, and that this current knowledge would need to be borne in mind when designing future research.
Dementia UK	Short	General	General	Overall we welcome the inclusion of family members and carers in assessment, diagnosis, decision- making and on-going care/ support. There should however be some consideration of how 'carers' are defined and who is involved in decisions especially where there are conflicting views and the person with dementia is unable to make decisions due to lack of capacity	Thank you for your comment. The committee agreed these issues were best addressed by the cross-reference in the guideline to the Mental Capacity Act and its accompanying Code of Practice, as well as a cross-reference to the NICE guideline on Decision-making and mental capacity (which is due to be published in July 2018).
Dementia UK	Short	General	General	Whilst there is recognition of the incidence of depression in family members/ carers and the risk of delirium in dementia; there is little reference to the risk of depression and anxiety for people with dementia. We recommend inclusion of how depression and anxiety can impact on assessment, diagnosis and treatment. Consideration of recommended tools for screening and use of psychological treatments including Cognitive Behavioural Therapy and psychotherapy is also suggested.	Thank you for your comment. The committee noted there was only limited evidence on assessing and managing depression in people living with dementia, and the identified trials covered a wide range of different interventions. The committee therefore agreed it was not possible to be more specific than the current recommendation in the guideline: "For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments."

Dementia: assessment, management and support for people living with dementia and their carers

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Dementia UK	Short	General	General	We are concerned that the guidelines offer little instruction for those who have not received a formal diagnosis for varied reasons. The presence of dementia may be clear to significant others but often leads to complex situations or crisis occurs before support is provided. Family/carers require education and coping strategies in these situations.	Thank you for your comment. The committee agreed that there was no evidence identified within the guideline that would enable them to make recommendations, but agreed this was a relevant issue. As noted within the committee's discussion of the evidence for the diagnostic section; "the committee commented that it was also important to consider situations where a patient may not want a referral for an assessment/diagnosis, and the potential disadvantageous outcomes that might result from this choice (e.g. problems with obtaining support, care and treatment)."
Dementia UK	Short	9	18/19	Capacity assessment and best interests should be considered by GP/practice nurse in non – specialist settings during assessment	Thank you for your comment. The committee agreed these were relevant issues to consider, if there were concerns about the person's capacity at the time of this initial assessment.
Dementia UK	Short	13	General	**Telling the difference between delirium and dementia** This highlights detecting delirium in the hospital setting but if applied in the community setting, unplanned admission to hospital may be avoided. However, no reference is made to obtaining history and presentation/ information from family/carer's who often notice changes but are not always listened to.	Thank you for your comment. The committee noted the evidence identified for this review question came from hospital settings, and therefore agreed it was appropriate to restrict their recommendations to that setting. They also noted that the question asked was not about what should prompt concern about whether a person has cognitive impairment/delirium, but how dementia and delirium should be distinguished once suspected.
Dementia UK	Short	13	12	In cases where diagnosis is uncertain suggest a follow-up appointment should be arranged to review any further deterioration in cognition	Thank you for your comment. The committee noted this suggestion, but agreed there was no evidence identified which would enable it to be included in the recommendations.

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Dementia UK	Short	13	22	We welcome the recommendation for a dedicated coordinator for intensive case management throughout the trajectory of dementia. We recommend from our clinical experience that this role requires a professional with specialist knowledge in dementia with knowledge and skills to support both person with dementia and carers. We believe Admiral Nurses can play a key role in intensive case management particularly for those with complex needs, requiring significant input from a variety of professionals; offering both face-to-face and telephone support for both the person with dementia and their family carers.	Thank you for your comment. The committee agreed with your points as to the skills such a person would need, but that in the evidence base considered, a number of different roles were responsible for care coordination (social workers, nurses, occupational therapists), and it was not possible to make recommendations on which of these was the most appropriate. They did agree that Admiral Nurses were one very obvious group of professionals to play a role in implementing this recommendation.
Dementia UK	Short	22	4	Consider appropriate observational skills and assessment tools to diagnose depression and anxiety in people with moderate to severe dementia or where person unable to articulate there mood/emotions	Thank you for your comment. The committee noted this suggestion but agreed that, in the absence of evidence meeting the inclusion criteria for the guideline, this was not something they were able to include in the recommendations.
Dementia UK	Short	24	General	**Palliative care** and advanced healthcare plans- we consider further education is required for out of hours staff, ambulance service and on call doctors who will often follow rigid procedures or easiest option without considering the needs/wishes of the person with dementia or carer. Access to	Thank you for your comment. The committee discussed these issues but agreed that, in the absence of any evidence being identified, it was not possible to make recommendations on this topic.

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				advanced decision documents or best interest decisions also needs to be considered.	
Dementia UK	Short	24	6	The offer of flexible referral to palliative care is a sensitive subject and consideration should be given to appropriate timing. This requires skilled support by a specialist nurse/professional who can provide information, the time and skilled support to ensure a seamless progression into End of Life care. Admiral nurses are concerned this may be carried out as a tick box exercise and not followed up.	Thank you for your comment. The committee agreed with this point, and this was behind the decision to recommend that the offer of palliative care should be both "flexible" and "needs-based."
Dementia UK	Short	25	General	**Supporting carers** - we note the need to consider anticipatory grief and follow-up bereavement support. Loss of significant others and the role of carer can also increase the risk of loneliness, isolation and depression.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in these issues.
Dementia UK	Short	26	10/11	Although group sessions are considered the most effective for carers; there is little guidance offered on the type of group intervention i.e. psycho-education, peer support, psychotherapeutic, etc. Clinical experience from Admiral Nurses indicates that groups are not always possible (due to availability of respite) or appropriate, as they do not always address the complexities and dynamics of families/carers.	Thank you for your comment. The committee noted that there were examples of the types of carer interventions recommended (such as the START intervention referenced in the full guideline) that could be implemented in a fully structured way. The committee agreed that although the evidence showed that groups were, on average, the most effective way to deliver these interventions, the support should be "provided in a format suitable for them (for example individual or group sessions, or online training and support)."

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				Time to provide individual coping strategies and building resilience is also often neglected. We would recommend a tailored approach, which offers flexibility and allows for individual choice.	
Department of Health and Social Care	Full	General	general	I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Down's Syndrome Association	Short	General	General	We know that individuals with a learning disability (and people with Down's syndrome, in particular) have been identified as a priority group of individuals who are more at risk of developing dementia and are more likely to be excluded from mainstream dementia services. Adults with a learning disability have been identified as a *seldom heard* group by the Dementia Action Alliance (The Down's Syndrome Association is a member of this network). In 2017 the Alliance produced a briefing paper on dementia and learning disability, outlining some of the agreed challenges. www.dementiaaction.org.uk/joint_work/dementia_and_seldome_heard_groups/people_with_learning_disabilities	Thank you for your comment. The committee agreed that there were particular issues around both diagnosis and management of dementia for people with learning disabilities (including Down's syndrome). Evidence on these issues was looked for throughout the guideline, but no evidence was identified which the committee felt enabled them to make specific recommendations for this population. The committee agreed that further research in this areas would be valuable, both generally around how LD services should be organised, and specifically around the interaction between LD and dementia services. The committee agreed that, as a response to a number of issues raised during the consultation around dementia in people with learning disabilities, it was appropriate to add a specific mention to learning disabilities in the recommendation on groups of people to whom service should be designed to be accessible.

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				We know that people with Down's Syndrome (DS) have a much higher risk of developing early onset dementia and also, therefore, premature mortality. It is estimated that the prevalence of DS is 0.66 per 1000 population such that there are over 40,000 people with DS in the UK. Since it has been estimated that the cumulative prevalence of dementia in this population is 95% by the age of 60, the public health imperatives concerning health and social care for people with DS are self-explanatory. (McCallion et al, 2017). However, people with DS are also at risk of diagnostic overshadowing i.e. the changes due to the onset of dementia being attributed to their underlying learning disability or certain health conditions associated with their condition (e.g. thyroid disorder, visual and hearing impairments). People with DS often present later for diagnosis or are the subject of misdiagnosis, due to ill-informed professionals misinterpreting symptoms as being dementia, when in fact they are due to another underlying, treatable, condition. From an end of life care perspective, evidence suggests that people with DS are a unique population within the wider population of people	

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				with LD. Their mortality profile is unique given that dementia will be the cause, or associated cause, of death for many adults with DS. The prevalence of dementia in this population has been reported to rise from 9% for adults with DS aged between 40-49 years to 32% for adults aged 50-59 years (Coppus et al, 2006). Sinai et al (2018) report that the average survival time following a diagnosis of dementia in this population is less than 4 years. The established link between DS and dementia implies also that people with DS are more likely than other people with LD to experience a death that will have been anticipated for some month or years (Todd, et al, in prep). Given the progressive nature of dementia and the imperative of actively involving the individual and carers in planning end of life care, early diagnosis has been linked with improved end of life care outcomes (Goodman et al, 2015). The situation of people with DS and dementia has, as yet not featured in the small but growing body of evidence concerning end of life care for people with LD (Stancliffe et al, 2017)	

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				There is evidence to suggest that people with LD are at risk of transitioning out of LD services in the last years of life. (Patti et al, 2010). End of life care should be identified at the time of diagnosis and this should be reviewed as the illness advances, and more so when the individual is recognised to be nearing the dying phase. These include: awareness of when the terminal phase of dementia has begun; appropriate referral to specialist palliative care services; advance care planning and person and carer involvement in this; ethical decisions in relation to medication and nutrition; under-treatment of pain relief; and over and burdensome treatment interventions (Sampson et al, 2009; Lillyman and Bruce, 2016). McCallion et al (2017) suggest that recognizing when an individual with LD and dementia is entering the dying phase of the illness is perhaps more difficult for people with DS since most tools (e.g. FAST) over-emphasize decline in everyday functioning. They suggest that attention to acute clinical events such as multiple hospitalisations, recurrent infections, aspiration pneumonia, pressure sores, weight loss and/or refusal to eat maybe more useful in this population.	

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Down's Syndrome Association	Short	5	7	We would support the call for improved research and in relation to the research priority of **staff training**, we would add that this should include training on condition specific risk factors that predispose some people with LD to develop dementia (and at an early age of onset). In relation to research relating to **care and support planning** we would highlight that people with DS are less likely to be married and unlikely to have children, therefore they are less likely to have the support of a partner or family-carers who are at an age where they have the capacity to provide direct care. Often people with DS have primary family-carers who are their parents, naturally they are likely to be older themselves and may not be a position to provide direct care to their loved one. People with DS who develop dementia in middle age may also be providing informal care for their parents and often the mutuality of this caring relationship is not fully recognised.	Thank you for your comment, and your support for these research recommendations. The committee agreed that future research should target the whole range of people who develop dementia, rather than being focused only on more common presentations. They also noted the guideline did contain a specific research recommendation on "the most effective methods of care planning for people who do not have regular contact with an informal carer."
Down's Syndrome Association	Short	7	10	We welcome approaches that will increase the accessibility of information provided to individuals with LD who develop dementia, however, we would stress that accessible written resources are only one small part of this. People need to have well-trained, supportive, staff, who	Thank you for your comment. The committee agreed with all the points expressed, and that time and appropriate follow-up appointments are necessary to ensure people receive the support they require.

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				have the skills and sufficient time to help explain complex information related to their dementia condition in an accessible and non-threatening way.	
Down's Syndrome Association	Short	8	3	In a recent trawl across the public health and third sectors, we failed to identify much in the way of accessible information about dementia for people with LD. We identified a particular gap in literature that could help to explain to someone with LD about a relative's dementia (if a parent was developing dementia, for example). We would like to see the commissioning of new materials to address this shortfall and would be pleased to be involved in this proves and share our experiences of working with adults with DS.	Thank you for your comment. The committee agreed there were gaps around information sources for many more unusual dementia presentations, including rarer dementia subtypes and people with comorbidities such as learning disabilities. They agreed it was important that accessible information is available that is tailored to an individual's particular circumstances, as mentioned in recommendation 1.1.4
Down's Syndrome Association	Short	8	12	We would draw attention to recently developed guidance from Public Health England on reasonable adjustments relating to dementia for people with LD. Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities. September 2013. Learning Disabilities Public Health Observatory. https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities	Thank you for your comment and for bringing this information to our notice.

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Down's Syndrome Association	Short	9	3	Advance Care Planning for adults with LD is an area which has been significantly overlooked. We would support a call for further research and development of protocols in this area and highlight the work undertaken by Dr Stuart Todd at The University of South Wales, UK.	Thank you for your comment. The committee agreed that for many areas throughout the guideline (including advance care planning) there was a lack of research with people with learning disabilities, and would welcome further research being conducted on these topics.
Down's Syndrome Association	Short	9	24	We would highlight that for people with DS there is a need to use adapted assessment tools to assess whether an individual is developing dementia (for example CAMDEX or DSQUID). Non LD accessible assessments will be of little use. We would also highlight the advantages of monitoring protocols that obtain baseline data relating to an individual's cognitive functioning (in order to quickly identify any decline). Some localities are establishing monitoring protocols for their population of adults with DS aged 30+ (e.g. Aneurin Bevan Health Board Learning Disability Directorate, Monmouthshire, UK) The signs of onset of dementia should be picked up through an Annual Healthcheck via the individual's GP, although we are aware that many people with a learning disability do not access this.	Thank you for your comment. The committee agreed it was important to appropriately tailor assessments, and the tools used, for people with learning disabilities. For this reason, the committee agreed it was appropriate to add a cross-reference to the NICE guideline on "mental health problems in people with learning disabilities", which includes specific recommendations on assessment tools to use in people with learning disabilities and suspected dementia.

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Down's Syndrome Association	Short	10	11	We would highlight the importance of suitably trained professionals carrying out a differential diagnosis when assessing someone with DS who maybe developing dementia, paying particular attention to associated health conditions such as thyroid disorder, visual and hearing impairments, which could mimic some symptoms of dementia.	Thank you for your comment. The committee agreed with this point, and made the following comments in their discussion of the diagnostic evidence in the full guideline: "The committee agreed that physicians should be aware of the additional challenges of diagnosing dementia in certain vulnerable groups, such as people with learning difficulties and Down's syndrome, and those people with language and sensory impairment, lower educational levels and a low standard of literacy. Whilst the evidence base did not allow them to make specific recommendations for how the diagnostic pathway should be different for these groups of individuals, they agreed that it was important that people from these more difficult to diagnose groups should be assessed by a clinician with specialist skills in those areas, who would be familiar with the difficulties and able to make appropriate adaptations to the process used."
Down's Syndrome Association	Short	10	20	Many within the dementia community object to be dementia being referred to as a *mental health condition*. Consideration should be given to the appropriateness of this term and it's continued use.	Thank you for your comment. The committee agreed with this point, and noted that at no point in the guideline dementia is referred to as a mental health condition. The only mention of this is in a cross-reference to the title of another piece of NICE guidance.
Down's Syndrome Association	Short	12	20	Although the most prevalent cause of dementia amongst people with DS is Alzheimer's disease, it should be noted that vascular dementia can also be present and that some individuals may experience the combined effect of both causes.	Thank you for your comment and for this information.

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Down's Syndrome Association	Short	13	13	We would stress the benefits of adults with DS who develop dementia remaining within the LD service provision, who should have expertise in meeting their specific needs (and will likely know the individual over a period of time). Dementia services are often not accessible to people with a LD and adults with LD who develop dementia are at risk of feeling excluded or experiencing barriers to accessing specialist dementia services, unless specific staff training and reasonable adjustments have been put in place.	Thank you for your comment. The committee agreed with this point, as given in the following point from their discussion of the evidence: "It was agreed that for the majority of people with learning disabilities who are subsequently diagnosed with dementia, their diagnosis and management of dementia would primarily sit within the learning disability pathway rather than the dementia one, and therefore recommendations on how those services should be organised fit better within a learning disabilities guideline."
Down's Syndrome Association	Short	13	22	We very much welcome better care coordination for those who need to access support around dementia. A keyworker approach would be helpful, however, this rarely happens in practice.	Thank you for your comment. The committee agreed this would represent a considerable change in practice in some areas, and hoped the guideline could act as a stimulus to promote these positive changes.
Down's Syndrome Association	Short	15	10	We recognise the benefits of therapies such as reminiscence, however we would highlight that, for adults with DS who develop dementia at a younger age, their reference points and life experiences might be very different from others who do not have a learning disability. This make accessing mainstream group activities more problematic and calls for a more tailored solution.	Thank you for your comment. The committee agreed with this point, and agreed it was appropriate to add people with learning disabilities as a specific group in the recommendation on groups to whom services should be made accessible.
Down's Syndrome Association	Short	16	3	Many pharmacological interventions for the treatment of Alzheimer's disease have a window of efficacy, meaning that early diagnosis is of	Thank you for your comment. The committee agreed with this point, and agreed it was appropriate to add people with

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				paramount importance. We again highlight that often adults with DS present late for diagnosis, as early signs of dementia are missed. We would also advocate for equality of access to appropriate drug treatments and that an individual's learning disability should be no barrier to these being prescribed.	learning disabilities as a specific group in the recommendation on groups to whom services should be made accessible.
Down's Syndrome Association	Short	20	24	The need to continue with a differential diagnosis approach to recognising changes in an individual's functioning continues beyond the point at which a diagnosis of dementia is made. Treatable conditions such as thyroid, visual and hearing impairments will still present and can be ameliorated with the correct interventions.	Thank you for your comment. The committee agreed with the point around the importance of appropriate management of comorbidities, and noted this was captured within the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Down's Syndrome Association	Short	22	1	We welcome approaches that promote personalised activities that suit an individual's needs. We would highlight that for this to take place, settings need to use regular staff who are appropriately trained and know the individual they are supporting.	Thank you for your comment and your support for this recommendation. The committee agreed with the importance of using regular staff, and that this would have advantages for the care and support provided in a range of situations.
Down's Syndrome Association	Short	22	13	We would add that people with DS are more likely to experience sleep apnoea and this should be taken into consideration when assessing needs. There is a 50-100% incidence of obstructive sleep apnoea in individuals with Down Syndrome, with almost 60% of children with	Thank you for your comment. The committee agreed that in the absence of any evidence on how sleep apnoea should be managed being identified, it was not possible to include recommendations on this topic in the guideline.

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				Down syndrome having abnormal sleep studies by age 3.5 – 4 years. The overall incidence of obstructive sleep apnoea increases as individuals grow older.	
Down's Syndrome Association	Short	22	17	We again highlight the need to be aware of diagnostic overshadowing – not assuming that changes in an individual are due to dementia, but also looking at other possible causes like thyroid and sensory impairments, which would have their own interventions.	Thank you for your comment. The committee agreed it was appropriate to add sensory impairment to the list of possible dementia mimics that should be investigated before a diagnosis is made.
Down's Syndrome Association	Short	24	2	We would question what joint work has been undertaken between Learning Disability Champions, appointed to coordinate better care of people with LD whilst in hospital. Our experience is that the understanding of the needs of people with LD in acute settings is variable and often lacking. Family carers often report that there is an expectation that they will remain with their relative for the entirety of the hospital stay as staff seem unable to communicate with of meet the basic care needs of some people with LD. This is an unreasonable expectation and demonstrates a lack of capacity (and thus a resource and training need) within some hospital settings.	Thank you for your comment. The committee noted these concerned, but agree that in the absence of any evidence being identified on this topic, it was not possible to make any recommendations about the organisation of hospital services for people with learning disabilities and dementia.

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Down's Syndrome Association	Short	25	1	We would be very supportive of strategies that help keep an individual at home, in familiar surroundings, as we know this does much to mitigate the effects of dementia. However, we would report that frequently individuals with LD and dementia do move, often to inappropriate nursing care provision due to lack of support provided to maintain them in their usual living situation. Often the funding of waking night staff in support staff is a stumbling block and the unwillingness of commissioners to provide funding for this means an individual is moved, purely on the basis of cost of a care package.	Thank you for your comment. The committee agreed that the were many advantages of people being kept in a familiar environment, and that it was appropriate for these advantages to be spelled out in the guideline, to hopefully motivate policies to be put in place to ensure this happens whenever possible.
Down's Syndrome Association	Short	25	15	We have recently identified a lack of accessible information explaining what dementia is to a person with LD who has a relative (often a parent) who is developing dementia. Often the person with LD is an informal carer for their loved one. We would like to see this commissioned.	Thank you for your comment. The committee agreed there were gaps around information sources for many more unusual dementia presentations, including rarer dementia subtypes and people with comorbidities such as learning disabilities. They agreed it was important that accessible information is available that is tailored to an individual's particular circumstances.
Down's Syndrome Association	Short	27	13	We would support the need to improve training for all relevant health and social care staff and would add to the list the need for condition specific training, targeted to learning disability social care staff, so that they have improved skills and knowledge to support an aging population of	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed

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				people with LD, who are increasingly likely to present as experiencing dementia.	it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
East of England Mental Health Clinical Network	Short	10	25	The use of scans / structural imaging is mentioned but should there not be more information and guidance provided to 'guide' the 'considerations' around deciding about a scan? There are numerous Scanning Guidance docs which go into considerable detail around this subject. Perhaps this doc should include some greater detail to reflect the 'complex' nature of deciding about when to scan and when not to scan?	Thank you for your comment. The committee agreed this recommendation could have been phrased more clearly, and has now been changed to "offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis. Be aware that structural imaging is not always needed, if dementia is well established and the subtype diagnosis is clear." This is more in line with the recommendation from the previous version of the guideline, which many stakeholders raised as being appropriate to retain.
East of England Mental Health Clinical Network	Short	13	13	Concern at the Guidance indicating that diagnoses of dementia have to be confirmed by a specialist memory assessment service. We are encouraging GPs to do more diagnosing, especially of people living in Care Homes, in order to make the diagnosis process simpler and where appropriate to avoid on ward referral to an MAS. Please clarify	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been

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					added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
East Sussex County Council	Short	General	General	**Unpaid care** This document starts by setting out the costs arising from dementia illnesses in 2013. Given the extent of the unpaid care contribution to supporting people with dementia, it is felt that the document as a whole needs to place a much greater emphasis on the role of unpaid carers in meeting the needs of people with dementia. This will be especially important as the number of people with dementia increases across the country and budgets for professional health and social care support come under increasing pressure.	Thank you for your comment. The committee noted that the guideline contained a specific section on the needs of unpaid carers, including recommendations for training and support interventions that should be rolled out to all carers of people living with dementia.
East Sussex County Council	Short	General	General	**Role of communities**	Thank you for your comment. The committee noted the current interest around dementia friendly communities, and

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				Greater management and support of people with dementia needs to be at a society level through dementia friendly communities that prevent, delay and manage the impact of dementia for as long as possible without the intervention of specialist health and social care services. This needs to be recognised in the guidance and would help provide balance to what currently reads as a medicalised approach to assessment, management and support for people with dementia and their carers.	other ways of modifying the environment to improve the experience of people living with dementia and their carers. However, they noted that in the absence of specific evidence of benefit from such approaches, it was not possible for them to make recommendations on this topic in the current iteration of the guideline.
East Sussex County Council	Short	General	General	**Partnership working** For achieving the benefits the recommendations are seeking, there also needs to be greater emphasis on very close working and communication between all agencies involved. The closer that services work together then the greater the opportunity for providing a coherent message to people with dementia and their carers and for achieving better outcomes. Integrated health and social care services can help here but can bring challenges associated with pooling budgets and maintaining a balance between medical and social models of intervention. Initiatives such as the Dementia	Thank you for your comment. The committee agreed that close integration between health and social care services was a key to delivering effective care. The committee noted that no evidence was identified that enabled recommendations to be made on specific interventions to achieve that integration, but this was an area where considerable innovation was currently going on at local levels, which would hopefully lead to more evidence in the future on how best this should be achieved.

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				Passport and Dementia Self-Assessment Framework can be useful tools for developing a joint assessment at the beginning of a person's dementia illness even if services are not formally integrated.	
East Sussex County Council	Short	4	16-17	This text needs to be stronger about involving people with dementia and their carers in decision making.	Thank you for your comment. The committee agreed the current wording, on "helping professionals to involve people living with dementia and their carers in decision-making" is an appropriate reflection of this particular aim of the guideline.
East Sussex County Council	Short	12	24	This recommendation would benefit from some clarity as to what constitutes case finding in this context.	Thank you for your comment. A definition of case finding has now been added to the guideline to provide this clarity.
East Sussex County Council	Short	13	23	We question whether it is feasible or desirable for every person with dementia to have a care co-ordinator from health or social care. If we are moving towards dementia friendly communities then the role of supporting people with dementia is in, and through, the community. Where a person's dementia has progressed to the point of needing active involvement of health and social care professionals then for a period of time professional care co-ordinators may be necessary but the aim should be to return the person to the care of the community wherever possible and not	Thank you for your comment. The committee agreed the evidence was clear that having a single named care coordinator was an effective intervention that improved the care and support for people living with dementia, and were therefore confident that it should be retained in the recommendations.

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				to have on-going secondary level professional support unless it is absolutely necessary.	
East Sussex County Council	Short	25	1	This section needs to include additional text explaining that people with dementia and their carers needs to be involved in the decision making process and the associated issues and risks explained at an early stage in their dementia illness. Feedback from practitioners is that families often view decisions of hospitals not to admit a patient with dementia being more about resource allocation for older people with dementia rather than risks of harm from admission. Addressing this issue early in a person's illness may help later when families believe a hospital admission is the best option. Further research may be beneficial to find out whether the perception that admission is being withheld due to resources and discriminatory views about the inpatient treatment of people with dementia are true. If hospitals changed the way they work for people with dementia then perhaps the risks of harm from a hospital admission for a person with dementia would be less. For example, in East Sussex we are beginning	Thank you for your comment. The committee agreed that it was important for people living with dementia and their carers to be informed and involved in decision-making throughout the life of a person living with dementia, and this was reflected in a number of recommendations through the guideline. The committee noted the suggestions for future research made, but agreed it was not as high a priority for research as those recommendations included in the guideline.

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				to look at a ward in a local general hospital where non-surgical patients with a dementia diagnosis will be cared for by a Multi-Disciplinary Team. Its objectives are better outcomes for patients and carers, reduced length of stay and better links to primary and community care on discharge associated with improved training around dementia care for the inpatient and community staff involved.	
East Sussex County Council	Full	38	13	This recommendation implies that carers would receive a separate assessment of their need for short breaks and other respite care. This would be considered as part of a formal carers assessment and may be explored as a way of meeting the carer's eligible support needs. There is no right to a separate assessment for this.	Thank you for your comment. The committee agreed this assessment should be carried out as part of a Carer's assessment. However, they noted that many carers were not aware this would form part of such an assessment, and therefore felt it appropriate to raise awareness of this within the recommendations.
East Sussex County Council	Full	38	27	This recommendation should include training in identifying depression in carers and signposting to support.	Thank you for your comment. The committee noted a number of suggestions from stakeholders about topics that could be included in training for carers, all of which the committee agreed were potentially relevant. However, they agreed that because of the potentially high cost of delivering training to all carers of people living with dementia, it was important to

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					restrict the recommendations to those areas where there was clear evidence of effectiveness and cost-effectiveness. On the specific issue raised, the committee noted that a research recommendation was made around interventions to reduce the risk of depression in carers of people living with dementia at high risk of developing it.
East Sussex County Council	Full	132	1	This section needs additional text to emphasise the need to proactively support people with dementia who do not have informal carers to ensure that information provided is understood, that they have support to consider Advance Care Planning and can make choices about their care and support.	Thank you for your comment. The committee agreed that no evidence was identified to enable a specific recommendation to be made in this area. However, they agreed this was covered by the more general recommendation that: "Service providers should design services to be accessible to as many people living with dementia as possible, including: • people who do not have a carer or whose carer cannot support them on their own."
Health Education England	Full	367	1-27	Health Education England (HEE) welcomes the opportunity to comment on the NICE Guidelines for Dementia. HEE notes the reference to the Dementia Core Skills Education and Training Framework within this guidance but would welcome a more explicit reference to the 3 levels/tiers of training that this encompasses particularly in section 16, ie the education and training recommendations section. Please see suggestion in red below- **16.1.6 Recommendations**	Thank you for your comment. The committee decided not to refer to the Dementia Core Skills Education and Training Framework document as part of the recommendations themselves, as these needed to be based on the evidence identified from the literature review. However, it was agreed to be appropriate to refer to this document within the list of relevant other guidance at the start of the document, alongside other Department of Health frameworks. The committee also noted the other suggestions for resources that could be referred to, but agreed it was important to keep this list focused on a small number of key references, as there

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				100. Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia. Dementia education and training should be aligned to the competencies set out in the Dementia Core Skills Education and Training Framework, ie all staff should receive dementia awareness training at tier 1, those working regularly with people living with dementia should undertake training at tier 2 and those in clinical expert or leadership roles should undertake training at tier 3. The subject areas of the Dementia Core Skills Education and Training Framework cover the following:- ~~☐ understanding the signs and symptoms of dementia~~ ~~☐ understanding the person as an individual, and their life story~~ ~~☐ respecting the person's individual identity, sexuality and culture~~ ~~☐ understanding the needs of the person and their family members or carers~~ ~~☐ the principles of the Mental Capacity Act.~~	were a large number of other sources that could possibly be referred to, with no obvious criteria as to which are the most important or relevant.

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				• Dementia awareness • Dementia identification, assessment and diagnosis • Dementia risk reduction and prevention • Person-centred dementia care • Communication, interaction and behaviour in dementia care • Health and well-being in dementia care • Pharmacological interventions in dementia care • Living well with dementia and promoting independence • Families and carers as partners in dementia care • Equality diversity and inclusion in dementia care • Law, ethics and safeguarding in dementia care • End of life dementia care • Research and evidence based practice in dementia care • Leadership in transforming dementia care **101. Care providers should provide additional face-to-face training and mentoring to staff who**	

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				deliver care and support to people living with dementia. This should include: understanding the organisation's model of dementia care and how it provides care how to monitor and respond to the lived experience of people living with dementia initial training on understanding, reacting to and helping people living with dementia who experience agitation, aggression, pain, or other behaviours indicating distress follow-up sessions where staff can receive additional feedback and discuss particular situations advice on interventions that reduce the need for antipsychotics and allow doses to be safely reduced promoting freedom of movement and minimising the use of restraint if relevant to staff, the specific needs of younger people living with dementia and people who are working or looking for work.	

Dementia: assessment, management and support for people living with dementia and their carers

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				HEE suggests that reference to the HEE Person-Centred Approaches Core Skills Education and Training Framework may also be a useful reference point. Person-centred approaches is a core skills education and training framework that articulates what it means to be person-centred and how to develop and support the workforce to provide care in this way. Developed in partnership with Skills for Health and Skills for Care, the Framework aims to distil best practice and to set out core, transferable behaviours, knowledge and skills. It is applicable across services and sectors (e.g. health, social care, local authorities and housing) and across different types of organisations (e.g. public, private and not for profit). HEE also suggests that it might be helpful if reference is made to the emerging findings of the 'What Works' Longitudinal Research Study into Dementia Education and Training led by Leeds Beckett University. This research sets out the hallmarks of effective dementia education training. The Dementia Training Design and Delivery Audit Tool (DeTDAT) and accompanying manual has been commissioned by HEE, and can	

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				be used by care and training providers, commissioners and others involved in training design, delivery or purchasing to assess how well a training package meets good practice criteria identified in the What Works study. The research findings and the tool can be found here:- http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/	
Innovations in Dementia	Short	General	General	Q1. There is no doubt that the draft advice offers excellent guidance on **clinical** care. The detail in the coverage particularly around the diagnostic process; delirium and dementia; modifying risk factors for the progression of dementia; pharmacological interventions; and medicines that may impair cognition is to be commended. It leaves clear step by step processes for medical practitioners.	Thank you for your comment and your support for these recommendations.
Innovations in Dementia	Short	General	General	We find that the detailed guidance on **clinical** excellence contrasts starkly with the coverage around care excellence, where there is much less	Thank you for your comment. The committee noted they had made recommendations in all areas where robust evidence of benefits was identified, and noted this included several areas,

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				certainty in the guidance offered. Regarding content, we also note that there is much less detail in the areas of support in and around the time of diagnosis; on emphasising the rights of people living with dementia beyond mental capacity legislation; on seeing dementia as a disability; and on addressing both sides of the caregiving relationship.	such as staff training and care coordination, that came firmly under the heading of care excellence rather than clinical excellence.
Innovations in Dementia	Short	General	General	We are concerned that by an almost exclusive focus upon the 'lots of research' (to quote the Easy Read version) it looked at, over any consultation with people with dementia, their families and care partners and other frontline staff; and that the vague nature of the guidance around care (particularly psychosocial interventions) results from this.	Thank you for your comment. This guideline was developed using NICE's standard methodology for producing guidelines, including a systematic review of the available literature, recommendations being drafted by a multidisciplinary committee of practitioners, people living with dementia and carers, and consultations on both the scope of the guideline and the recommendations produced.
Innovations in Dementia	Short	General	General	Despite the declared aim in the easy read document, '**NICE is writing advice to make sure people with dementia get the right care',** we fear that, without a more equal focus on all three	Thank you for your comment. In common with all NICE guidance, this guideline was produced by a group of people

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				corners of the 'triad' of Person, Staff and Care Partner, this guidance may only serve to perpetuate the 'doing to' approach that has characterised dementia care for so long.	including health and social care professionals, people living with dementia and carers of people living with dementia. The guideline also contains specific sections on support for staff (section 1.1.13), support for carers (section 1.11) and support for people living with dementia (the majority of the rest of the guideline).
Innovations in Dementia	Short	General	General	Q.3 In the light of point 6, there is a growing evidence base of the voice of people living with dementia through the following resources we wish be recommended: • The Dementia Engagement and Empowerment Project (DEEP), the growing UK Network of Dementia Voices (http://dementiavoices.org.uk/), currently made of over 90 predominantly activist peer advocacy groups; • the 'Dementia Diaries' programme (https://dementiadiaries.org/); • and the expanding resource of personal blogs, social media posts, memoirs and books by people living with dementia.	Thank you for your comment. The committee noted the value of these and other programmes to increase the involvement of people living with dementia in decision making. However, in the absence of evidence meeting the inclusion criteria for the guideline, the committee agreed it was not possible to make recommendations on these topics.

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Innovations in Dementia	Short	1	7	Here the text states that the guidance is for professionals, commissioners and people living with dementia and carers. However, the aims above it are stated as making recommendations on staff training and on helping carers. We are concerned that an important corner of the triad of Person, Staff and Family is being neglected. For significant change and impact for people living with dementia, we would expect it also to cover listening to the voice and capturing the experience of people living with dementia and the promotion of self-care and rights of people living with dementia, for example.	Thank you for your comment. In common with all NICE guidance, this guideline was produced by a group of people including health and social care professionals, people living with dementia and carers of people living with dementia. The guideline also contains specific sections on support for staff (section 1.1.13), support for carers (section 1.11) and support for people living with dementia (the majority of the rest of the guideline).
Innovations in Dementia	Short	3	27	The list of complexities and challenges in this field do not include - listening, capturing and responding to the experience, opinions and rights of people living with dementia. This significant challenge needs to be recognized and addressed	Thank you for your comment. This is not meant to be an exhaustive list of all the possible challenges, but merely some illustrative examples.

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Innovations in Dementia	Short	5	24	Q3. This refers to the PM's Challenge that seeks to ensure every person diagnosed with dementia receives 'meaningful' care. However, there is little in the guidance that helps define or identify 'meaningful' care. Again the inclusion of guidance around rights and the specifics of gauging opinions, feelings and experiences of people living with dementia are essential. http://dementiavoices.org.uk/	Thank you for your comment. The committee agreed the recommendations included in the guideline were as comprehensive as was possible given the evidence available.
Innovations in Dementia	Short	6	23	This refers to the centrality of relationships to the wellbeing of the person with dementia, yet this is not reflected in any specific recommendations in the guidance and we are concerned about the limited impact of this statement. Q3. Innovations in Dementia CIC has developed 'Getting Along', a relationship-centred programme with the specific aims of supporting care partners to adjust to the inevitable change in relationship dynamic brought about by the presence of a dementia. There is growing	Thank you for your comment. The committee noted the importance of this issue, but agreed that in the absence of any evidence meeting the criteria for inclusion in the guideline, it was not possible for them to make recommendations on this topic.

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				evidence of its benefit that merits a recommendation for further roll-out and evaluation. https://www.youtube.com/watch?time_continue=130&v=gEe9NbCq2Pg	
Innovations in Dementia	Short	7	5	Q1 We recognize and welcome the acknowledgement of the need for 'Involving people living with dementia in decisions about their care'**.** Q3 We would however like to see recommendations as to how **specifically we can capture** opinions, feelings and experiences of individuals by, for example, following guidance written by and with people with dementia. Good examples are 'Tips for Consulting people living with dementia' and 'Collecting the views of people with dementia'; available at http://dementiavoices.org.uk/resources/deep-guides/	Thank you for your comment. The committee agreed it would have been helpful to be able to provide recommendations on how to capture the opinions and feelings of people living with dementia, but in the absence of evidence on particular tools or approaches to use, they did not feel able to make recommendations on this topic.

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Innovations in Dementia	Short	8	3	Here begins an overwhelming list of what could be offered 'at diagnosis'. We have learnt from people with dementia that the pace, presentation, timing and environment of information-giving are all vital. Too much information given at the same time in the wrong way by the wrong people may be unhelpful at best. Q3. An example of good practice in the delivery of this kind of information would be the offering of a Post diagnostic course, co-produced locally by people with dementia, with people with dementia as tutors on those courses. (A pilot programme of this will be underway in York April-May 2018)	Thank you for your comment. The committee agreed that it was important to offer additional opportunities for people to receive information, as people will often not be able to take everything in at the time of diagnosis, but agreed that in the absence of evidence it was not possible to specify how and when these should be done. They noted the guideline did also contain recommendations to "direct people and their family members or carers (as appropriate) to relevant services for information and support", and to ensure "they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service."
Innovations in Dementia	Short	8	3	Q1 The phrase 'at diagnosis' concerns us as we feel there is a missed opportunity here to include guidance DURING the diagnostic process. The detailed guidance around the clinical diagnostic process gives a clear indicator of the length of time involved. During this time there is no	Thank you for your comment. The committee agreed that in the absence of evidence it was not possible for them to make recommendations on support during the diagnostic process. However, they agreed that should of effective interventions become available either for this period, or the post-diagnostic support period you mention, then this should be included in future updates of the guideline.

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				acknowledgement of the continued unattended impact of the presence of an obvious cognitive impairment upon an individual and their whole network of relationships. Q3. We have frequently been told by people affected by dementia that the first approach to a GP followed a period of up to two years of concern, difficulties and antagonisms. We believe that psychosocial diagnostic involvement can begin long before the medical diagnostic process is complete and that this needs to be recommended. An example would be Innovations in Dementia's relationship-centred support programme 'Getting Along', with recommendations for further research into its efficacy at this crucial period in and around the time of diagnosis. https://www.youtube.com/watch?time_continue=130&v=gEe9NbCq2Pg	
Innovations in Dementia	Short	8	5	This refers to providing information on the type and progression of dementia. It is of vital importance that the unpredictable nature of progression is taken into account, especially in those causes of dementia whose progression is	Thank you for your comment. The committee agreed with this point, and the wording of this recommendation has been changed to "what their dementia subtype is and the changes they might expect as the condition progresses."

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				often stepped, as is the case with vascular dementia**.**	
Innovations in Dementia	Short	8	5	Q1. For a greater impact, it is also important to recognise that cognitive decline is not necessarily equated with decline of quality of life. Kate Swaffer has spoken eloquently about 'prescribed disengagement', whereby she was told at diagnosis effectively to go home and get her affairs in order. (Kateswaffer.com) Her experience is not an isolated case, and we have heard over the years from many, many people with dementia who formed the impression at the point of diagnosis that their 'life was over'. Q3. Some have indeed discovered that their lives are better than they were previously! The resources here are growing resources of evidence of the experience of people living with dementia (http://dementiavoices.org.uk/ and https://dementiadiaries.org/)	Thank you for your comment. The committee agreed there was not a linear relationship between cognition and quality of life, and throughout the guideline evidence was looked for on changes in quality of life directly, independently of the way interventions may affect cognition.
Innovations in Dementia	Short	8	12	Q1 We are encouraged by the referral to the Equality Act. However, duties under the Equality	Thank you for your comment. The committee agreed there was a wider range of issues relevant to people living with dementia

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				Act – and the requirements of the UNCRPD (United Nations Commission on the Rights of People with a Disability) - go way beyond reasonable adjustments at work, but also cover rights to equality and non-discrimination, access to information, transport, leisure and community activities, rights to live independently, rights to personal mobility, respect for home and the family, rights to an adequate standard of living and social protection, and rights to habilitation and rehabilitation. Q3 These rights have been explained in the co-produced report by the Dementia Policy Think Tank, which was submitted to the United Nations Committee in August 2017 in Geneva. (http://dementiavoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717_1.pdf) We recommend that people affected by dementia are also pointed to the only booklet on rights specifically written by and for them: "Our	from the Equality Act, and therefore agreed it was appropriate to include the Equality Act in the list of relevant legislation at the start of the guideline.

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				Dementia, Our Rights" (http://dementiavoices.org.uk/deep-groups-news/our-dementia-our-rights/)	
Innovations in Dementia	Short	13	27	This refers to initial assessments being carried out by named 'care coordinators' face to face 'if possible'. We find the vague nature of this approach quite puzzling, considering the rigour of other parts of the guidance. Q3 As we have already mentioned above, we feel the recommendation for initial assessments by named care coordinators should come much earlier - during the diagnostic process for an obvious cognitive impairment - thus allowing the build-up of trusting relationships. This could well be over two years too late, thus nullifying the potential impact of a named care coordinator	Thank you for your comment. The committee noted that there were situations where it may not be possible or practical to conduct this initial assessment face to face, and therefore it was important to include this caveat in the recommendation. A reference to the section on care coordination has now been added to the section on directing people to appropriate services after diagnosis.
Innovations in Dementia	Short	13	27	We are very concerned and are baffled by the idea that any assessment NOT be carried out face to face. What sort of person-centred assessment could be carried out without face to face	Thank you for your comment. The committee noted that in some areas, for people with mild dementia, an initial assessment was carried out by telephone, with face to face assessments only used if needed. Whilst the committee were keen to promote face to face assessment as much as possible, they agreed there was not sufficient evidence for them to be able to mandate this in all cases.

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				meetings; without truly including the person with dementia?	
Innovations in Dementia	Short	14	6	We repeat the comments in response 17 as with regard to a broader sharing and understanding of the rights of people affected by dementia.	Thank you for your comment. The committee agreed there was a wider range of issues relevant to people living with dementia from the Equality Act, and therefore agreed it was appropriate to include the Equality Act in the list of relevant legislation at the start of the guideline.
Innovations in Dementia	Short	14	25	This calls for services to be accessible to as many people with dementia as possible. Although we welcome the reminder to think about people living on their own, people in rural areas and younger people of working age, there are no guidelines as to what **specifically** could be offered or considered for those groups. Q3. **Page 14 line 25:** This calls for services to be accessible to as many people with dementia as possible. Although there is a reminder to think about people living on their own, people in rural areas and younger people of working age, there are no guidelines as to what specifically could be offered or considered for those groups. Most people with dementia find signage, published	Thank you for your comment. The committee noted and agreed these were real concerns, but agreed that in the absence of any evidence they were not able to make recommendation on how best service should be tailored to be most accessible to these groups.

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				materials, design, way finding, health, and social welfare benefit systems complex, confusing and inaccessible. We would suggest a recommendation to offer the use of resources such as the audits for inside and outside public spaces recently developed in a collaboration between groups from the UK network of Dementia voices (DEEP) and Professor Mary Marshall (available at http://dementiavoices.org.uk/resources/). At a time when we are learning more and more about the benefits of co-production, recommendations for consultation with groups of people living with dementia are conspicuous by their absence.	
Innovations in Dementia	Short	15	5	The recommendations around interventions to promote cognition, independence and wellbeing are again quite vague, although we appreciate the quest for rigorous high quality evidence will limit any strong recommendations. We welcome then	Thank you for your comment and your support for the research recommendations made.

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				the research recommendation in the full guideline in this area.	
Innovations in Dementia	Short	20	19	Managing non-cognitive symptoms. We welcome the recognition of the primary importance of psycho-social and physical environmental factors in the behaviour of people with dementia, rather than an automatic assumption that such behaviour is a 'symptom' of dementia.	Thank you for your comment and your support for this recommendation.
Innovations in Dementia	Short	25	15	Q3. This highlights the detailed recommended content of a psychoeducational course for carers. We applaud the detail in this, but immediately note the absence of recommendations for equivalent courses for people with dementia themselves anywhere in the guidance. If it is because there is currently little evidence of the benefits of such interventions, we would welcome the recommendation for research into this	Thank you for your comment. You are correct that the lack of a recommendation is based on the lack of evidence for these interventions for people living with dementia, and noted the guideline did include a research recommendation on "the effectiveness and cost-effectiveness of self-management training for people living with dementia."

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Innovations in Dementia	Short	25	15	Q3. Traditionally services have focused on the unique set of difficulties of either the carer or the person with dementia in isolation of each other. The failure to recognise the interdependent nature of relationships can only hamper any self-management approaches that the full guidance refers to. Once again a key feature of the Innovations in Dementia 'Getting Along' programme is to work with care partners together and equip them to live well and better with the presence of dementia where they spend most of their time - which is NOT in dementia care services. This gap in addressing the interdependence of relationships has been very clearly identified in the recent work of Bielsten and Hellstrom (2017) whose review recommended that *"people with dementia should be included in the assessment of the relationship in order to gain an overall picture of relationship dynamics and to*	Thank you for your comment. The committee noted the points raised, and agreed they were relevant considerations in the design of interventions, which will hopefully be tested in future research. However, they agreed that for the current guidance, they could only make recommendations on interventions for which there was robust evidence of effectiveness and cost-effectiveness.

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				increase tailored support in couple-centred interventions" Bielsten, Therése & Hellström, Ingrid. (2017). A review of couple-centred interventions in dementia: Exploring the what and why - Part A. Dementia (London, England). 1471301217737652. 10.1177/1471301217737652. In Part B of the same article they highlight a *"negative approach of outcomes, lack of a genuine dyadic approach, lack of tailored support, neglect of interpersonal issues and the overlook of the views of people with dementia".*	
Innovations in Dementia	Short	25	19	Q3. This referral to 'how to understand and respond to changes in behaviour' reveals the need for an equivalent course for people with dementia to better understand and respond to the changes in behavior of carers. A more	Thank you for your comment. The committee agreed this was an interesting topic for future research, but that at present there was not sufficient evidence to be able to make recommendations.

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				detailed commentary on the rationale for a more balanced sharing of information can be found here: https://dementiafriendly.wordpress.com/2015/09/21/one-sided-or-lob-sided-dementia-care-is-still-way-off-balance/ As mentioned earlier, the York 'Minds and Voices' DEEP group has developed and is piloting such a course – with people with dementia as course designers and course tutors too.	
Innovations in Dementia	Full	General	General	We welcome the enormous amount of work that has gone into producing such a volume of information to present not only suggestions and recommendations for practice but also recommendations for future research.	Thank you for your comment and your support for the guideline
Innovations in Dementia	Full	General	General	Q3. To compensate for the difficulties in achieving a clearer focus on the vague are of 'care excellence, we recommend that a broader definition of evidence be adopted similar to that by The Wales School for Social Care Research (http://www.walessscr.org/en/index) which promotes the recognition and the exploration of diverse types of evidence (from people, research	Thank you for your comment. The evidence included in the guideline was of varying types, included quantitative, qualitative, grey literature and audit data.

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				policy and practice). Their work aims to support bridging the gap between academic research and care services to support the flow of knowledge from research into practice **and vice-versa.**	
Innovations in Dementia	Full	General	General	We feel that the relatively vague nature of recommendations around care excellence compared with detailed recommendations for clinicians - reveals a need for further research recommendations and also for more diverse methods of gathering evidence.	Thank you for your comment. The committee agreed with the need for more research to be conducted in the area of social care. The high quality research identified in areas such as social worker led case management and training of social care staff demonstrate that it is feasible for research to be conducted that leads to the ability to make strong recommendation on these topics. The committee would welcome more research in these and other areas of care, which could be made use of in future updates of this guideline, and have made a number of recommendations for future research on these topics.
Innovations in Dementia	Full	General	General	Despite consultation with 'some people with dementia', health and care professionals and family and informal carers, the content of the guidance seems to focus predominantly on only two corners of that triad.	Thank you for your comment. In common with all NICE guidance, this guideline was produced by a group of people including health and social care professionals, people living with dementia and carers of people living with dementia. The guideline also contains specific sections on support for staff (section 1.1.13), support for carers (section 1.11) and support for people living with dementia (the majority of the rest of the guideline).

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Innovations in Dementia	Full	General	General	We feel there has been a missed opportunity in limiting 'care' recommendations to the post diagnostic phase, when families may have been struggling for a couple of years without any support to live with the presence of a dementia in their midst.	Thank you for your comment. The scope of this guideline was only to make recommendations from the point where someone enters the dementia diagnostic pathway, and therefore it was not possible to make recommendations before this time.
Innovations in Dementia	Full	General	General	Below we list a summary of recommendations we recommend be included, either as guidelines for practice or as research suggestions: • Research on a relationship-centred approach in and around the time of diagnosis - with a particular focus on the 'Getting Along' programme that is designed specifically for delivery during this period. https://www.youtube.com/watch?time_continue=130&v=gEe9NbCq2Pg • A more explicit recommendation for research on - or sharing of evidence into - the benefits of peer-led groups, such as those that form the growing DEEP network of dementia	Thank you for your comment. The committee agreed with the importance of a wide range of research in dementia, and added an additional recommendation in the final version of the guideline to tell people living with dementia about research studies they could participate in. The committee noted that it was only possible for them to make research recommendations in areas where evidence had been looked for as part of developing the guideline, and therefore decided not to considerably expand their list of research recommendations from the consultation version of the guideline.

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				voices. http://dementiavoices.org.uk/ https://dementiadiaries.org/ • Adoption of a broader definition of evidence, which promotes the recognition and the exploration of diverse types of evidence (from people, research policy and practice). Following a similar approach to that adopted that by The Wales School for Social Care Research (http://www.walessscr.org/en/index) which promotes the recognition and the exploration of diverse types of evidence from people, research policy and practice. • An equity of consultation with people living with dementia as well as with carers and professionals, making use of established guidelines around consultation. http://dementiavoices.org.uk/resources/deep-guides/ • Timely and appropriate post diagnostic information and learning for people with	

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				dementia such as that currently being piloted by York Minds and Voices DEEP group. • Investigation of the benefits of pre- and peri-diagnostic involvement. • A greater focus on the awareness and understanding of rights of people with dementia beyond specific legislation such as the Mental Capacity Act, but an understanding much more broadly grounded in the United Nations Convention on the Rights of Persons with Disabilities, to which the UK is of course a signatory.	
Innovations in Dementia	Full	11	20	Q1We note, and are pleased from reading both the short and full draft guidance, that it is intended to be a 'living' document, able to respond to the creation of new evidence-based practices and resources. As this draft has been produced at a time of great change, particularly in terms of the growth of the voice of people living dementia and recognition of	Thank you for your comments. The individual suggestions you make around tools and resources have been responded to where they appear.

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				the rights of people with dementia, we are concerned that the NICE guidance not remain 'behind the curve. Thus we have mentioned resources, checklists, guides, and courses, all co-produced with and alongside people living with dementia as worthy of further research or as recommended practice resources. We would like greater emphasis on this being a 'living' document. This will ensure the guidance is not seen as something set in stone, which might not only perpetuate the 'doing to' approach but also stifle innovation.	
Innovations in Dementia	full	154	6	We are concerned at the inclusion of a recommendation that initial assessments may be carried out face to face ***'if possible'.*** We fail to see how such an approach can in any way be person-centred.	Thank you for your comment. The committee noted that in some areas, for people with mild dementia, an initial assessment was carried out by telephone, with face to face assessments only used if needed. Whilst the committee were keen to promote face to face assessment as much as possible, they agreed there was not sufficient evidence for them to be able to mandate this in all cases.

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Innovations in Dementia	Full	265		Q3. We noted that no recommendations could be made around non-pharmacological interventions due to the lack of robust evidence. We were struck by mention of a particular variable being the fact that some people may have received some beneficial support pre-diagnosis. This would skew attempts to evaluate some post diagnostic support. Our view is that the efficacy of support much earlier (as we have mentioned already in this response) is surely an area for further recommended research. We would therefore like to see a recommendation for research in this area of the efficacy of pre and peri-diagnostic support.	Thank you for your comment. The committee discussed this issue and agreed about the complexity of the interactions between pre and post-diagnostic support. The committee ultimately decided against recommending further research in this area at this time, as they agreed there were not yet clear hypotheses that could be tested, and trials undertaken without such ran the risk of replicating the findings of the post-diagnostic support trials, where very intensive interventions are found not to be better than moderately intensive ones, but the more fundamental questions about the important elements of support are not answered. However, they agreed this was an important question to revisit in the future, for the purposes both of making recommendations and research recommendations.
Innovations in Dementia	Full	301	8	Q3. We welcome the specific calls for research into unstructured group activities and into the effectiveness of self-management training. The Innovations in Dementia Getting Along programme is specifically aimed at equipping couples to live well and better with the presence of dementia and for couples to come up with their own strategies to use ahere they spend most of their time together - NOT in dementia	Thank you for your comment and your support for this recommendation.

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				care services. https://www.youtube.com/watch?time_continue=130&v=gEe9NbCq2Pg	
Institute of Mental Health, University of Nottingham	summary	15	9-11	*1.4.2 Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them.* 'Consider' There is robust evidence from systematic reviews and trials for the benefits of Cognitive Stimulation Therapy for dementia. It has been recommended in the NICE guidance in 2006, also by Alzheimers Disease International in their World Alzheimers Report 2011 'The strongest evidence by far for efficacy relates to interventions applying principles of cognitive stimulation'. For group CST (eg Spector et al 2003, Knapp et al 2006) there are clear benefits to cognition, quality of life and it is cost effective. *'including elements of cognitive stimulation and reminiscence'* This wording here wrongly seeks to bundle up group CST and reminiscence as if they were much	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				the same thing when in fact they have different psychological mechanisms of action, different key principles, different formats (CST without family carers; and reminiscence often including family carers), different durations and very different evidence in terms of outcomes from trials, different systematic reviews (Cochrane - Cognitive Stimulation 2012, Reminiscence 2018), and economic results. I am concerned that this approach suggesting two different interventions be combined in 'elements' trivialises over 20 years of painstaking high quality research and in doing so will expose NICE to potential reputational damage. NICE would not for example apply the same approach to antidepressants or antidementia drugs and there are no reasons why psychological interventions should be devalued in this way especially with all the evidence available. Furthermore in the full guidance CST and reminiscence are described separately highlighting the inconsistency and artificiality in combining them in the recommendations. Brief group CST for dementia has been highlighted as one of the top 100 impact case study successes of the first 10 years of the impact	

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				NIHR in their report conducted by the RAND Corporation (2016 p57). CST is also now used in over 26 countries although a number of the trials are omitted from the NICE evidence. CST is endorsed by the UK Memory Services National Accreditation Programme which includes over 100 memory services. Due to the strength of the specific evidence for group CST MSNAP requires all memory services to provide it, providing benefits to people with dementia all over the country. I would advise that the 2006 NICE guidance is followed *"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia"*.	

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Institute of Mental Health, University of Nottingham	short	6	general	There needs to be a recognition that person-centred care may not be the only viable model of dementia care and that this is likely to be context specific. As such, other models of care, such as those derived from Occupational Therapy, may be of more relevance in a setting. Residential homes may find it difficult to deliver person-centred care and the model might not always be the ideal fit for this context.	Thank you for your comment. The committee agreed that other models of care may be appropriate in specific circumstances, but agreed it was appropriate that person-centred care be given prominence within the guideline.
Institute of Mental Health, University of Nottingham	short	7	1.1	To review on a regular basis, especially following transitions in care or a change in progression of dementia	Thank you for your comment. The committee agreed it was important to encourage people living with dementia to give their views and opinions at all stages of care and support, as is given in the first recommendation in the guideline.
Institute of Mental Health, University of Nottingham	short	26	1.11.2	Available regardless of a clinical diagnosis of dementia. This acknowledges that there are many reasons why a formal diagnosis of dementia may be unachievable	Thank you for your comment. The committee discussed this suggestion, and noted that the decision as to the type of support a carer required should be based on their own circumstances and needs, and those of the person they are caring for. They agreed this principle is already enshrined within the Care Act.
Institute of Mental Health, University of Nottingham	short	26	1.11.3	It cannot be assumed that group are universally supportive; they have to be managed by trained/experienced facilitators who can deal with dominant voices.	Thank you for your comment. The committee agreed the evidence available, from both subgroup analyses of the RCT data and the meta-regression model, showed that on average,

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					group sessions were more effective than individual, telephone or online sessions. However, the committee also agreed both that the group sessions would need to be well run/moderated, and that this format would not be the most suitable for all individuals, due to differences in their circumstances and preferences. They therefore agreed it was appropriate for the recommendation for group sessions to be kept at the weaker "be aware" level, and that the guideline should also recommend support for carers is "provided in a format suitable for them (for example individual or group sessions, or online training and support)", to ensure this is not taken as a blanket statement that group sessions are the most appropriate format for all carers.
Institute of Mental Health, University of Nottingham	short	27	1.13	All programmes of training, regardless of level and context, need to include compulsory dementia training. Professional qualification courses at degree and post graduate levels provided by universities need to include a mandatory minimum level of dementia training to include communication skills. Carers in the private and statutory sector also need to have mandatory training, which is monitored as part of the CQC inspections to ensure all staff are adequately trained within the probationary period of employment.	Thank you for your comment. The committee agreed that high quality training was a key issue in ensuring effective dementia care, but noted that the specific issues raised are outside of the remit of NICE guidance.

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Institute of Mental Health, University of Nottingham	Full	273-274	10-29	The NICE guidance has chosen to omit the definitive health economic paper by Knapp et al (2006) showing that group CST was cost effective for cognition and quality of life. Instead only the paper by D'Amico on long term CST is reported. This approach gives an incomplete picture of the evidence and is therefore misleading.	Thank you for your comment. The effectiveness measures used in cost-effectiveness portion of Knapp (2006) were the QoL-AD and MMSE, and therefore were not consistent with the NICE reference case, which uses QALYs. As a result, it is inaccurate to state that this analysis showed that CST is cost effective, as no threshold value has been established for these instruments against which gains could be assessed. The effectiveness evidence underpinning the Knapp (2006) paper was based on Spector (2003), and was included in our quantitative synthesis of parameters for the model.
Institute of Mental Health, University of Nottingham	Full	296		*The committee agreed it ……..it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity.* See point 1 above. This approach trivialises the evidence and generally undermines the psychological therapies for mental health problems including dementia. The committee seems to believe that any activity groups for people with dementia will offer worthwhile cognitive, quality of life and economic benefits which is not at all in line with the evidence. In the Cochrane review several trials compare Cognitive Stimulation with an active, social control group, and the findings were consistently in favour of	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				structured group Cognitive Stimulation over a social control (Woods et al, 2012) and suggest that the effects of social groups were neutral. The major study on family carer delivered CST has been ignored (iCST) (Orrell et al., 2017) Orrell, Martin, Lauren Yates, Phuong Leung, Sujin Kang, Zoe Hoare, Chris Whitaker, Alistair Burns et al. "The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial." PLoS medicine 14, no. 3 (2017): e1002269. *They also noted that in practice the two interventions were not mutually exclusive, with cognitive stimulation therapy often including elements of reminiscence and vice versa.* There are aspects of reminiscence which can be used in CST but they key distinction is that CST is connecting the past with the present. The committee might as well argue that counselling is a key part of many psychological approaches so they are basically the same.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." The Orrell 2017 study cited has been included in the review, but is indexed under Orgeta 2015, which is the original HTA report published on the study. The committee noted the evidence was consistently stronger for group versus individual CST, and therefore agreed group CST should be the focus of the recommendation.

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Institute of Mental Health, University of Nottingham	Full	297		*Cognitive rehabilitation and occupational therapy* Again combining these approaches in the recommendations is misleading and does not do justice to either especially since OT has a wide range of approaches. These approaches should all be separated in the recommendations	Thank you for your comment. The committee agreed it was not appropriate to suggest these interventions are interchangeable, and to clarify this the recommendation has been reworded as "consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia."
Institute of Mental Health, University of Nottingham	Full	300	4-9	*75. Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them.* *76. Consider providing a needs-based reablement programme (including elements of cognitive rehabilitation and/or occupational therapy) to people living with mild to moderate dementia who are not already accessing them.* Again combining these approaches in the recommendations is misleading and does not do justice any of them and all these approaches should all be separated with specific recommendations for each.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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					recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." The committee also agreed it was not appropriate to suggest cognitive rehabilitation and occupational therapy are interchangeable, and to clarify this the recommendation has been reworded as "consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia."
Institute of Mental Health, University of Nottingham	Full	301	9-12	*13.2.7 Research recommendations* *10. What is the effectiveness of unstructured community activities on wellbeing for people living with dementia?* There are numerous studies already. From the technology point of view how would unstructured interventions be defined and monitored, and would the control groups not be allowed to do activities. I think the further this recommendation was explored the more difficulties would be revealed with a failure to develop a robust design.	Thank you for your comment. The committee noted the concern about the research recommendation on unstructured activities, but agreed this was still a promising area of research and one worth recommending. The committee agreed that if the currently ongoing studies on self-management training were to come back with results that were either clearly negative or clearly positive, this would potentially remove the need for future research to be conducted in this area.

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				11. What is the effectiveness and cost-effectiveness of self-management training for people living with dementia and their carers? This is an interesting question but there are a number of major studies taking place and it would be prudent to see the results of these before recommending more research.	
Institute of Mental Health, University of Nottingham	Full	369		The panel "noted that the review was not focused on identifying interventions that improve the experience of staff and, therefore, trials that only reported on outcomes for staff would not be relevant to include within the review." To limit the staff angle to focus on skills, education & training is missing an opportunity. Many other aspects of staff's experience impact on their engagement, job satisfaction, turnover, turnover intention, performance and their health and wellbeing, but also indirectly on the quality of care for patients/residents and their families - eg. the way the staff's work is designed, organised and managed (including the quality of senior and line management), the physical work environment, career opportunities, etc.	Thank you for your comment. The committee agreed these were all important issues, but in a guideline focused on improving the care and support for people living with dementia and their carers, it was important that interventions were judged based on the difference made to those groups. The committee noted that staff training was an area that was both highly important for outcomes, and one in which there was sufficient evidence to be able to make strong recommendations.

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Institute of Mental Health, University of Nottingham	Appendix L	10		*What is the effectiveness of unstructured community activities on wellbeing for people living with dementia? Similar effect sizes were found for a range of group, activity based interventions for people living with dementia. One possible interpretation is that the benefits of many of these interventions were driven less by the specific content of the interventions, and more by the benefits from support groups more generally.* See note 6 above. There is clear evidence unstructured 'social' groups are of no tangible benefit to outcomes although of course they should be designed to be popular and enjoyable. *If this is true, these groups could potentially be delivered more cheaply than structured interventions, therefore a larger number of people could have access to them.* This is highly speculative especially since the vast majority of the cost of running groups is staff time which would be needed for structured or unstructured approaches. It is frivolous wasting taxpayers' money on vague research ideas where there is already sufficient evidence of no benefit.	Thank you for your comment. Having reconsidered the evidence on cognitive situation therapy and reminiscence therapy, the committee agreed it was appropriate to remove the recommendation for structured group activities, and replace it with two separate recommendations focusing specifically on CST and reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia." "Consider group reminiscence therapy for people living with mild to moderate dementia." The committee remained of the opinion, however, that there was only very limited evidence on unstructured activities for people living with dementia, and therefore agreed to maintain the research recommendation for unstructured group activities.

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				I am concerned that this could look like part of a political agenda which would reduce access to effective psychological therapies in the NHS CST groups for example are not only clinically effective but also very cheap to run needing only one manual and some basic kit which can be used over and over again. This is why CST groups have been found to be useful in a range of low and middle income countries.	
Institute of Public Health, University of Cambridge	Full	General/ 111-120		We note delirium is considered and we are surprised that the 4AT has not been described. We note the full report for "***HTA 11/143/01 - The 4AT delirium assessment instrument: qualitative evaluation and diagnostic accuracy study"*** was submitted in December 2017 to the HTA. This has relevant information to the assessment of dementia and delirium and choice of .assessment tools.	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was

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					unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.
Institute of Public Health, University of Cambridge	Full	109	10-24	<u>Diagnosing Alzheimer's disease</u> We believe clinical guidelines have to reflect ambiguity about the knowledge base currently available. The recommendations incorporate suggestions which are not yet proven to be of value in the context of current diagnostic processes, particularly given the known complexity of dementia neuropathologically, and represent premature translation. If the evidence is not sufficiently robust there is a significant risk of unnecessarily subjecting people with dementia to tests which do not have evidenced diagnostic value. The introduction of invasive and expensive biomarkers should be limited to those situations in which it is likely to make a meaningful difference to patient care. Given the porosity of the boundary between dementia and MCI, there needs to be attention to the potential for "diagnostic creep".	Thank you for your comment. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."

Dementia: assessment, management and support for people living with dementia and their carers

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Institute of Public Health, University of Cambridge	Full	109	10-24	Diagnosis in specialist clinical services The literature suggests the research diagnostic criteria for Alzheimer's disease dementia, which incorporate biomarkers, have been put forward to be used in research and highly specialised clinical research settings (McKhann 2011) but as yet the clinical validation of AD biomarkers (clinical biomarker development for Alzheimer's disease pathology) does not meet the rigorous standards required for the translation from research to clinical settings (Frisoni 2017; Brayne 2014). For instance: • Procedures for performing the clinical assay for CSF biomarkers need to be optimised; the reproducibility of the assay within and between laboratory needs to be assessed; a standardised optimum protocol for handling of CSF samples needs to be developed and implemented; covariates (age, gender, education level, APOE genotype, etc.) associated with biomarker status or level in control subjects need to be assessed; thresholds for test positivity may need to be defined separately for target subpopulations (Mattson 2017; Frisoni 2017)	Thank you for your comment. Please find below a response for each of the papers you cited. Caroli (2012) was excluded because their target group were people who did not have suspected dementia at baseline or need a dementia subtype diagnosis. Frisoni (2013) was excluded because the study design did not meet the inclusion criteria for the review, as it was a case-control study. Brayne (2014) would have been excluded because this paper is not a research study but a comment. The following papers would have been excluded because these papers are not diagnostic accuracy studies: Frisoni (2017) Frisoni (2017) Garibotto (2017) Mattson (2017) McKhann (2011) Perani (2014)

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				• Procedures for acquiring FDG PET images have been standardised, but procedures for assessing typical AD pattern (temporoparietal and posteriocingulate metabolism) have not (Frisoni 2017a). Automated or semi-automated metrics can usefully complement traditional visual read (Perani 2014), but supporting evidence on its incremental added values is still preliminary (Caroli 2012; Frisoni 2013). There is insufficient evidence on the effect of covariates (Age, APOE genotype, disease duration) on hypometabolism (FDG PET) in patients with Alzheimer's disease pathology (Frisoni 2017; Garibotto 2017). Despite all these very obvious evidence gaps, ambiguity and uncertainty in the scientific evidence and without a consistent framework to assess clinical validity and utility of AD biomarkers, many memory clinics have incorporated them into routine clinical practice on the assumption they inform assessment and management of patients; therefore, their use has been heterogeneous and resulted in 'informative' values of biomarkers which certainly cannot be used with full reliability in clinical practice (Frisoni 2017). This creep of insufficiently validated	

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				measures into clinical practice is both expensive and also has ethical implications for those receiving the results References: • Caroli A, Prestia A, Chen K, Ayutyuanont N, Landau SM, Madison CM, et al. Summary metrics to assess Alzheimer's disease-related hypometabolic pattern with 18-F-FDG PET: head-to-head comparison. *J Nucl Med 2012;**53**:592-600* • Frisoni G, Bocchetta M, Chetelat G, Rabinovici G, de Leon M, Kaye J, et al. Imaging markers for Alzheimer's disease: which versus how. *Neurology 2013;**81**:487-500* • Brayne C. A population perspective on the IWG-2 research diagnostic criteria for Alzheimer's disease.*Lancet Neurol.* 2014 Jun;13(6):532-4. • Frisoni G, Boccardi M, Barkhof F, Blennow K, Cappa S, Chiotis K, Démonet JF, Garibotto V, Giannakopoulos P, Gietl A, Hansson O (2017) Strategic roadmap for an early diagnosis of Alzheimer's disease based on biomarkers. *Lancet Neurol* **16**, 661-676.	

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				• Frisoni G, Perani D, Bastianello S, Bernardi G, Porteri c, Boccardi M, et al. Biomarkers for the diagnosis of Alzheimer's disease in clinical practice: an Italian intersocietal map. *Neurobiology of Aging 2017a;**52**:119-131* • Garibotto V, Herholz K, Boccardi M, Picco A, Varrone A, Nordberg A, et al. Clinical validity of Brain fluorodeoxyglucose positron emission tomography as a biomarker for Alzheimer's disease in the context of a structured 5-phase development framework. *Neurobiology of Aging 2017;**52**:183-95* • Mattson N, Lonneborg A, Boccardi M, Blennow K, Hannson O, for the Geneva Task Force for the Roadmap of Alzheimer's biomarkers. *Neurobiology of Aging 2017;**52**:196-213* • McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Jr., Kawas CH *et al.* The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement* 2011;**7**:263-9.	

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				- Perani D, Della Rosa PA, Cerami C, Gallivanone F, Fallanca F, Vanoli F, et al. Validationj of an optimized SPM procedurevfor FDG-PET in dementia diagnosis in a clinical setting. *Neuroimage Clin 2014;**6**:445-54*	
Institute of Public Health, University of Cambridge	Full	109	10-24	Combined biomarkers in clinical settings The literature illustrates the findings achieved with a combination of amyloidosis biomarkers with neurodegeneration biomarkers are inconsistent and simply suggest that use of biomarkers ***might*** improve accuracy (Frisoni 2017). The committee indeed acknowledged inconsistency of the results of combined CSF p-tau 181, and total tau and amyloid beta between studies (Toledo 2012; Frisoni 2009 and Dumurgier 2015) due to the mean age of participants amongst studies. In addition, it is important to highlight other sources that may lead to inconsistent and/or conflicting biomarker results in diagnostic accuracy studies: i) study design; ii) sample procedure and sample size; iii) participant characteristics; iv) different settings across specialist dementia services; v) variability in selected thresholds for the test abnormality	Thank you for your comment. The committee agreed that there were still considerable uncertainties in the evidence base around biomarkers for the diagnosis of Alzheimer's disease, but agreed the current evidence was robust enough to justify a 'consider' recommendation, with a caveat about the reduced specificity as people get older. The committee agreed there would be value in future research to address issues around specific thresholds to use for both CSF testing and FDG-PET scans, but the fact that optimal values had not yet been determined did not make it inappropriate to use these tests in specialist settings. The committee noted that the recommendations for CSF examination and FDG-PET came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it

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				(positivity); vi) variability in immunoassays for CSF biomarkers used, etc. The Committee recommend that the use of biomarker in specialist clinical settings should be ***'considered'*** for diagnosis if Alzheimer's disease is suspected and uncertain, based on sensitivity, specificity, and positive and negative LRs; the biomarker evidence ranging from low to high quality. We would like to express our significant concerns regarding the accuracy and certainty in diagnosing Alzheimer's disease dementia by specialist clinicians in a clinical scenario above. • The cut off values for the abnormal ranges (test positivity) are not specified for immunoassays for CSF p-tau 181, and total tau and amyloid beta • The positivity threshold for each metrics (each readout procedures) for FDG PET are not specified We would argue that considering and using AD biomarkers without detailed clinical guidelines, based on high quality research evidence, their use	was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."

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				will continue to be heterogeneous and lead to inconsistent 'informative' values. We would suggest that there is compelling need for rigorous research to validate individual and combined biomarkers with longitudinal clinical outcomes in different types of settings in which dementia diagnoses are made in order to fully reflect the variety of populations (including different age groups). The same concerns as noted above are relevant here too. References: • Dumurgier J, Schraen S, Gabelle A, Vercruysse O, Bombois S, Laplanche J-L, Peoc'h K et 31 al. Cerebrospinal fluid amyloid-β 42/40 ratio in clinical setting of memory centers: a 32 multicentric study. Alzheimer's Research & Therapy 2015; 7:30-38. • Frisoni GB, Prestia A, Zanetti O, Galluzzi S, Romano M, Cotelli M, Gennarelli M, Binetti G, 43 Bocchio L, Paghera B, Amicucci G,Bonetti M,Benussi L, Ghidoni R, Geroldi C. Markers of 44 Alzheimer's disease in a population attending a memory clinic. Alzheimers Dement 2009; 5: 45 307- 317.	

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				- Frisoni G, Boccardi M, Barkhof F, Blennow K, Cappa S, Chiotis K, Démonet JF, Garibotto V, Giannakopoulos P, Gietl A, Hansson O (2017) Strategic roadmap for an early diagnosis of Alzheimer's disease based on biomarkers. *Lancet Neurol* **16**, 661-676. - Toledo JB, Brettschneider J, Grossmna M, Arnold SE et al. CSF bimarkers cutoffs: the 21 importance of coincident neuropthological diseases. Act Neuropathol 2012; 124: 23-35. - Noel-Storr AH, McCleery JM, Richard E, Ritchie CW, Flicker L, Cullum SJ, Davis D, Quinn TJ, Hyde C, Rutjes AW, Smailagic N, Marcus S, Black S, Blennow K, Brayne C, Fiorivanti M, Johnson JK, Köpke S, Schneider LS, Simmons A, Mattsson N, Zetterberg H, Bossuyt PM, Wilcock G, McShane R. Reporting standards for studies of diagnostic test accuracy in dementia: The STARDdem Initiative. Neurol. 2014 Jul 22;83(4):364-73.	
Institute of Public Health, University of Cambridge	Full	109	9	The term 'Alzheimer's disease' The literature suggests the term 'Alzheimer's disease' may describe different entities in biomarker studies. For instance, AD is described as: i) a clinical probabilistic diagnosis of AD	Thank you for your comment. The committee noted this concern, but agreed that the usage of the term Alzheimer's disease currently in the guideline is one that would be commonly understood be both health and social care staff, and therefore was the appropriate one to maintain. The committee

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				dementia coupled with AD related neuropathological diagnosis [Hyman 2012; Montine 2012] – the currently accepted "gold standard"; ii) a clinical probabilistic diagnosis of AD dementia coupled with biomarker evidence of ante-mortem changes in the brain and confirmed by AD related neuropathological diagnosis – Probable AD dementia with evidence of AD pathophysiological process [McKhann 2011]; iii) a neuropathological entity, independent of the degree of clinical disability [Blass 2002], etc. We would recommend that the term 'Alzheimer's disease' is changed to 'Alzheimer's disease dementia' or 'Dementia due to Alzheimer's disease pathology' although even for this the relationship of AD pathology and the expression of dementia changes across age groups (Savva 2009). References: • Savva, G.M., et al., *Age, neuropathology, and dementia.* N Engl J Med, 2009. **360**(22): p. 2302-9 • Hyman BT, Phelps CH, Beach TG, Bigio EH, Cairns NJ, Carrillo MC *et al.* National Institute	agreed that in the future in may be necessary to reconsider this terminology if the diagnostic pathway considerably changes.

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				on Aging-Alzheimer's Association guidelines for the neuropathologic assessment of Alzheimer's disease. *Alzheimers Dement* 2012;**8**:1-13. • Montine TJ, Phelps CH, Beach TG, Bigio EH, Cairns NJ, Dickson DW *et al.* National Institute on Aging-Alzheimer's Association guidelines for the neuropathologic assessment of Alzheimer's disease: a practical approach. *Acta Neuropathol* 2012;**123**:1-11. • McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Jr., Kawas CH *et al.* The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement* 2011;**7**:263-9. • Blass JP. Alzheimer's disease and Alzheimer's dementia: distinct but overlapping entities. *Neurobiol Aging* 2002;**23**:1077-84.	
Institute of Public Health, University of Cambridge	Full	170	8.1.5	We note with interest the views of the committee concerning the evidence base for hospital care. We would like to point out the following initiative in the field of acute hospital care in dementia- the	Thank you for your comment. The committee agreed that the types of interventions discussed in these studies would be of interest to the guideline, and that future updates of the guideline should consider the results of the PERFECT-ER study

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				key location of the development and evaluation is at www.perfected.ac.uk. This Peri-operative Enhanced Recovery hip FracturE Care of paTiEnts with Dementia is a National Institute for Health Research (NIHR) funded Applied Research Programme. This finished recruiting on the 1/2/18. We note the key Cochrane work has been referenced by the committee- (Smith et al 2015). We note that additional references may be of use and have not been mentioned: • Gill N, Hammond S, Cross J, Smith T, Lambert N, Fox C. Optimising care for patients with cognitive impairment and dementia following hip fracture Zeitschrift für Gerontologie und Geriatrie May 2017. 50 (2), 39-43 • Simon P. Hammond SP et al. PERFECTED enhanced recovery (PERFECT-ER) care versus standard acute care for patients admitted to acute settings with hip fracture identified as experiencing confusion: study protocol for a feasibility cluster randomized controlled trial *Trials* 2017 **18**:583 https://doi.org/10.1186/s13063-017-2303-y	when it is published, and any other studies addressing similar questions. NICE's surveillance team will be notified of this work for consideration during future surveillance of the guideline.

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Institute of Public Health, University of Cambridge	Full	252	6 - 22	We are concerned that key papers were not included in the systematic literature review and we note these papers have been considered in other guidelines: • Fox C, Livingston G, Maidment I, Coulton S, Smithard D, Boustani M, Katona C. 2011. The impact of anticholinergic burden in Alzheimer's dementia-The laser AD study. *Age and Aging* 40(6):730-5 ***This paper indicated that there was no impact in established dementia of taking anticholinergic medication on key outcomes.*** • C, Richardson, K Maidment I, Smithard D, Katona C, Boustani M, Savva G M, Coulton S, Matthews F E, l Brayne C on behalf of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). Anticholinergic Medication Use and Cognitive Impairment in the Older Population: The Medical Research Council Cognitive Function and Ageing Study. *J Am Geriatr Soc*. 2010 Aug;59(8):1477-83. ***This ground breaking highly cited analysis highlighted a dose response effect of anticholinergic medication on cognition and mortality.***	Thank you for your comment. Please find below a response for each of the papers you have cited. Fox (2011) was excluded because the paper reports on correlation between total number of drugs and anticholinergic load which is not the outcome for this review question. Smith (2018) was published after the cut-off date for evidence to include within the guideline. However, this reference has been passed to the NICE surveillance team for consideration in planning future updates of the guideline. Richardson (2010) was already included in Appendix N. Matthews (2010) would have been excluded because this paper is not related to any of the review questions for this update. Richardson (2016) and Grossi (2016) would have been excluded because conference abstracts were excluded as a source of evidence for this guideline.

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				• Matthews FE, Muniz-Terrera G, McKeith I, Brayne C, MRC CFAS. Who will be eligible? An investigation of the dementia population eligible for cholinesterase treatment following the change in NICE guidance. *Int J Ger Psych*. 2010 25:719-724. • Smith T, Cross J, Poland F, Clay F, Brookes A, Maidment I, Penhale B, Laidlaw K, Fox C. Systematic Review Investigating Multi-disciplinary Team Approaches to Screening and Early Diagnosis of Dementia in Primary Care - What are the Positive and Negative Effects and Who Should Deliver It? Curr Alzheimer Res. 2018;15(1):5-17. doi: 10.2174/1567205014666170908094931. In addition we believe the following key recent abstracts should be considered in the section on anticholinergic medication - we can provide copies if needed: • Richardson K, Fox C, Maidment I, Steel N, Loke Y, Arthur A, Grossi C, Bennett K, Myint P, Campbell N, Brayne C. Medications with Potent Anticholinergic Activity and Incident Dementia Diagnosis in the UK Older	

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				Population. Pharmacoepidemiology and Drug Safety 2016 Aug 1 (Vol. 25, pp. 361-361). • Grossi CM, Maidment I, Richardson K, Fox C, Brayne C, Matthews F, Robinson L, Savva GM. Increasing Prevalence Of Anticholinergic Medication Use Over 20 Years In The UK Older Population: Cognitive Function And Ageing Study I and II. Pharmacoepidemiology and Drug Safety 2016 Aug 1 (Vol. 25, pp. 360-361).	
Institute of Public Health, University of Cambridge	Appendix L	1	L.1	The same research question should be considered regarding other biomarkers that are recommended (as 'consider') for the diagnosis of Alzheimer's disease (if the diagnosis is uncertain and Alzheimer's disease is suspected), as following • CSF phosphorylated-tau • CSF total tau • CSF amyloid beta 1-42 • CSF amyloid beta 1-42/ CSF amyloid beta 1-40 ratio • FDG PET SPECT	Thank you for your comment. The committee noted that the level of evidence on amyloid PET imaging was lower than for the other tests you mention, and this was why the committee prioritised future research in this area. However, they agreed that studies which directly compared amyloid imaging to other imaging or biomarker tests would also be of value, and therefore agreed it was appropriate to extend this research recommendation to not just cover the diagnostic accuracy of amyloid imaging, but also the comparative accuracy to the other tests you cite. These changes have been made to the research recommendation in appendix L.
Janssen UK	Short	General	General	Janssen welcomes and thanks NICE for the opportunity to comment on the consultation for	Thank you for your comment and your support for the guideline.

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				the draft NICE Clinical Guideline (CG) 'Dementia: assessment, management and support for people living with dementia and their carers'. Overall Janssen is supportive of the new recommendations and the clinical guideline. Janssen particularly welcomes the new recommendations regarding the methods of diagnosing and assessing dementia and Alzheimer's disease. This supports the innovation in diagnostic methods and also helps to support future technologies which are currently being develop for the treatment of Alzheimer's disease, which rely on early and accurate diagnosis.	
Janssen UK	Short	General	General	Janssen fully supports the principle of patient education and patient empowerment. As the science is evolving to understand Alzheimer's disease very early in the disease process, there needs to be consideration on how to educate individuals regarding potential Alzheimer's disease risk status - family history, APOE4 status, comorbid risks, amyloid status, etc. When appropriately informed of potential risk factors, this could allow for proper planning for individuals and their families. Understanding the risk factors will also empower individuals to engage with a conversation with GPs regarding	Thank you for your comment and your support for these recommendations. The committee agreed that, if there are significant changes in the future around diagnosis or management of particular dementia subtypes, these would need to be reflected in the type and timing of information offered to people living with dementia and their carers.

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				Alzheimer's disease. As the therapies that are currently being developed are for the earliest stage of the disease, the patient/GP conversation will need to take place well before the current conversation regarding dementia.	
Janssen UK	Short	4	7	Janssen welcomes the recognition that new methods for diagnosing and assessing dementia have been developed. Both amyloid imaging techniques and cerebrospinal fluid examination represent reliable methods for diagnosing dementia and Alzheimer's disease. New developments in diagnosing Alzheimer's disease continue to be made, some of these maybe blood tests others could be sensitive digital cognitive tests. For example, researchers presenting findings at the Alzheimer's Association International Conference 2017 demonstrated that a blood test could indicate the presence of amyloid in the brain indicative of Alzheimer's pathology. These developments, along with ongoing innovations in clinical practice and technology, mean that the National Health Service must ensure that it takes opportunities to combine new methods for diagnosing and assessing dementia and Alzheimer's disease with	Thank you for your comment. The committee agrees with the importance of evaluating the accuracy and effectiveness of newer diagnostic tests, and notes that future updates of the guideline should take account of any new evidence published in these areas.

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				existing clinical practice to enhance the reliability of diagnostic criteria.	
Janssen UK	Short	7	14	Janssen supports providing people with dementia, their family members or carers (as appropriate) with oral and written information on topics such as their legal rights and responsibilities, their right to reasonable adjustments (in line with the Equality Act 2010) and how to access local support groups and advocacy services. However, we recommend that, at the point of diagnosis and during the course of the illness, people should be asked if they are interested in taking part in research and healthcare professionals should share information on research activities with people diagnosed with dementia, their family members and carers. We would also recommend that people at risk of developing dementia are asked if they are interested in taking part in research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
Janssen UK	Short	9	4	The recommendations regarding advance care planning for people living with dementia and people involved in their care is welcomed. These recommendations ensure that these people are offered an opportunity and chance to review and change any advance statements and decisions they have made regarding their care. Both the	Thank you for your comment and your support for these recommendations.

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				burden of the disease and impact on quality of life varies over the course of the disease. The opportunity to consider these changes in the disease and to match them to the evolving needs and preferences of people living with dementia is therefore welcomed.	
Janssen UK	Short	9	24	Janssen welcomes the recommendation to use a validated cognitive instrument when using cognitive testing. Janssen suggests that NICE should encourage wider use of cognitive screening instruments to enable diagnosis of earlier stages of disease, such as mild cognitive impairment (MCI). Wider use of instruments such as the Montreal Cognitive Assessment (McCA), the GP Cog and ongoing focus on improving accuracy of screening instruments, will improve the accuracy of diagnosis on early disease and the cost effectiveness of applying biomarker tests. In addition, new research diagnostic criteria, including the National Institute of Neurological Disorders and Stroke– Alzheimer's Disease and Related Disorders Association (NINCDS–ADRDA) criteria, the National Institute on Aging–Alzheimer's Association (NIA–AA) criteria, and the revised criteria of the International Working	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed. The committee noted that there was considerable ongoing work around updated diagnostic criteria for various dementia subtypes, and that it would be appropriate to consider those newer criteria in future updates of the guideline.

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				Group (IWG-2) offer the potential to combine cognitive assessment with biomarkers. These approaches have the advantage not only of introducing biomarkers but also provide criteria for the diagnosis of prodromal Alzheimer's disease on the basis of symptoms and biomarkers or even on the basis of biomarkers alone. While these tests are not yet used in clinical practice, Janssen supports efforts focused on developing new methods to diagnose dementia at an earlier stage of the disease. This is vital because future treatments are likely to deliver the greatest benefit to patients when initiated at the early stages of the disease and a diagnosis provides people with dementia with an opportunity to plan for their future care needs.	
Janssen UK	Short	11	15	Janssen notes and welcomes changes to the recommendations regarding the diagnosis of Alzheimer's and dementia in the new CG. Specifically, recommendation 1.2.12: If the diagnosis is uncertain and Alzheimer's disease is suspected, consider either: • examining cerebrospinal fluid for: ○ phosphorylated-tau 181 and	Thank you for your comment and your support for these recommendations. The committee fully agreed that all the information available on an individual should be considered when making a diagnosis, and that individual test results should never be considered in isolation.

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				- total tau and - either amyloid beta 1–42 or a ratio of amyloid beta 1–42 and amyloid beta 1–40 or - FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or perfusion SPECT (single-photon emission CT) if FDG-PET is unavailable. If a diagnosis cannot be made after one of these tests, consider using the other one.or FDG-PET, or perfusion SPECT if FDG-PET is unavailable as methods of diagnosing dementia. The inclusion of this recommendation in the CG is welcome, as it represents latest methods to diagnosis Alzheimer's disease and supports clinician and patient choice regarding the method of diagnosis. Further, Janssen also support the option to use either cerebrospinal fluid or FDG-PET, if a diagnosis cannot be made after one of these tests, and therefore allowing clinicians to consider using the other test to confirm diagnosis if necessary.	

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				In addition, Janssen suggest that these methods should be used in combination with cognitive assessment rather than solely on their own if the diagnosis of dementia is uncertain. We suggest that NICE updates the CG to reflect this and to ensure the appropriate diagnosis of Alzheimer's disease. The use of biomarkers obtained from cerebrospinal fluid or FDG-PET, alongside cognitive tests to support the diagnosis of dementia during the earlier stages of the disease will insure that future treatments in development are able to positively modify disease outcomes.	
Kent and Medway NHS Partnership Trust	short	general	general	Overall the guideline was very medical in its orientation with very little mention of the important and wide-ranging role that psychologists can play in the assessment, diagnosis, treatment and support for people with dementia and their families from pre-diagnosis to end of life	Thank you for your comment. The committee noted they were only able to make recommendations in areas where evidence was available, but agreed that psychologists could play an important role in implementing many of the recommendations included in the guideline.
Kent and Medway NHS Partnership Trust	short	6	8	It might be useful to include a reference to MSNAP standards here	Thank you for your comment. The committee agreed that there were many relevant documents that could be linked to, and it was not possible to include all of the links in this section.
Kent and Medway NHS Partnership Trust	short	10	5	Could also add 'do not assume dementia solely because a person scores below the suggested cut-off – consider several streams of information	Thank you for your comment. The committee agreed that this was a relevant point, but agreed the purpose of this section was to decide which individuals should be referred on for full

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				before coming to a diagnostic decision and consider whether the person may have performed poorly on testing due to other factors such as visual impairment, hearing impairment, anxiety, low mood, long standing learning disability etc.'	diagnostic assessment, and therefore the issue should not arise of people being inappropriately diagnosed solely on the basis of cognitive scores. They also noted the evidence showed these tests had, on average, lower sensitivity than specificity, and therefore at an individual level false negative results were more likely than false positive ones.
Kent and Medway NHS Partnership Trust	short	15	21-22	Not clear what the message is here – talking therapies could be useful in helping people to adjust to the diagnosis of dementia and to think about how to cope with the related changes they are experiencing	Thank you for your comment. The committee noted this recommendation is solely that interpersonal therapy not be offered to treat “the cognitive symptoms of Alzheimer’s disease.” If people living with dementia had another condition or problem for which interpersonal therapy were indicated, the committee agreed it would be correct to offer them to people living with dementia in the same way as those without.
Kent and Medway NHS Partnership Trust	short	20	19 onwards	Should also include recommendation to refer to a specialist team for the assessment and management of BPSD, including the use of formulation and the Newcastle Model	Thank you for your comment. This recommendation has been rewritten to make clear a structured assessment should be the first stage of the process, in order to: “• explore possible reasons for the person’s distress and • check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).” The committee agreed no evidence was identify to enable recommendations on who should conduct that assessment, and what specifically it should contain.
Kent and Medway NHS Partnership Trust	short	22	5	Ideally psychological interventions would be provided by psychology clinicians within specialist older people’s services, not in primary care	Thank you for your comment. The committee agreed that no evidence was identified that enabled them to recommend who these interventions should be delivered by, or in what setting.

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Kent and Medway NHS Partnership Trust	short	25	14 onwards	There should also be specific mention of Admiral Nursing service	Thank you for your comment. The committee agreed it was not appropriate to list all groups that could be involved in delivering services, but did agree that Admiral Nurses were one obvious group that could be involved in implementing a number of the recommendations included in the guideline.
Kent and Medway NHS Partnership Trust	short	27	28	The document generally needs more guidance re the specific needs of younger people with dementia and those of their carers – should be an additional section to address these	Thank you for your comment. The committee agreed at this time it was appropriate to include recommendations for younger people living with dementia as subsets within the broader recommendations, as the amount of evidence specifically on younger people living with dementia is still small. However, this is currently an area where a considerable amount of research is ongoing, and the committee hope it will be possible to make more specific recommendations on this in future updates of the guideline.
Kent and Medway NHS Partnership Trust	short	28	1	Should also include people with dementia in staff training, not just their carers	Thank you for your comment. The committee discussed this issue but agreed that, in the absence of any evidence, it was not possible to include this within the recommendations.
Kent and Medway NHS Partnership Trust	short	31	6 onwards	Some topics for research were not very clearly worded (e.g. high intensity case management) – no obvious references to research into psychology-specific topics such as neuropsychological assessment or talking therapy	Thank you for your comment. The committee noted that only their five highest priority research recommendations were included in the short guideline, and there are a considerable number of extra research recommendations in the full version of the guideline.
Leeds and York Partnership NHS Foundation Trust	Short	7	17	We are concerned that the statement "stage of their condition" is vague and subjective. Needs to be written using plain, clear language. Felt there	Thank you for your comment. The committee noted the concerns around the lack of specificity in the language "stage of their condition". However, they agreed that because of the considerable heterogeneity in individual people's trajectories,

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				may be a risk that assumptions may then be made about how information is shared.	it was not possible to be more specific than this in the recommendation.
Leeds and York Partnership NHS Foundation Trust	Short	8	4	This should read oral information then written information.	Thank you for your comment. The committee agreed the current wording was clear that both oral and written information should be provided at this time.
Leeds and York Partnership NHS Foundation Trust	Short	8	27	We are concerned that this may be challenging to implement due to the differing provider pathways.	Thank you for your comment. The committee noted this concern, but agreed this was important to minimise the chance of people being lost to the health and social care system at a time when they may need support.
Leeds and York Partnership NHS Foundation Trust	Short	9	11	May be challenging for these conversations to occur if training and support is not available.	Thank you for your comment. The committee agreed with this, and this formed part of the thinking behind the recommendation that "health and social care professionals advising people living with dementia (including those involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations."
Leeds and York Partnership NHS Foundation Trust	Short	9	14	May be challenging in practice if it is not made explicit whose role this would be	Thank you for your comment. The committee agreed that offering this opportunity would be the responsibility of whoever is running the care review.
Leeds and York Partnership NHS Foundation Trust	Short	9	26,27	May be challenging in practice if the assessor does not make it clear as to which cognitive test is used	Thank you for your comment. The committee agreed the evidence showed these tests were all approximately equally accurate, and therefore any of them would be appropriate to use in a primary care setting.
Leeds and York Partnership NHS Foundation Trust	Short	10	1,2,3,4	May be challenging in practice if the assessor is not clear as to which cognitive test is used	Thank you for your comment. The committee agreed the evidence showed these tests were all approximately equally accurate, and therefore any of them would be appropriate to use in a primary care setting.

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Leeds and York Partnership NHS Foundation Trust	Short	13	18	We are concerned that this recommendation is not making it clear as to who is responsible for 'monitoring'.	Thank you for your comment. The committee agreed they would have liked to be able to make more specific recommendations on how these service should be organised, but this was not possible based on the evidence available.
Leeds and York Partnership NHS Foundation Trust	Short	13	23	We are concerned that it has not been made clear as to who would be the single named health and social care professional – does this sit with the GP?	Thank you for your comment. The committee agreed that in the evidence base considered, a number of different roles were responsible for care coordination (social workers, nurses, occupational therapists), and it was not possible to make recommendations on which of these was the most appropriate.
Leeds and York Partnership NHS Foundation Trust	Short	14	15,16,17, 18,19,20, 21, 22,23,24	Overall, this section related to transferring information between services and care settings is challenging in itself. Would be useful to see the role of service user held information such as the 'All About Me" document.	Thank you for your comment. The committee agreed with was a challenging area, but that the current evidence base did not enable them to make more specific recommendations than those currently included in the guideline.
Leeds and York Partnership NHS Foundation Trust	Short	21	11	May be challenging to complete depending on where the person was (i.e. care home)	Thank you for your comment. The committee agreed that in review of the well-established and serious risks of antipsychotics in people living with dementia, frequent monitoring was essential to ensure use was for the shortest possible time.
Leeds and York Partnership NHS Foundation Trust	Short	22	19	We are concerned that this may be challenging to achieve – depending on pathways and resources	Thank you for your comment. The committee noted this concern but agreed that for interventions for comorbidities that have been shown to be effective and cost-effective for people without dementia, it would not be appropriate to deny

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					these interventions to people with dementia, unless there was specific evidence the interventions were less effective in this group.
Leeds and York Partnership NHS Foundation Trust	Short	22	25,26	May be useful to have a hyperlink for these pain assessment tools which are cited within the guidance when published. (*we appreciate this is available in the long form)	Thank you for your comment. The committee agreed there was no evidence to recommend a particular pain assessment tool over any other, and therefore this was not something that could be included in the recommendations.
Leeds and York Partnership NHS Foundation Trust	Short	23	1,2	May be useful to have a hyperlink for the structured observational tool within the guidance when published (*we appreciate this is available in the long form)	Thank you for your comment. The committee agreed there was not sufficient evidence to recommend a particular pain assessment tool over any other, and therefore this was not something that could be included in the recommendations.
Leeds and York Partnership NHS Foundation Trust	Short	23	18	We are concerned about the subjective language of 'advanced' dementia and why the multi-factorial risk assessment may not be suitable.	Thank you for your comment. The committee's rationale behind this recommendation is explained in the relevant section of the full guideline. Specifically: "The committee noted that there was a specific area where the evidence on falls management in people living with dementia did not align with that of people without dementia, which was the effectiveness of multi-factorial interventions. These interventions are recommended in the falls guideline (CG61) but the evidence presented did not show a significant effect in a population of people living with dementia. The committee noted that the population in this RCT contained a significant proportion of people identified as having severe dementia and this raised concerns that the interventions may be less effective in this group, and that this may be attributable to the intensity of the interventions and the large number of tests

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					involved, which may cause additional distress to someone living with dementia and in particular severe dementia. These negative factors would outweigh any benefits of the intervention. The committee discussed the evidence noting that it was strong enough to recommend that such interventions should not be used in people with severe dementia without consideration, on a case-by-case basis, to ensure that the benefits of the intervention were expected to be greater than the possible harms."
Leeds and York Partnership NHS Foundation Trust	Short	25	1	Maybe useful to be more explicit about who would be responsible for the assessment – is this a specialist role or a role within primary care?	Thank you for your comment. The committee agreed there were a range of issues that could affect interpretations of test scores, including language, education, learning disabilities or age. It was for this reason the committee agreed it was not appropriate to set cut-offs to use for the particular tests, but they should instead be considered alongside a broader assessment including a history (including cognitive, behavioural and psychological symptoms), a physical examination and appropriate blood and urine tests to exclude reversible causes of cognitive decline.
Leeds Beckett University	Short	8	5	In this section can it be specified that people who have received a diagnosis of MCI should be advised about disease progression and how to re-access services, on the basis of recommendations to re-assess after 6 months, to ensure that people are offered appropriate information to this effect	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team

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					within NICE for consideration when the topics of future guidelines are discussed.
Leeds Beckett University	Short	10	22	It would be useful to define specialist diagnostic services as diagnosis may be delivered in Primary care not suggested by the terminology "specialist" see (Wells & Smith, 2016)	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Leeds Beckett University	Short	15	9	We query the terminology "consider" and why these recommendations are not stronger given the evidence that CST has a meaningful effects for	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST than was in the

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				individuals, with particular relation to group activities. Given the paucity of research indicating benefits from pharmacological interventions and increasing growth in the availability of and evidence for psychosocial interventions (due to difficulties funding and conducting RTCs in this domain) on balance this could be better reflected in the guidelines. At a minimum the evidence would suggest that Group based cognitive activities should be recommended.	draft guideline, and the recommendation was therefore upgraded to an 'offer'. Specifically; "offer group cognitive stimulation therapy to people living with mild to moderate dementia".
Leeds Beckett University	Short	16	2	Although the recommendations include adopting a person centred approach throughout, our experience working with practitioners delivering diagnosis and qualitative review of patients receiving diagnosis suggests that the way in which medication is offered and explained to people with dementia is a critical consideration in initiating treatment. i.e. recommendation – has the efficacy and side effects of the treatment been communicated to the patient in a way that is appropriate. Although this is indicated on page 7- suggest that the need to communicate effectively using a modified approach where appropriate is reiterated at decision points in the assessment and diagnosis process.	Thank you for your comment. The committee agreed that appropriate communication was an important issue throughout the pathway for both people living with dementia and their carers. The committee agreed this was appropriately covered by both the recommendation you mention on adapting communication techniques, and a recommendation in the section on staff training on adapting communication styles.

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Leeds Beckett University	Short	25	15-29	We have co-developed an education and support programme (with carers and staff from TIDE carers network and Carer's Leeds) funded by the Prime Minister's Challenge on Dementia 2020 training fund administered by Dept of Health and Social Care. It is a 7-week programme that covers all of the areas identified in the guideline (and additional support materials), to be delivered in a group. We are currently making final revisions to the materials following delivery and evaluation of a pilot programme. The programme evaluated well with carers. We will be making the materials freely available on our web-site with a manual for facilitators by May 2018. We have a publication to be submitted for peer review under development. We would be happy to share these with NICE and for them to be accessed/recommended as a freely available resource that can help organisations to meet this item of the standard.	Thank you for your response. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
Leeds Beckett University	Short	27	3	Not all training is effective at achieving desired outcomes such as knowledge gains, improved attitudes, changing practice/behaviours of staff or improving outcomes for people with dementia and their family members. It is important to highlight the need to consider the features of	Thank you for your comment. This study did not meet the inclusion criteria for the review question on staff training (which included randomised controlled trials and systematic reviews of randomised controlled trials) and therefore it was not possible to include this work as part of the guideline.

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				effective training as the correct content is only part of the picture. We have led the 'What Works in dementia education and training?' evaluation funded by NIHR PRP and commissioned on behalf of Health Education England. The two year study sought to understand what methods and conditions are most likely to lead to dementia training being effective in improving outcomes for people with dementia and their family. There are a number of key features of training design and delivery identified through an extensive systematic review, surveys and in-depth case studies in care provider organisations. We have a couple of publications already Surr et al (2017) http://bit.ly/2hYYkJB (open access paper) and Surr and Gates (2017) http://bit.ly/2xuNkGE (we are happy to provide you with a copy of this paper if required) and the remainder are due for submission imminently and into April/May 2018. The final reports have been submitted to NIHR PRP and are under peer review. We would be willing to share them confidentially with NICE in support of developing this component of the guideline. We have produced an audit tool and manual that includes some of the key components for effective training design and delivery. These are freely available from our study	However, the committee agreed that the development of materials to support staff training was a highly valuable area of research, and we will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement

Dementia: assessment, management and support for people living with dementia and their carers

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				web-site http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/. We believe they will be useful for organisations who wish to consider how to best design and deliver their training or in the purchase or commissioning of training. The audit tool is used by HEE as its standard mechanism for review of materials ahead of them being made available via the HEE dementia page on their web-site.	
Leeds Beckett University	Short	27	4	The guideline should make reference to the Skills for Health, Health education England, Skills for Care (2015) Dementia Core Skills Education and Training Framework. http://www.skillsforhealth.org.uk/services/item/176-dementia-core-skills-education-and-training-framework This provides the gold standard in terms of the core skills and knowledge staff working across health and social care need and thus should be provided with through training. As part of the What Works in dementia education and training study we have developed a document to help providers to map their training against the framework learning outcomes. It can be freely accessed from our web-site http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/	Thank you for your comment. The committee decided not to refer to the Dementia Core Skills Education and Training Framework document as part of the recommendations themselves, as these needed to be based on the evidence identified from the literature review. However, it was agreed to be appropriate to refer to this document within the list of relevant other guidance at the start of the document, alongside other Department of Health frameworks.

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Leeds Beckett University	Short	28	1-2	This point is unclear – is this for the carers to attend and learn alongside staff or for carers to be part of the delivery team? The outcomes of the What Works? study suggest that involving people with dementia or family carers in the training facilitation team can be very powerful and help staff to develop empathy and understanding. However, we would not recommend including family members in staff training as learners as their learning needs are very different and this may impact on how well training can meet the needs of both staff and carers.	Thank you for your comment. The committee noted these points but agreed that in the absence of robust evidence, they were not able to be more specific about the roles carers or people living with dementia should play in staff training.
Leeds Beckett University	Short	28	13	The What Works? study has also identified the importance of the organisation culture and leadership in supporting attendance at and then subsequent implementation of training in practice. Supportive leadership and management is key to staff being able to put their learning into practice and thus for training to be able to effect change. We wonder if consideration of the organisational context and support for staff to put learning into practice should be highlighted within the guidelines.	Thank you for your comment. The committee agreed that in the absence of any evidence meeting the inclusion criteria for the guideline, it was not possible to make recommendations on this topic. However, they did note that the recommendations on staff training included training in "the organisation's model of dementia care and how it provides care."
Leeds Beckett University	Full	33	47	Perhaps the above should say "…before and after every transition."	Thank you for your comment. The committee considered this suggestion but agreed that, on the basis of the evidence

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					available, it was not possible to be more specific than the current recommendation for review after transition. In particular they noted there may be little value in some occasions on assessing before a transition, if the person then transfers to a very different setting where those needs and wishes may be considerably different.
Leeds Beckett University	Full	39	6	Perhaps the above recommendation should also include people living with dementia who are in a situation where pain is more likely, such as people living with dementia who are in hospital or are seriously/terminally ill? The same point is also relevant to 107, line 12, on the same page.	Thank you for your comment. The committee noted that the evidence available to support these recommendations was limited, and therefore agreed it was not appropriate to extrapolate beyond the population where evidence had been identified. The committee noted that most of the people mentioned here would be captured buy the recommendation for those with "moderate to severe dementia."
Leeds Beckett University	Full	40	11	Why limited to people with severe dementia, detrimental effects of hospital admissions are documented for people with various degrees of dementia, albeit most significantly for people with more advanced dementia. For example, whilst in-hospital mortality rates are four times higher for people with more advanced dementia, in-hospital mortality rates for people with any stage of dementia are still twice as high as their cognitively well counterparts (Sampson et al, 2009).	Thank you for your comment. The committee noted this, but also agreed that for people with milder dementia, there may be issues around people being inappropriately denied treatment for comorbidities if too strong a position was taken on not admitting them to hospital. The committee therefore agreed it was appropriate to restrict this recommendation to severe dementia, where the evidence on harms was strongest.

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Leeds Beckett University	Full	40	24	Is this in relation to hospitalised people with dementia (the immediately preceeding section), or all people with dementia? It isn't clear from the text.	Thank you for your comment. This recommendation applies to all people living with dementia. This confusion should be addressed in the published version of the guideline, where there will be clear headings separating the recommendations.
Leeds Beckett University	Full	133	32	It is important to stress the specific need to ensure opportunites for people living with dementia and their supporters/family to have opportunities to discuss current and future care plans at key transition points, such as during hospital admissions, when many important decisions about future care are made, and when people with dementia may be particularly vulnerable, due to ill health and unfamiliar environments and people, to having their needs and wishes overlooked. In hospital settings, for example, meetings to discuss future care often take place either amongst professionals only, or amongst professionals and carers - it is common for people living with dementia and their familesi to feel that they are only involved late in the day, in a very limited fashion, or without access to information to support decision making that is available to professionals.	Thank you for your comment. The committee agreed with the importance of people living with dementia being offered multiple opportunities to discuss these issues as their condition progresses. The committee noted that although there was no specific evidence on when these discussions took place, they agreed the principle was covered by the statements to "offer early and ongoing opportunities for people living with dementia and people involved in their care" to discuss these issues.
Leeds Beckett University	Full	171	Other	Given the extremely limited quantitative data (5 studies) from which the section on caring for people with dementia who are admitted to	Thank you for your comment. The decisions about which reviews should contain qualitative data were made by the committee at the start of the systematic reviewing process,

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			considerations	hospital is based, the decision not to include other forms of evidence, such as qualitative data and reports such as 'Counting the Cost' by the Alzheimer's Society, seems surprising, especially when other sections of the guidance have included such data. The section on hospital care provides very little in the way of guidance to help hospital staff consider how they might improve experiences or outcomes of care for people living with dementia. What about environmental adaptations, family involvement in care provision and decision making, the use of 'This is Me' or similar booklets, recommendations not to move people with dementia around hospitals unless it is completely necessary, early engagement with families and the person themselves, etc? Several recent reviews have, for example, reviewed existing literature on the involvement of families of people with dementia in general hospital settings - it might be possible to refer to these reviews and their findings without significant additional work. Boltz et al (2015) and Porock et al (2015) are two examples of recent reviews of literature in this area.	and this was not one of the questions prioritised for qualitative literature. The committee noted that the large NIHR TEAM trial, if it had produced more positive results, could have led to a number of strong recommendations being made around how care in hospitals should be organised, and agreed it was unfortunate that meaningful benefits for people living with dementia were not identified in this study.

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				By excluding the wider literature, the section on hospital care for people with dementia appears to rely overly on data from a small number of RCTs which have demonstrated limited effects, and completely excludes literature where people with dementia, families and staff set out their difficulties and suggested improvements to hospital care. Might it be valuable to include, at the very least, reference to the kinds of care improvements that are discussed in the non-trial/quantitative literature, even if these are unable, at present, to be supported or refuted by more compelling evidence.	
London Dementia Clinical Network	Short	8	3-17	Written information on progression of disease. It is very difficult to predict accurately the progression of dementia in an individual, there is also very little published information for people with dementia on this. It might be better to say "provide people with a chance to discuss the changes they might expect as the condition progresses, especially issues of particular concern to individuals and carers" This in our view requires a sensitive and individualised approach. Evidence shows that delivery of diagnosis is often quite poor, let alone discussion on prognosis, so it	Thank you for your comment. The committee agreed with the point around the difficulty of predicting progression, and therefore this recommendation has been rephrased as "the changes they might expect as the condition progresses." The committee noted that recommendation 1.1.6 does include reference to written information, as the committee agreed people often struggle to take in all the necessary information orally. The committee also agreed with the concerns around how diagnosis is delivered, and amended one of their recommendations around staff training to clarify that it did cover this particular situation: "Health and social care

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				might be worth recommending that best practice would be a written care plan at feedback to include all of the elements of 1.1.6	professionals advising people living with dementia (including those involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations."
London Dementia Clinical Network	Short	8	3	**Information at diagnosis** It would be more logical if this section is after the diagnosis section 'What their dementia subtype is'. In practice people are sometimes given a diagnosis before the subtype is clear. Carer support and information should not be delayed if subtype unclear. Would suggest rewording *'what their dementia subtype is (if established)'*. This wording was not discussed at the committee. Consent for research – there was no discussion from the committee about giving information about research. Something on join dementia research should be included here. There is evidence that participation in research is of benefit to patients and it is also important that we build an evidence base for treatments of dementia. Despite the lack of RCT evidence we	Thank you for your comment. The committee agreed that if someone was given a diagnosis before a subtype is established then it would not be possible to give this information in full, but it should still be possible to mention which subtypes have been ruled out and which are still possible diagnoses. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in." The committee also agreed it was appropriate to add a cross-reference to the NICE guideline on hearing loss, in order to raise awareness of the recommendations you mention. The committee agreed that in the absence of evidence it was not possible to make specific recommendations around the treatment of vascular risk factors. However, they agreed this was covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				believe that encouraging participation in research (for both carers and people with dementia) should be supported, and at least people should be made aware of the opportunities. The draft NICE document, "Hearing loss in adults: assessment and management" states, 'Consider referring adults with diagnosed or suspected dementia or mild cognitive impairment, to an audiology service for a hearing assessment'. There was no discussion about including this in the dementia guidelines, please could the committee consider this. Giving people information about the importance of treatment of vascular risk factors if these are not already being treated in our view is good practice. There is limited evidence that this improves prognosis in dementia but people with dementia should not be denied a discussion with their GP about evidence based treatment for vascular risk factors. https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-014-0160-z	

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London Dementia Clinical Network	Short	9	14	**Advance Care planning** Important that care plans are reviewed at transitions of care – recommend incorporating this into the recommendation	Thank you for your comment. The committee agreed with this point, and recommendation 1.12.2 states that advance care and support plans should be reviewed afters every transition between care settings.
London Dementia Clinical Network	Short	9	21	**Initial assessment** 'If possible , from someone who knows the person well' – this needs to be emphasised as extremely important for diagnosis	Thank you for your comment. The committee agreed with the importance of this recommendation as part of an accurate assessment.
London Dementia Clinical Network	Short	9	18,23	**Initial assessment** We are concerned that GPs may not promptly refer for specialist assessment as they have not had time to complete cognitive testing. Specialist settings currently do not require GPs to complete cognitive tests to encourage referrals. Suggest rewording to 'consider using cognitive testing'	Thank you for your comment. The committee agreed that because all the instruments recommended are brief cognitive instruments, there should be no impact on time to referral from their use.
London Dementia Clinical Network	Short	9	17 – 27	This section lacks recommendation as to when the diagnosis of dementia can be made in a non-specialist setting e.g. advanced dementia in care homes - https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in

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					the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
London Dementia Clinical Network	Short	10	1-21	This section lacks recommendation as to when the diagnosis of dementia can be made in a non-specialist setting e.g. advanced dementia in care homes - https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also

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					involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
London Dementia Clinical Network	Short	10	11	The previous NICE guidance indicated that it was good practice to request basic blood investigations as part of the assessment of cognitive impairment. We are uncertain why this is not in the current guidance. We would suggest recommending that either GPs provide results of standard blood tests to exclude reversible causes and check for common factors contributing to cognitive impairment – i.e. FBC, U and E, LFTs, HbA1C, B12, folate, Fe, Ca, TFT, (and HIV and syphilis serology where appropriate)- or memory services complete these as part of their initial assessment.	Thank you for your comment. The committee agreed with the suggestion, and agreed that it was appropriate to retain the recommendation from the previous guideline, and therefore "conduct a physical examination and undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline" has been added to the recommendation for initial assessment in non-specialist settings.
London Dementia Clinical Network	Short	10	23	**Diagnostic Services** Test for verbal episodic memory - It was thought this was an overly specific recommendation. The correct phrasing might be "Cognitive assessment tools relevant to the presentation should be used,	Thank you for your comment. These recommendations have now been modified to make reference to "an appropriate neurological examination and cognitive testing" as part of

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				for example using tests of verbal episodic memory if AD is suspected and using tests to assess executive function if fronto-temporal dementia is suspected" The MoCA was shown to have high sensitivity and specificity but the committee's discussion appears to have led to it not being recommended. In our experience clinicians are favourable towards the use of the MoCA in clinical practice.	initial specialist assessment, to make clear the test of verbal episodic memory is just one part of a broader assessment. The committee agreed that there was no evidence found that specific tests were more effective than others for use in specialist settings, and therefore agreed it was not appropriate to include a reference to specific tests to use in this section.
London Dementia Clinical Network	Short	10	25	**Diagnostic Services** There is a lack of evidence for the use of CT / MRI scan in diagnosis of dementia - http://apt.rcpsych.org/content/18/6/457/full-text.pdf+html Despite the lack of evidence the committee stated 'consider structural imaging to rule out reversible causes of cognitive decline'. We suggest adding 'if the history suggests these are possible', and possibly also the sentence "Younger patients (under 70) and older patients with a history not typical for AD need a scan. But older people with a clear history of gradual cognitive decline and cognitive deficits compatible with AD do not require neuroimaging	Thank you for your comment. The committee noted the evidence base for CT/MRI for the diagnosis of Alzheimer's disease was limited, but noted there was strong evidence for its use in diagnosing or ruling out other subtypes of dementia and other non-dementia causes of cognitive decline. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly an additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."

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				to rule out reversible causes". Neuroimaging is costly, for some it is distressing, it can wastes time, and can delay a diagnosis being made. It should only be done where the scan is needed to inform management, or where patient /carer express a strong opinion about having a scan.	
London Dementia Clinical Network	Short	10	25, 26	**Diagnostic services** The wording of this section implies that everyone with an uncertain diagnosis should have specialist investigations 'If the diagnosis is unclear…' The committee discussed – *that it was important to use these tests only if they are required to reduce diagnostic uncertainty.* The wording should be changed to reflect the committee's discussion 'These tests should only be conducted if they are required to reduce diagnostic uncertainty'.	Thank you for your comment. The committee agreed it was appropriate to include an additional recommendation to capture this point. Specifically, to "only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
London Dementia Clinical Network	Short	11	15	Access to lumbar puncture for CSF and PET scanning is not widespread. Both procedures are expensive, potentially distressing, and not always accurate or helpful (clinical experience indicates that these tests often do not give an answer,	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these test could be of

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				particularly in older people with multiple medical co-morbidities. The recommendation needs more clarity or it could be interpreted in the wrong way. It might be useful to start by saying for whom such investigations are not helpful i.e. older people with a clear history of gradual cognitive decline and cognitive deficits compatible with AD. The investigations are *primarily indicated for younger people where neuropsychological testing and MRI/CT have not clarified the diagnosis.*	diagnostic value in some cases, and therefore were appropriate to include in the recommendations. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
London Dementia Clinical Network	Short	13	2	We are unclear as to why the Short CAM was not recommended The committee discussed that the length of delirium tools need to be short. The long CAM is lengthy to complete in a busy acute hospital setting. Although data from research is from the long CAM the short CAM is recommended in the delirium NICE guidelines.	Thank you for your comment. The committee noted that the evidence available all came from the long CAM, and therefore agreed this was the appropriate one to include in the recommendations. The committee noted there had been some confusion at consultation as to the meaning of the included

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					recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.
London Dementia Clinical Network	Short	13	9	No information on what should be included in care plan – the committee might want to consider referencing NHSE good care planning guide https://www.england.nhs.uk/wp-content/uploads/2017/11/dementia-good-care-planning-v2.pdf Important also to highlight in this section that care plan should be person centred (one care plan for one person, not one condition)	Thank you for your comment. This resource has been linked to as suggested. The committee also agreed it was appropriate to add a separate point under the recommendation on care and support plans to "ensure it contains information on the management of any comorbidities the person has."

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London Dementia Clinical Network	Short	13	23	Care navigators – who provide most of the standard post-diagnostic support to navigate the system are often from the voluntary sector – therefore recommend changing 'health or social care professional' to include "or appropriately trained voluntary sector care coordinator" We suggest that you may want to recommend a research question to review the most effective care coordinator model (e.g. voluntary sectors vs primary care nursing / use of risk stratification)	Thank you for your comment. The committee noted that the research evidence included used either social workers, nurses or occupational therapists as care coordinators/navigators, and therefore agreed it was appropriate to retain "health or social care professional" in the recommendation. However, they agreed there was considerable value in future research about how best care coordination should be conducted, and noted a number of research recommendations had been made on this topic.
London Dementia Clinical Network	Short	15	5	Appears errorless learning was not considered as part of the review questions – review of literature here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3775624/	Thank you for your comment. Errorless learning was not one of the interventions prioritised by the committee for this reviews question (see appendix O for details), and therefore evidence on this was not specifically searched for. The committee did note that While there is evidence for benefits of errorless over trial-and-error learning in some groups, the situation is much less clear with regard to people with dementia. The literature suggests that people with dementia differ in regard to which learning or relearning strategies are most helpful (see, for example, the detailed review by Clare & Jones, 2007). Therefore it is important to establish for each individual which strategies are beneficial. The recent REDALI-DEM trial (Voigt-Radloff et al., 2017) compared errorless and trial-and-error learning as instructional methods for training activities of daily living and found no difference between the two approaches. Errorless learning is

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					one of a number of strategies that could be used in cognitive rehabilitation therapy to enable people to meet their goals and improve functional ability; the Committee included a recommendation to 'consider' offering cognitive rehabilitation for people with concerns about functional ability and activities of daily living.
London Dementia Clinical Network	Short	15	9,10, 11	1. New proposed wording, which suggests 'elements' of cognitive stimulation and reminiscence therapy and uses the words 'consider' rather than 'recommend'. Evidence for CST has expanded since 2006, so we question why the wording has changed and recommend that NICE revert to their 2006 wording.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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London Dementia Clinical Network	Short	15	9, 10, 11	This recommendation shows a significant shift in language from the 2006 NICE guidelines. There is no evidence to suggest that "elements" of cognitive stimulation and reminiscence therapy is effective. The positive evidence is for structured CST, following a manualised approach. Manualised CST programme works well in community services, where staff needs to have structured guidance.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
London Dementia Clinical Network	Short	16	19	It would be useful to include the definition of moderate disease that was used in the literature to guide clinicians	Thank you for your comment. The common definitions of moderate disease used in the research studies were based solely on the MMSE, and therefore the committee agreed not to include this definition to avoid giving the impression cognitive scores were the only important element in decision making.

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London Dementia Clinical Network	Short	19	17	There is no information on SSRIs for FTD; this appears not to have been discussed by NICE. Although the evidence may be limited, these drugs are frequently used in clinical practice. Could NICE consider reviewing the evidence? http://www.theaftd.org/understandingftd/healthcare-professionals/treatment	Thank you for your comment. The questions on pharmacological treatment of non-cognitive symptoms of dementia in the guideline (did look for evidence on the use of SSRIs for FTD. However, no relevant evidence was identified, and therefore it was not possible for the committee to make recommendations on other medicines.
London Dementia Clinical Network	Short	20	14	Example given is the anticholinergic burden scale – this scale is reliable but now slightly out of date. Please consider also mentioning the AEC scale which was designed as an update to other scales and is freely available in a simple useable form on line (medichec.com) (reference- Bishara D et al Anticholinergic effect on cognition (AEC) of drugs commonly used in older people (Int J Ger Psych 2016).	Thank you for your comment. The committee noted the existence of this new and potentially improved tool, but were not aware that it had yet been validated in the same way as the other tools included in the review. As a result, the committee agreed it was best to retain the reference to the ABS, but that this was presented solely as an example, and that the use of more modern validated scales would be appropriate when they are available.
London Dementia Clinical Network	Short	20	19	It is important for the guidance to state that antipsychotic medication can be appropriately prescribed for the treatment of psychosis in dementia. This includes both the treatment of long standing psychotic disorders and the treatment of psychotic symptoms in the context of dementia.	Thank you for your comment. The committee agreed with this point and noted the guideline allowed the use of antipsychotics for people with "hallucinations or delusions that are causing them severe distress."

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London Dementia Clinical Network	Short	20	24	The section on managing non-cognitive symptoms in dementia – in particular section 1.7.2 needs some expansion and linking to other sections. 1. It should be mentioned that for residents in care homes interventions for BPSD should be aligned to an appropriate training/support programme for staff (section 1.13 lines 20-24). Good practice is that interventions will include supporting staff to improve communication skills and their delivery of person-centred care (which Livingston (2014) found as core components of effective interventions for managing distress/agitation in people with dementia in care homes). 2. The WHELD model of care (Ballard et al) is emerging as an effective model and publications are starting to come out of this. This model supports specialist staff mentoring and supporting "dementia champions" in care homes to deliver person-centred care, antipsychotic reductions and social and exercise interventions. We were unsure whether the committee looked at this model.	Thank you for your comment. Please find below a response for each of the papers you cited. Ballard (2018) was published after the cut-off date for evidence to include within the guideline. However, this reference has been passed to the NICE surveillance team for consideration in planning future updates of the guideline. Ballard (2016) was excluded because the study was not relevance to the review question. Ballard (2016) is not in Appendix F because the study was excluded during the screening at title and abstract level. We found two references of systematic review published by Livingston in 2014. Both systematic reviews were excluded. One review was excluded because relevant studies were previously identified for inclusion and the other review was excluded because data was not pooled, but individual studies within the review were checked for eligibility within the guideline.

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				3. Similarly work with carers living with a person with dementia at home who has BPSD must include the psychoeducational approaches recommended in Section 1.11 lines 17-29. 4. The clinical reality is that drug interventions for BPSD have very limited efficacy, so inevitably the bulk of the care of the person with dementia with non-cognitive symptoms rests with untrained family members or junior care staff. Hence the need for support training and information in line with sections 1.13 and 1.11 must be emphasised more clearly at the start of section 1.71.	
London Dementia Clinical Network	Short	21	11	We wonder whether review of medication every 6 weeks is impractical for a busy community mental health team and in the absence of clear evidence to support the correct frequency of review, we suggest that every 3 months might be a more pragmatic recommendation.	Thank you for your comment. The committee agreed that in review of the well-established and serious risks of antipsychotics in people living with dementia, frequent monitoring was essential to ensure use was for the shortest possible time.
London Dementia Clinical Network	Short	22	5	This recommendation states: "For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider	Thank you for your comment. For the recommendation on treating anxiety and depression, the committee agreed this should remain a 'consider' recommendation for two reasons.

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				psychological treatments".. As above question why "consider" is used, rather than "recommend", given the evidence displayed. A review of the included studies indicates that there are not many which have included cognitive and behavioural therapies. We argue that the wording "psychological treatments" is ambiguous and our understanding is that the best evidence base for anxiety and depression is for CBT. Suggest recommendation is changed to "Cognitive behaviour therapy is recommended for people living with mild to moderate dementia who have mild to moderate depression and/or anxiety".	First, because the evidence covered a range of different interventions and it was not possible to identify which ones were effective, and secondly because there are people with dementia who will have been diagnosed with mild depression and for whom alternatives such as "active monitoring" (recommended in the NICE depression guideline) would be appropriate instead of a psychological intervention.
London Dementia Clinical Network	Short	22	11	We were concerned that just stating not to use melatonin to manage sleep problems may lead to inappropriate use of diazepam, zopiclone or other sedative drugs which are known to be ineffective and increase risk of falls in people with dementia. We propose a change in the wording 'Do not offer pharmacological treatments to manage sleep problems in people living with dementia'	Thank you for your comment. The committee noted this concern, but agreed there was not sufficient evidence on other pharmacological treatments to be able to make recommendations (either positive or negative), and agreed that an absence of alternatives was not a reason to promote the use of a drug (melatonin) where there is evidence of a lack of efficacy.

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London Dementia Clinical Network	Short	22	19	The committee discussed - *The committee noted there was often concern that people living with dementia were often not offered equitable access to treatment for comorbidities they may have.* In clinical practice this also includes access to rehabilitation (e.g. post fractured neck of femur). Proposed change : 'Ensure that people living with dementia have equivalent access to treatments, rehabilitation and care for comorbidities to people who do not have dementia. ' NICE intermediate care guidance - *Do not exclude people from intermediate care based on whether they have a particular condition, such as dementia* - *Consider reablement for people living with dementia, to support them to maintain and improve their independence and wellbeing*.	Thank you for your comment. The committee agreed access to rehabilitation services would be covered by the references to treatments and care services in the recommendation.
London Dementia Clinical Network	Short	22	25	We suggest removing the word 'consider'. The evidence is that pain is very poorly managed in severe dementia. We need to be recommending	Thank you for your comment. The committee discussed this and agreed that, because of the limited nature of the evidence base available on pain assessment, a 'consider' recommendation remained the most appropriate.

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				that proactive assessments are made and analgesia given when appropriate.	
London Dementia Clinical Network	Short	24	1	Other risks during hospital admission have not been reviewed • Falls • Pressure ulcers • Dehydration There is evidence from the RAID model of liaison mental health services that mental health interventions in the general hospital can reduce length of stay for people with dementia. We recommend that access to old age liaison services is an important part of dementia care in the general hospital	Thank you for your comment. The committee noted that the list of factors given here were only examples, and there were many other factors that would need to be taken in to account in individual cases. The specific examples on the list were chosen by the committee as those they agreed were likely to be the most common problems encountered.
London Dementia Clinical Network	Short	25	1	We suggest that NICE recommends involvement of local palliative service / GP OOH / electronic anticipatory care planning for everyone with end stage dementia In recommended research. We suggest we need more research into delivery of diagnosis and discussion on prognosis and on what people with dementia and carers experience in their interaction with dementia services - evidence on this is lacking from the guidance.	Thank you for your comment. The committee discussed this point around end stage dementia, and agreed the guideline was clear both that opportunities for advance care planning should be offered from diagnosis, and that "an anticipatory healthcare planning process" be used for those approaching the end of life. The committee discussed this suggestion for future research, but agreed it was not as high a priority as the other recommendations for research included in the guideline.

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London Dementia Clinical Network	Full	General	General	Prevention appears to be out of scope – it would be useful to guide clinicians to other appropriate guidelines.	Thank you for your comment. You are correct that prevention of dementia was not in the scope of this guideline, and therefore it was not possible to make recommendations or links to other guidance in this area.
London Dementia Clinical Network	Full	General	General	There appears to be a lack of any cultural considerations in the recommendations	Thank you for your comment. Cultural issues were considered by the committee at each stage of the process, but it was agreed that there was currently not sufficient evidence to make clear recommendations on this issue, other than the many references through the guideline to care being tailored to an individual's needs, preferences and circumstances.
London Dementia Clinical Network	Full	General	General	Several other reports have endorsed CST since the 2006 guidelines. For example, the World Alzheimer Report (Alzheimer's Disease International), in 2012 and subsequently; have stated that CST should routinely be given to people with early stage dementia.	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST and the recommendation has therefore been amended to an 'offer'. Specifically, "offer group cognitive stimulation therapy to people living with mild to moderate dementia".
London Dementia Clinical Network	Full	General	General	I am concerned that the wording for non-pharmacological and psychological interventions is "consider", and the wording for pharmacological interventions is "recommend" or "offer". (E.g. short guidelines 1.5.1 recommend AChE, but section 1.4.2 states "consider elements of cognitive stimulation", despite both CST and AChE having similar benefits). Similarly, the	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST and the recommendation has therefore been amended to an 'offer'. Specifically, "offer group cognitive stimulation therapy to people living with mild to moderate dementia". For the recommendation on treating anxiety and depression, the committee agreed this should remain a 'consider'

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				wording for psychological treatments for anxiety and depression (short guidelines 1.7.9) is consider, despite the evidence being strong for this intervention.	recommendation for two reasons. First, because the evidence covered a range of different interventions and it was not possible to identify which ones were effective, and secondly because there are people with dementia who will have been diagnosed with mild depression and for whom alternatives such as "active monitoring" (recommended in the NICE depression guideline) would be more appropriate than a psychological intervention.
London Dementia Clinical Network	Full	277	37	This section considers the economic analysis of CST, but uses a base case model, rather than published health economic studies. There have been 2 key papers published considering the cost effectiveness of manualised CST (Knapp et al, 2006 which considered CST; D'Amico et al, 2015 which considered maintenance CST). Both are listed in the references in Appendix J, but only D'Amico et al (2015) has been considered in the evidence. These papers show evidence for the cost effectiveness of manualised CST. The NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-	Thank you for your comment. The Knapp (2006) paper was not a cost-utility study and therefore did was not consistent with the reference case. As a result, it is inaccurate to state that this analysis showed that CST is cost effective, as no threshold value has been established for the effectiveness instruments used against which gains could be assessed. The D'Amico (2015) paper however, was a cost-utility study and was eligible for inclusion as part of the economic review. Please note that the effectiveness evidence used in Knapp (2006) was based on Spector (2003), and has been considered by this guideline by the way of inclusion in our quantitative synthesis of parameters for the model developed by NICE.

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				Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually. References D'Amico F, Rehill A, Knapp M, Aguirre E, Donovan H, Hoare Z, Hoe J, Russell I, Spector A, Streater A, Whitaker C, Woods RT, Orrell M (2015) Maintenance cognitive stimulation therapy: an economic evaluation within a randomised controlled trial. Journal of the American Medical Directors Association, 16 (1): 63-70. Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? British Journal of Psychiatry, 188: 574-580.	
London Dementia Clinical Network	Full	295	5	1. Review of incorrect evidence for Cognitive Stimulation and misinterpretation of results	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the

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				The research evidence for Cognitive Stimulation has grown since the 2006 guidelines. A synthesis of 22 systematic reviews on psychosocial interventions for dementia, including 197 unique studies, has just been published (McDermott et al, 2018). Only two interventions were specifically recommended in the conclusions: group Cognitive Stimulation and Multi-component exercise. Of the former, they concluded that 'group Cognitive Stimulation improves cognitive function, social interaction and quality of life'. A Cochrane review (Woods et al, 2012) of CST found consistent evidence of benefits to cognition and of improved quality of life in mild to moderate dementia. In summary: • There is consistent evidence that Cognitive Stimulation improves other domains in addition to cognition. • The evidence reviewed (listed in Appendix E) omitted several key trials. •	recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you have cited. All included papers in the review by McDermott (2018) had been already considered in Appendix O and the updated

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				• <u>2) No evidence that the effects of Cognitive Stimulation went away after the intervention stopped</u> Since the 2006 guidelines, Orrell et al (2014) has shown that weekly CST results in continuous benefits to quality of life for up to six months. This work was not commented upon in the conclusions. 3) <u>Unclear whether it was specific content of the interventions or simply being part of a group.</u> Whilst the literature on non-pharmacological interventions spans several decades and hundreds of studies, the evidence base for manualised CST is stronger than for other interventions, including Reminiscence. Olazaran et al (2010) concluded that CST demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions. Several trials within the Cochrane review compared CST with an active, social control group, the results were consistently in favour of CST (Woods et al, 2012). 4) <u>The two interventions are not mutually exclusive</u>	search for RCTs would have been found individual studies included in these reviews. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST. Orrell (2014) reported an improvement in QoL-AD, but the pooled result of the meta-analysis including the other relevant studies could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Olazaran (2010) was included as a systematic review in Appendix O but data was not extracted because Olazaran (2010) did not report details of the individual studies in included in their systematic review.

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				Cognitive Stimulation incorporates some aspects of Reminiscence. However, the key focus of CST is on generation of *new* thoughts, ideas and associations within the sessions. It shifts the focus to the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). We believe that this provides a different message and thus reduces stigma. • 5) Both interventions forming part of activities The evidence base for CST is stronger than for Reminiscence. There is no evidence for any benefits if just elements of the programme are used and no evidence, in general, for structured group activities. Further, having a clear manual, which can be followed by a range of health and social workers at all levels of expertise; eases implementation and minimises preparation time, providing a highly cost-effective intervention. 5) No difference in cost of delivery The NICE report states "there would be no difference in cost of delivery between providing an intervention with a more varied range of components". This assumption cannot be made without a cost effectiveness analysis. There is	

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				strong evidence for the cost effectiveness of manualised CST, with two key papers published since the 2006 guidelines (Knapp et al, 2006; D'Amico et al, 2015). Appendix J (p.10) considers the cost of providing CST. There are several errors in this table. Firstly, it states that band 4 or 6 staff are required to run sessions, when in reality it is often band 2 staff. Secondly, it states that groups are for 5 people, when in fact the key research trials included between 5-10 people in each group and many trusts offer groups for up to ten people. The total cost per session is calculated as £233.19. The Knapp (2006) paper calculated the cost per session as £90. Using the Knapp cost per session calculation, even with just 5 people in each group, the total cost per patient per CST course (14 sessions) is £252, compared to NICE's estimate of £652.94. Additionally, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as	

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				the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually.	
London Dementia Clinical Network	Full	300	4	*"Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them"* CST is suitable for all different types of dementia, it also shows improvement on measures such as quality of life and mood, as well as cognition. We would suggest the wording is changed to be more similar to the 2006 guidelines *"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia"*.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
02/01/2018-13/02/2018

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Marie Curie	Short	8	23-24	It is unclear what services the guideline is referencing (GPs, social care or DVLA, for example), and this should be made explicit.	Thank you for your comment. The committee noted that the list of relevant services would be different for different individuals, depending on their individual needs, including any comorbidities. Due to these complexities the committee agreed that it was not appropriate to construct a specific list of services.
Marie Curie	Short	9	3	We are concerned that the guidance's language is not strong enough in the section on advance care planning (ACP). ACP only works for the individual when their plans are frequently updated, and the importance of advance care plans being a 'living document' should be highlighted more strongly in this section. The guidance should be more prescriptive in stating that health professionals must offer opportunities to update these plans at care reviews and as circumstances change.	Thank you for your comment. The committee agreed with the importance of ensuring these documents are up to date, and noted the guideline already contained a recommendation to "at each care review, offer people the chance to review and change any advance statements and decisions they have made."
Marie Curie	Short	9	3	The guidance on ACP would be greatly enhanced if it included a recommendation on the practicalities of ACP. Basic information such as who needs to be collaborating in the planning process (for example carers, the individual, their GP and other health and social care professionals who are involved) and what information is needed would help to make the guidance more practically applicable. ACP is a process that needs to involve a range of people involved in the	Thank you for your comment. The committee noted that only limited evidence was identified on how advance care planning should best be undertaken, and therefore agreed it was not possible to be any more prescriptive in the recommendations made.

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				individual's care, and this guidance should make that clear.	
Marie Curie	Short	13	22	We are concerned that the guidance is vague about who should be a care co-ordinator. As it will be unclear who should take on responsibility for this role, it could potentially lead to no one being appointed and people continuing to miss out on care co-ordination.	Thank you for your comment. The committee agreed that in the evidence base considered, a number of different roles were responsible for care coordination (social workers, nurses, occupational therapists), and it was not possible to make recommendations on which of these was the most appropriate. They did also note that local areas would need to have clear policies on who is responsible for this in their service, to avoid the risk you mention from occurring.
Marie Curie	Short	14	22	The guidance recommendation that care should maximise continuity and consistency needs to be clearer on who that involves and how it could be achieved. 'Staff delivering care' should be expanded to explicitly include social care professionals and even legal staff and solicitors, who may have access to information that needs to be shared between care settings. The guidance should be more explicit about the need to provide information to the person with dementia and to their family and carers where relevant.	Thank you for your comment. The guideline contained a specific review question on the integration of health and social care services, including how to maximise consistency and continuity, but only a limited amount of evidence was identified and the committee agreed it was not possible to make more directive recommendations than those currently included. The committee noted the guideline already contained specific recommendations both on providing information, and on their being a single named person coordinating care for people living with dementia.

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				The guidance should also highlight the value of named coordinators in these situations, as a single point of contact through which information can be shared to ensure continuity between settings. NICE's previous research has shown these roles to be effective, such as the 2016 guidance *Social care for older people with multiple long-term conditions*. The absence of the coordinator function in this section is unfortunate, given how relevant it is to the specific needs of people living with dementia.	
Marie Curie	Short	15	5	Despite describing the terms used, it is still unclear how cognitive training and cognitive stimulation are substantially different. This is particularly important when one is recommended for use and the other is recommended not to be used.	Thank you for your comment. The committee noted these interventions are very different both in theory and practice. In particular, they noted than cognitive stimulation therapy is a structured and manualised intervention, and therefore one it is easy for practitioners to implement consistently.
Marie Curie	Short	20	20	When the guidance discusses agitation, aggression and distress, it should also consider the wellbeing of the family, carer or those close to the person. Any changes in these people or different people being used for care may indirectly affect the person living with dementia.	Thank you for your comment. The committee agreed that the wellbeing of carers should be considered throughout the treatment and care pathway for people living with dementia, but there was no evidence on which to make specific recommendations about this in this section.

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Marie Curie	Short	20	21	Arthritis can often be a cause of agitation and is commonly missed. It would be valuable for the guidance to highlight this alongside pain.	Thank you for your comment. The committee noted it was not possible to provide an exhaustive list of things that may be associated with agitation, and agreed arthritis would be covered under "clinical causes".
Marie Curie	Short	22	4	This section is too limited in the information provided. Depression has many overlapping symptoms with dementia and therefore requires a different approach in dementia to identify, diagnose and treat, yet there is no information about possible strategies for diagnosis such as using the Cornell Scale for Depression in Dementia. Details on 'psychological' treatments are also very vague and would likely differ to depression in non-cognitively impaired individuals.	Thank you for your comment. The committee agreed they would have liked to be able to make more specific recommendations in this section, but agreed that because of the very limited evidence available, it was not possible to be more specific. A research recommendation was made on the topic of "the most effective psychological treatments for managing depression or anxiety in people living with dementia at each stage of the condition," and the committee hope further research will enable more specific recommendations to be made in future updates of the guidance.
Marie Curie	Short	22	10	We were surprised that the guidance does not consider the effect of environment in sleep management, such as how dark the room is, the level of noise, or disruptions by staff. These would be particularly relevant in care home and hospital settings.	Thank you for your comment. Evidence on these points was looked for as part of the review on the management of sleep problems in people living with dementia, but no evidence was identified for the committee to use to make recommendations.
Marie Curie	Short	24	6	We are concerned that this section being labelled 'Palliative care' is not clear enough in recommending that a palliative approach needs to be adopted at the start of the dementia trajectory, to ensure discussions and future	Thank you for your comment. The committee agreed this was clear in the recommendation to:

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				planning start while the person with dementia still has capacity. Making it clear that palliative care is not solely for 'end of life' in this section would help to strengthen the recommendation that a palliative approach is an integral part of caring for people living with dementia from diagnosis onwards.	"From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be."
Marie Curie	Short	24	16	The guidance's signposting to additional guidance on care for dying adults is sensible; however we would recommend that the guidance references the principles for care at end of life developed by the National Palliative and End of Life Care Partnership, *Ambitions for Palliative and End of Life Care.* These ambitions summarise key principles that health professionals should consider when approaching care for someone at the end of life, such as co-ordinated care, holistic care, fair access, and maximising comfort and wellbeing. While these ambitions are reflected in the linked guidance, making them explicit in this document would help to cement them in the case of people living with dementia. In addition, the European Association for Palliative Care's *White Paper on palliative care in*	Thank you for your comment. The committee agreed there were a number of good sources of information about both the principles and practical aspects of delivering palliative and end of life care that were available. However, they also agreed that it was not appropriate for the guideline to pick out any individual documents to reference within the guideline.

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				dementia offers a thorough and considered examination on the value of palliative care's application in caring for people living with dementia, and the guidance would benefit from referencing its detailed and practical recommendations for care.	
Marie Curie	Short	24	23	The nutritional needs of people with dementia approaching the end of their lives are accounted for in this section; however we are concerned about the absence of detail and by the absence of any reference to mouth care in the text. More emphasis on the likelihood of people with dementia being unable to eat or drink as well as reference to the need for proper mouth care would give health professionals a better idea of what to expect when caring for people with dementia at the end of life. Health professionals should consider the person's familiarity with the individual who is helping them to eat, and what can be done to put the person at ease. We are also extremely concerned that there is an implication that people living with dementia should not be fed if there is risk. Comfort feeding can be a very useful intervention when the	Thank you for your comment. The committee noted that a decision-aid is going to be produced to accompany the guideline, covering issues around eating and drinking. The committee agreed this should hopefully address many of the points raised. The committee also agreed it was appropriate to add a recommendation to this section on involving a speech and language therapist, if there are concerns about the safety of oral eating and drinking.

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				person lacks capacity and if family carers or advocates and the multidisciplinary team are involved in the decision making. Stating that feeding should not occur when there is risk may increase the use of inappropriate feeding tubes.	
Marie Curie	Short	25	1	We are concerned that the guidance does not take a strong enough stance on the admittance of dying people with dementia to hospital. While this section highlights a range of potential negative outcomes of a hospital admission, it fails to be appropriately prescriptive in saying that these people should not be admitted to hospital unless absolutely necessary. The impact of an unfamiliar environment on these individuals frequently outweighs the benefits of the care they can receive in hospital, particularly as appropriate care is often available in community settings via district nurses and specialist services. The wording of the guidance is too neutral on the issue to adequately convey the negative impact of a hospital admission. In addition, the guidance does not reference the impact of hospital admissions on carers and loved ones. These hospital admissions can be	Thank you for your comment. The committee noted this, but also agreed that for people with milder dementia, there may be issues around people being inappropriately denied treatment for comorbidities if too strong a position was taken on not admitting them to hospital. The committee therefore agreed it was appropriate to restrict this recommendation to severe dementia, where the evidence on harms was strongest.

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				disruptive, and may introduce distress and complication to the circumstances of the individual and their loved ones unnecessarily.	
Marie Curie	Short	25	15	Paragraph 1.11.1 of 'Supporting carers' lists a range of support that carers should be offered, however this list does not note that it is likely that some will not be available in different geographical areas. For example, training in providing care and responding to changes in behaviour (lines 19 and 21) may not be available to staff in care homes or acute settings, let alone to family members and carers. Similarly, the availability of psychological therapies for carers (line 27) is not universal, and in many areas such services will not exist. While we recognise that in describing best practice the guidance should highlight these services, we believe that it should also note that these services are subject to availability, so as to reflect the realities that many professionals will be facing.	Thank you for your comment. The committee noted there was robust evidence that the carer interventions included in the guideline were both effective and cost-effective, and therefore agreed it was appropriate to recommend they be offered to all people living with dementia. They noted this may involve an expansion of the carer support services available, but agreed the evidence showed this would be a worthwhile use of resources.
Marie Curie	Short	25	27	This point should expand on exactly what 'relevant services' consist of to offer professionals practical direction when searching for available	Thank you for your comment. The committee noted that the range of services available would differ between areas, and

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				services. For example, specifying that support services can be local charity groups, support lines run on a national basis or online communities would help professionals to find services appropriate for carers in their remit.	therefore it was not possible to be specific about which services people should be informed about.
Marie Curie	Short	26	6	The guidance should be clear that support for carers should also be available at a time they can access as well, for example outside of normal working hours.	Thank you for your comment. The committee agreed with this point, and that this was covered by the recommendations in the guideline around ensuring the support provided to carers is accessible.
Marie Curie	Short	26	10	We are concerned that the evidence was not clear enough across all interventions to make the case that group sessions are more likely to be effective than individual sessions with family carers.	Thank you for your comment. The committee agreed the evidence available, from both subgroup analyses of the RCT data and the meta-regression model, showed that on average, group sessions were more effective than individual, telephone or online sessions. However, the committee also agreed both that the group sessions would need to be well run/moderated, and that this format would not be the most suitable for all individuals, due to differences in their circumstances and preferences. They therefore agreed it was appropriate for the recommendation for group sessions to be kept at the weaker "be aware" level, and that the guideline should also recommend support for carers is "provided in a format suitable for them (for example individual or group sessions, or online training and support)",

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					to ensure this is not taken as a blanket statement that group sessions are the most appropriate format for all carers.
Marie Curie	Short	26	16	We are concerned that generic depression services for older people may not address the specific needs of carers of people with dementia who might be experiencing depression in combination with carer burden, grief and anxiety. The guidance should be clear that generic services may not be sufficient in these cases, and specialist services or professionals with the specialist expertise should be approached. In addition, it would be helpful for the guidance to reference the fact that carers are at higher risk of not just depression, but also increased risk of poor physical health and increased mortality.	Thank you for your comment. The committee agreed there may be differences in the most effective interventions for carers either with or at high risk of depression, but that currently the evidence was not sufficient to make different recommendations for this population than for the general population with diagnosed depression. They also agreed this was an important area for future research, and a research recommendation was made on "the effectiveness and cost-effectiveness of group-based cognitive behavioural therapy for carers of people living with dementia who are at high risk of developing depression." The committee noted that carers may experience a range of other physical and emotional problems as well as depression, but agreed that depression was a particularly important issue that merited specific mention in the guideline.
Marie Curie	Short	26	19	The 'Moving to different care settings' feels too generic given the importance of this area in providing a good standard of care for people living with dementia. While it links to further guidance, that guidance is primarily focussed on hospital admissions and discharge over non-acute care settings. This section should stress that the	Thank you for your comment. The guideline did look for evidence on how transitions should be managed for people living with dementia. However, the evidence found for this review question was not sufficient to allow any recommendations to be made, and it was for this reason the guideline chose to make cross-references to the existing NICE

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				priority in these cases should be limiting the number of moves a person with dementia needs to undergo. This section needs to explicitly link moving between care settings to disorientation in people with dementia to ensure that health professionals are aware of the risks involved in these moves. In addition, this section fails to consider the decision making process of moving into a care home setting. Neither this section, nor the carer section describes the significant impact that this decision has on the wellbeing of family and carers who often describe this as the most difficult decision of their life. There is a need for information and support throughout this process and also emotional support available to carers after the move.	guidelines on transitions between care settings, rather than different recommendations being made for this guideline.
Marie Curie	Short	27	1	There is a need to consider the family, carers or those who care for them regarding their needs and the support available to them after each transition.	Thank you for your comment. The committee agreed with this point and noted that the other NICE guidelines on transitions between care settings referenced here did include specific recommendations around carers.
Marie Curie	Short	27	4	This section offers clear advice on the training required for staff that care for people living with	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely

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				dementia. We recommend adding 'managing behaviours that challenge in people living with dementia' as a further element of training required. Behaviours that challenge are a key issue in caring for people living with dementia, and the guidance should encourage greater training in its management.	delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
Marie Curie	Full	General	General	We are concerned that the guidance makes no mention that dementia is a life-shortening condition, or that a palliative approach offers a focus on comfort and planning ahead through the different stages of dementia.	Thank you for your comment. The committee agreed with the importance of adopting a palliative care approach from an early stage, and therefore made a recommendation that people living with dementia be offered "flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be" from the time of diagnosis.
Marie Curie	Full	General	General	The wording of 'family members or carers' throughout the document should be reshaped into 'family, carer or those close to the person with dementia'. Not all will classify themselves as carers and not all will have family members, but rather friends who act as their proxy or closest person.	Thank you for your comment. The phrase "family members or carers" is a standard one used throughout NICE guidance, and the committee agreed it was therefore appropriate to retain this wording for consistency.
Marie Curie	Full	General	General	We believe that the guidance does not give adequate attention to access to assessment for people living with dementia. Many people living with dementia are not known to social care or	Thank you for your comment. The guideline did not contain a review question on what factors should trigger an assessment

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				health professionals and this is not reflected in the guidance, which throughout assumes that people will have proper access to assessment. The guidance should be explicit regarding when assessments are required, with whom and in what setting to ensure that health professionals are clear on when they need to instigate assessments for dementia.	for dementia, and therefore it was not possible to include recommendations on this topic. The committee noted there were particular issues around people living with dementia being lost from the system, and hoped this would be addressed by the recommendations to "provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care" and to "ensure that people living with dementia and their carers know how to get more information and who from if their needs change."
Mencap	Short	General	General	There are several groups for whom the risk of dementia is high, one of which is people with learning disabilities – especially those with Down's Syndrome. However, awareness of this tends to be low. Therefore, we would like to see the issues related to dementia for people with learning disabilities reflected in the guidance. More awareness is needed among carers, medical professionals and social care staff of the increased risk and the signs that someone could be developing dementia – which can be different from the general population. This could be achieved by additions to the sections which address prevalence, diagnosis and training.	Thank you for your comment. The committee noted that evidence on people with learning disabilities and dementia was looked for throughout the guideline, but little evidence was identified from which to make recommendations. However, the committee agreed it was appropriate to add a specific reference to learning disabilities in the section of the guideline on making services accessible to specific groups.
Mencap	Short	General	General	The following passage is directly quoted from CIPOLD, (2013): "Dementia is a significant and	Thank you for your comment. The committee noted that evidence on people with learning disabilities and dementia was

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				common health condition in people with Down's syndrome, often with a more rapid and consistent progression than in other people. Dementia care pathways should identify issues that are likely to arise, such as potential swallowing difficulties, incontinence and reduced mobility, and allow them to be addressed proactively. However, a considerable amount of planning appeared to be responsive to problems that arose, rather than being anticipatory of problems arising in the future. This made people more vulnerable, for example, making them more susceptible to aspiration pneumonia which was a significant cause of death." Whilst of course it is vital that services are able to react quickly to changing needs, the draft guidance does not, in our opinion, pay sufficient attention to the importance of proactive planning, which is vital for people with dementia and particularly for those with complex needs, such as having a learning disability.	looked for throughout the guideline, but little evidence was identified from which to make recommendations. However, the committee agreed it was appropriate to add a specific reference to learning disabilities in the section of the guideline on making services accessible to specific groups.
Mencap	Short	General	General	There are several groups for whom the risk of dementia is high, one of which is people with learning disabilities – especially those with Down's Syndrome. However, awareness of this tends to be low. Therefore, we would like to see	Thank you for your comment. The committee noted that evidence on people with learning disabilities and dementia was looked for throughout the guideline, but little evidence was identified from which to make recommendations. However, the committee agreed it was appropriate to add a specific

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				the issues related to dementia for people with learning disabilities reflected in the guidance. More awareness is needed among carers, medical professionals and social care staff of the increased risk and the signs that someone could be developing dementia – which can be different from the general population. This could be achieved by additions to the sections which address prevalence, diagnosis and training.	reference to learning disabilities in the section of the guideline on making services accessible to specific groups.
Mencap	Short	5	28	The Equality Act should be included in the relevant legislation and statutory guidance as reasonable adjustments can be an important part of meeting the needs of people with a learning disability.	Thank you for your comment. The committee agreed with this suggestion and the Equality Act has been added to the list of relevant legislation in the introduction to the recommendations.
Mencap	Short	7	5	This section seems to assume that people are not already in contact with services. However, this is not likely to be the case for a number of people with learning disabilities, particularly those with higher needs. This section also needs to reflect the possible need for existing social care staff to be involved/informed in decision making and how social care staff will also be able to support understanding and decision making. Social care staff, providers and commissioners may also require information to understand a diagnosis to	Thank you for your comment. The committee discussed these issues, and agreed that these recommendations would be equally relevant for people either newly coming in to contact with service, or those who are already using services for another reason.

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				allow them to consider adaptations to services and to support an individual.	
Mencap	Short	9	1.2	We note the referral to the mental health problems in people with learning disabilities guidance, however, we would also like to see the guidance reflect that some methods of diagnostic testing, such as cognitive testing instruments may not be suitable or effective for people with learning disabilities. There is more detailed information on suitable assessment tools and difference in presentation in the British Psychological Society's 2015 guide to Dementia and People with Intellectual Disabiltiies, available here: https://www1.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf This guidance also points out the difficulties of using certain diagnostic imaging techniques for people with Down's syndrome, who may already exhibit some of the medical indicators of dementia. We would also like the guidance to affirm the importance of taking a baseline assessment for people with Down's syndrome before possible signs of dementia develop.	Thank you for your comment. Evidence was looked for as part of the guideline on specific instruments to use in the dementia assessment process for people with learning disabilities. However, not studies met the criteria for inclusion, and therefore the committee agreed it was not possible to make specific recommendations within the guideline.

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Mencap	Short	14	25	The section, making services accessible, also needs to include people with a learning disability.	Thank you for your comment. The committee agreed with this suggestion and it has been added to the recommendation.
Mencap	Short	15	7	It is important that activities are also adapted to accommodate the needs of people with a learning disability, including the different needs a younger adult may have to an older adult – in addition to being tailored to suit personal preferences and tastes.	Thank you for your comment. The committee agreed with this point, and agreed it was appropriate to add people with learning disabilities as a specific group in the recommendation on groups to whom services should be made accessible.
Mencap	Short	20	19	Due to the risks of people with learning disabilities being over medicated – it is estimated that every day about 35,000 people with learning disabilities or autism are prescribed psychotropic medicines without an appropriate clinical indication - this section should refer to the STOMP initiative being led by NHS England.	Thank you for your comment. The committee noted the existence and relevance of this initiative, but agreed it was not an appropriate thing to refer to within the recommendations of a NICE guideline, as no evidence no it was identified as part of the literature searches undertaken for the guideline.
Mencap	Short	26	19	This section focuses on moving to different care settings, however there must also be a section on changing needs and how to support someone for as long as possible in an existing care setting, which may be considered by someone as their home. The guide from the British Psychological Society sets out the three options for people with learning disabilities living with dementia as – staying and dying in their existing housing, moving to a specialist learning disability setting or being referred out of learning disability and into a	Thank you for your comment. The guideline did not include a specific recommendation on keeping people within their existing care setting for as long as possible. The committee noted, however, that implementation of many of the recommendations in the guideline (for example, those on promoting cognition and independence, carer support and staff training) would be highly likely to have this effect in practice.

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				specialist dementia setting. These options are ranked from best to worst. It is important there is understanding of the value in people with learning disabilities with a dementia diagnosis staying in their existing accommodation, particularly if they have lived there for a long time, or there are staff or other residents that know them well. Training and support may be needed for services to adapt to accommodate changing needs and for commissioners to ensure appropriate services are provided. There may also be other measures to consider, for example, ensuring a low staff turnover.	
Mencap	Short	27	3	Training for staff also needs to include: learning disability training mapped to the Learning Disability Core Standards Education and Training Framework from Health Education England for staff in dementia and medical services, and training for social care and general medical staff to have awareness in spotting the signs of dementia in people with a learning disability. CIPOLD (2013) identified dementia training as one of the most reported training needs for health and social care staff.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.

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				Carers of those with a high risk of developing dementia will also benefit from an increased awareness of this issue and symptoms to look out for, eg behavioural changes.	
Merck Sharp and Dohme	Short	General	General	MSD welcomes the opportunity to respond to this consultation. Given MSD's experience in this area, our response focuses on: • Increasing understanding of dementia and the diseases that cause it amongst healthcare professionals • The importance of NICE clinical guidelines keeping pace with clinical developments in dementia and Alzheimer's disease • The diagnosis of dementia and Alzheimer's disease • Laying the foundations for the early detection of Alzheimer's disease	Thank you for taking the time to comment on the guideline. Individual comments have been responded to where they appear.
Merck Sharp and Dohme	Short	4	7	MSD welcomes the recognition that new methods for diagnosing and assessing dementia have been developed. Both amyloid imaging techniques and cerebrospinal fluid examination represent reliable methods for diagnosing dementia and Alzheimer's disease. New developments in diagnosing Alzheimer's disease continue to be	Thank you for your comment. The committee agrees with the importance of evaluating the accuracy and effectiveness of newer diagnostic tests, and notes that future updates of the guideline should take account of any new evidence published in these areas.

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				made. For example, researchers presenting findings at the Alzheimer's Association International Conference 2017 demonstrated that a blood test could indicate the presence of amyloid in the brain indicative of Alzheimer's pathology.[ii] These developments, along with ongoing innovations in clinical practice and technology, mean that the National Health Service must ensure that it takes opportunities to combine new methods for diagnosing and assessing dementia and Alzheimer's disease with existing clinical practice to enhance the reliability of diagnostic criteria.	
Merck Sharp and Dohme	Short	7	14	MSD supports providing people with dementia, their family members or carers (as appropriate) with oral and written information on topics such as their legal rights and responsibilities, their right to reasonable adjustments (in line with the Equality Act 2010) and how to access local support groups and advocacy services. However, we recommend that, at the point of diagnosis, people should be asked if they are interested in taking part in research and healthcare professionals should share information on	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				research activities with people diagnosed with dementia, their family members and carers. Research is vital to improving the outcomes of people diagnosed with dementia in the UK and there is significant public appetite to participate in dementia research. A poll conducted by *YouGov* on behalf of Alzheimer's Research UK in 2015, found that almost two thirds (62%) of respondents would be willing to take part in dementia research, but more than four out of five people (81%) would not know how to volunteer.[iii] Recent years have seen progress in supporting people to access dementia research. Between 2012 and 2015, Government funding for dementia research doubled, to over £60m a year.[iv] Launched in 2014, Join Dementia Research (JDR) has played an important role in encouraging more people diagnosed with dementia to take part in research.[iii] To enhance recruitment to clinical trials in the UK it is vital that GPs, community pharmacies and memory clinics both ask people diagnosed with dementia if they would like to participate in research and provide information on opportunities to do so.	

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Merck Sharp and Dohme	Short	9	4	MSD welcomes advance care planning to offer early and ongoing opportunities for people living with dementia and people involved in their care to discuss the benefits of planning ahead and their values regarding their future care. As noted above, we contend that people living with dementia should discuss their interest in participating in dementia research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
Merck Sharp and Dohme	Short	9	24	MSD welcomes the recommendation to use a validated cognitive instrument when using cognitive testing. However MSD believes this list should either be exhaustive (e.g. it currently omits the Montreal Cognitive Assessment (MOCA)) or not include specific examples of cognitive tests. NHS staff should be fully trained to diagnose dementia using the appropriate cognitive tests in a timely and appropriate manner. In addition, new research diagnostic criteria, including the National Institute of Neurological Disorders and Stroke– Alzheimer's Disease and Related Disorders Association (NINCDS–ADRDA) criteria, the National Institute on Aging–	Thank you for your comment. The committee noted that the MOCA did not show any evidence of superior accuracy to the shorter tests recommended, and therefore agreed it was appropriate to recommend those tests that could be completed in a shorter amount of time, if they provided the same value at this stage of the diagnostic process. The full explanation is given in the "evidence to recommendation" section of the diagnostic chapter, and an extract of the relevant section is given below: "The committee also noted that more complex (and therefore time-consuming) tests did not appear to be more effective at detecting dementia than shorter and simpler tests, and it was therefore a more efficient use of resources to use these briefer tests within a time-constrained primary care setting."

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				Alzheimer's Association (NIA–AA) criteria, and the revised criteria of the International Working Group (IWG-2) offer the potential to combine cognitive assessment with biomarkers.[v] These approaches have the advantage not only of introducing biomarkers (discussed below) but also provide criteria for the diagnosis of prodromal Alzheimer's disease on the basis of symptoms and biomarkers or even on the basis of biomarkers alone. While these tests are not yet used in clinical practice, MSD supports efforts focused on developing new methods to diagnose dementia at an earlier stage of the disease. This is vital because future treatments are likely to deliver the greatest benefit to patients when initiated at the early stages of the disease and a diagnosis provides people with dementia with an opportunity to plan for their future care needs. To support the early diagnosis of dementia we suggest that NICE recommends that the diagnosis of dementia is integrated and aligned with Public Health England's *NHS Health Check* programme on dementia and clinicians are supported to understand the very early signs and symptoms of dementia and Alzheimer's disease.	The committee noted that there was considerable ongoing work around updated diagnostic criteria for various dementia subtypes, and that it would be appropriate to consider those newer criteria in future updates of the guideline.

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Merck Sharp and Dohme	Short	11	15	MSD welcomes the inclusion of examining cerebrospinal fluid, FDG-PET and perfusion SPECT as methods of diagnosing dementia. However, MSD contends that these methods should be promoted in suspected cases in combination with cognitive assessment rather than solely if the diagnosis of dementia is uncertain. Wider use of biomarkers can reduce misdiagnosis of dementia and Alzheimer's disease. Diagnosing dementia is complex with most clinical diagnoses made at the dementia stage.[iv] However, people with a clinical diagnosis of Alzheimer's disease, when followed to post mortem, do not always exhibit pathology associated with dementia and Alzheimer's disease. It has been suggested that around 20% of people may have been misclassified during their life.[iv] Alzheimer's disease is a progressive neurodegenerative disease that can manifest years before symptoms occur. At present, the standard methods for diagnosis of dementia are focused on diagnosing dementia between the mild and severe stage. Current testing practice doesn't support the early and timely diagnosis of dementia. As such, it is vital that biomarkers are	Thank you for your comment and your support for these recommendations. The committee fully agreed that all the information available on an individual should be considered when making a diagnosis, and that individual test results should never be considered in isolation. The committee noted the guideline does contain reference to a number of sets of clinical criteria that can be used to assist the diagnostic process. The committee agreed diagnostic uncertainty would refer to a situation where all the previous steps of the diagnostic pathway have been conducted and these criteria considered, and it is still not possible to make a confident diagnosis of a dementia subtype.

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				used in combination with cognitive tests to support the diagnosis of dementia during the earlier stages of the disease, when future treatments are likely to have the greatest impact.[ii] MSD would welcome clarity on what is meant clinically when a diagnosis is not certain of Alzheimer's disease. This paragraph seems to conflate Alzheimer's disease with Alzheimer's dementia and MSD would suggest a broader discussion around the distinction between diagnosing Alzheimer's dementia and Alzheimer's disease.	
Merck Sharp and Dohme	Short	11	28	Although analysis of Alzheimer's Disease Neuroimaging Initiative (ADNI) data showed that the diagnostic accuracy of the tau/Aß42 ratio was higher in the younger (<75) than in the older (>75) due to reduced specificity in older people, MSD notes that using a combination of biomarkers, may still show satisfactory sensitivity and specificity in older people.	Thank you for your comment. The committee agreed there was no clear age threshold above which biomarkers should not be used. However, they noted the evidence did show that the utility of CSF testing was lower in older people, and this was what led them to make a recommendation to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination will be."
Merck Sharp and Dohme	Short	12	24	MSD notes that the guideline states that case finding for suspected dementia should only be undertaken as part of a clinical trial that provides	Thank you for your comment. The committee agreed about the importance of access to an accurate and early diagnosis, but agreed this was different from implementing a system of active

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				an intervention to people diagnosed with dementia. While case finding for suspected dementia will not always be appropriate, MSD believes that people with dementia should be able to access diagnostic services. There are over 850,000 people currently living with dementia in the UK, many of whom who have not had a formal diagnosis of their condition.[vi] Alzheimer's Research UK estimate that the dementia diagnosis rate in the UK was 69% in 2015/16, with significant variation across the UK, which means that many people are unable to access post-diagnostic support and care to better support people living with dementia and help them learn to live well with dementia.[vii] Healthcare professionals should be supported to diagnose suspected dementia and identify the early signs and symptoms of the condition to ensure that people can access care and support. There may also be opportunities to align NHS Health Checks with new methods of diagnosis to ensure that those at a high risk of developing dementia are closely monitored for the very early signs of the condition.	case finding, which would need to have clear evidence of benefits to justify the costs of such an approach, which could otherwise be used to provide care for people with diagnosed dementia.

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Merck Sharp and Dohme	Short	27	3	Recent years have seen remarkable progress in increasing awareness and understanding of dementia amongst the public and healthcare professionals. Nevertheless, it is essential that healthcare professionals have an understanding of the pathology of dementia and Alzheimer's disease. The findings from a 2016/17 pilot project on dementia risk reduction, run in partnership between Public Health England (PHE), the Alzheimer's Society and Alzheimer's Research UK, have shown varying levels of knowledge among healthcare professionals.[viii] Some were knowledgeable, having worked with the elderly, while others had specialist experience of dementia or have previously undertaken training on the topic. However, others had limited knowledge on the topic and, similar to the general public, were surprised that lifestyle factors and changes to behaviours could reduce the risks of developing dementia. To enhance understanding of Alzheimer's disease and support the earlier diagnosis of the condition, MSD recommends that care and support providers should train healthcare professionals in	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.

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				the pathology of Alzheimer's disease, in addition to the signs and symptoms of the condition, to improve awareness of the very subtle changes associated with early Alzheimer's disease. In addition, MSD recommends that relevant NHS personnel should receive training on how and when to use cognitive assessments and other methods of diagnosis including FDG-PET and CSF.	
Merck Sharp and Dohme	Short	31	6	MSD welcomes the decision of the guideline committee to include a number of recommendations for research. MSD suggests that an additional research recommendation should be included on preparing for the early detection of dementia, including the use of new technologies and cognitive assessment. In 2015 the National Screening Committee concluded that it was not appropriate to introduce screening for dementia, highlighting the lack of biomarkers to identify those with, or at risk of, dementia, and the absence of effective early treatment for the condition.[ix] Nevertheless, it is imperative that the NHS is prepared to	Thank you for your comment. The committee agreed that the earlier detection of dementia was a relevant topic for future research, but agreed it was not as high a priority as the other recommendations included in the guideline. In particular, they noted that it was not currently clear which tools or tests should be prioritised for future research, and only when this became clearer would it be possible to make practical recommendations for future research.

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				support detection and early diagnosis, keeping pace with developments in diagnostic technology. As noted above, early detection of pathological changes in the brain is already a component of clinical trials of new treatments for Alzheimer's disease. The NHS should consider opportunities to better link risk factor identification to clinical trial recruitment so that more people can participate in initiatives such as Join Dementia Research.	
National Collaborating Centre for Mental Health	Full/Short	5	15	Relating to statutory and non-statutory guidance. NHS England has recently published an Implementation guide on dementia care, with supporting benchmarks. A longer document with shortly be published by the National Collaborating Centre for Mental Health. It may be worthwhile referencing this in statutory/ non-statutory guidance section. This is probably a discussion point that needs to happen with ?? Worthwhile to raise. https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf	Thank you for your comment and your support for the guideline. A reference to this implementation guide has been added to the introduction of the guideline, as suggested.

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				Apart from that good document – well done!	
National Community Hearing Association	Full	General	General	The NCHA welcomes this opportunity to provide feedback on this guideline. Our feedback is as follows: 1. We understand that review questions and search strategies explain the content of this NICE guideline. **2. We are however concerned that this guideline is inconsistent with other NICE guidelines, and that more could be done to minimise the risk of providers breaching the Equality Act 2010 by following this NICE guideline.** Our feedback below focusses on point two. • We agree, that *"**Common dementia mimics** in primary care include ….sensory impairments such as **hearing loss**"* (lines 19-20, page 43 Full Version) (our emphasis). In our view, a hearing test should therefore be a clear priority in this guideline. Especially given the prevalence of hearing loss (and its	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes the recommendations you quote on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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				severity) increases exponentially with age, and given that people aged 70 and older are more likely to have unmet hearing needs and be at greater risk of developing dementia. This was also the view of the committee developing the NICE draft Hearing loss in adults: assessment and management guideline. That NICE committee provided different recommendations for people with, or at risk of, dementia, stating ○ *"Consider referring adults with diagnosed or suspected dementia or mild cognitive impairment to an audiology service for a hearing assessment, because hearing loss is a comorbid condition"* ○ *"Consider referring adults with diagnosed dementia or mild cognitive impairment, without hearing loss, to an audiology service for a hearing assessment every 2 years."* **We would therefore ask NICE to consider more consistent guidance across its guidelines for the same population.**	

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				• We agree that the evidence supporting the use of hearing aids for people with dementia is limited and of low to moderate quality (Lines 27-32, page 399 Full Version). Although we understand the dementia subgroup might have different characteristics, this should not have resulted in hearing tests or hearing aids not being recommended in this guideline. For example, the NICE draft Hearing loss in adults: assessment and management guideline found that hearing aids are cost-effective for the general population with age-related hearing loss (Annex N of that guideline). It is unclear how ethics approval could be achieved to test the benefits of hearing aids in a population with dementia. The goal of hearing aids is not to try and reduce dementia progression, but to aid communication and reduce the risk of social isolation and depression, points which are covered in the draft Hearing loss in adults: assessment and management guideline.	

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				In fact, overlooking sensory support (hearing and sight) is likely to make life more difficult for service users and carers. There is also a clear duty for the NHS to meet individuals' communication needs and, given the prevalence of hearing and sight loss in people with dementia (largely due to age), it is unclear how a NICE guideline titled *"Dementia: assessment, management and support for people living with dementia and their carers"* would miss the opportunity to advance equality in this population. **The NHS Accessible Information Standard, Equality Act 2010 and NICE draft Hearing loss in adults: assessment and management guideline appear to conflict with this draft NICE guideline on dementia.** In our view, based on the above, **it is important for the Committee to re-consider the benefits of recommending that people with, or at risk of, dementia are referred for a hearing test. This can simply be the same recommendations as in the NICE draft**	

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				Hearing loss in adults: assessment and management guideline. We acknowledge that this draft guideline on dementia does make a weak reference to sensory support – for example. encouraging healthcare professionals to take sensory impairments into account when assessing the severity of dementia, and for them to receive training in giving multi-sensory stimulation for people with dementia and communication difficulties. They should be doing this already to comply with existing laws, but it does not happen as often as it should. The NICE committee on adult hearing loss understood this, and that informed their recommendations. Also, to be clear, this feedback is not to suggest there is evidence that hearing aids or spectacles reduce the rate of decline in people with dementia – to the best of our knowledge there is no robust data to support that claim. For example, a widely cited Lancet commission on dementia has identified hearing loss as a main modifiable risk factor for dementia, but the full paper explains there is a lack of evidence to support hearing aids modifying that risk. This is about ensuring people with dementia, or at risk of	

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				it, who might otherwise struggle to access services, have the opportunity to receive hearing and sight tests so they can see and hear as well as possible, and if not that their care package is adapted to reflect this. If the NICE committee can address this, it would help tackle existing inequalities in NHS and social care.	
National Federation of Women's Institutes	short	14	1	In contrast with the previous guideline which placed greater emphasis on the importance of good communication between carers, people living with dementia and healthcare professionals (page 8), this recommendation does not adequately reflect the role and value of carers of people with dementia as partners in care. NFWI research shows that unpaid carers are often heavily relied upon to speak on their loved ones behalf and relay important information about their health and care needs to medical staff. Only 30% of respondents to our survey of 221 carers said that hospital staff recognised and valued their role as a carer all or most of the time, highlighting the need to convey this more clearly in the guideline.	Thank you for your comment. The committee agreed with the importance of good communication, and noted this was included not just in the recommendatinos you mention, but also in the sections of the guideline on staff training, and support for informal carers.

Dementia: assessment, management and support for people living with dementia and their carers

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National Federation of Women's Institutes	short	14	6	Clarification is needed as to whether 'people' refers to patients, carers or both.	Thank you for your comment. This whole section refers to care coordination for the person living with dementia themselves. The committee did also look at evidence on case management for carers of people living with dementia, but agreed the evidence there was not sufficient to be able to make recommendations.
National Federation of Women's Institutes	Short	25	14	The NFWI is concerned that the recommendations do not fully take account of the experiences and support needs of unpaid carers when someone with dementia is admitted to hospital. To help ensure that carers receive the support they require during hospital admission, the NFWI would welcome the inclusion of guidance that reflects the benefits of the following to carers of people with dementia, people living with dementia and hospital staff: 1. Allowing carers to visit patients with dementia outside of normal visiting hours 2. The ability to book appointments so that carers can meet with nursing or medical staff caring for their loved one 3. The chance to complete a carer's survey	Thank you for your comment. The committee noted that the list of factors given here were only examples, and there were many other factors that would need to be taken in to account in individual cases. The specific examples on the list were chosen by the committee as those they agreed were likely to be the most common problems encountered. The committee noted that the large NIHR TEAM trial, if it had produced more positive results, could have led to a number of strong recommendations being made around how care in hospitals should be organised, and agreed it was unfortunate that meaningful benefits for people living with dementia were not identified in this study. The committee agreed that, given the results of this study, it was not possible to include any strong and definitive recommendations in this section.

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				4. The offer of a carer's passport 5. The opportunity to be shown around the ward and explained the hospital routine In 2017, the NFWI conducted research into dementia care and support for carers. An online survey was completed by 221 WI members and non-members, each with experience of caring for someone living with dementia who has spent time as an inpatient within the last five years. 18 telephone interviews were also held with survey respondents. Our research found that only 38% of respondents were able to visit their loved one outside of normal visiting hours and even fewer (26%) had unrestricted access. The most common reason provided by hospital staff was that it would have been disruptive to ward routines (20%) followed by a lack of space or the ward not been designed for it (17%). In total, 26% of respondents felt that their loved one was adversely affected because they were not allowed on the ward and involved in their care as much as they wanted to be. (This percentage is of 177 - the total number of valid responses for this question).	

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				The importance of flexible carer access was highlighted by many respondents who reported that their presence on the ward provided great comfort and reassurance to their loved one in what can be a very unfamiliar and disorientating environment. Flexible access also meant that carers were better able to fit visiting in around other commitments and had the option of being present, such as during meal times, to assist their loved one and hospital staff. Further, it enabled respondents to be more involved in decisions about care and treatment, the benefits of which are widely recognised by best practice guidelines such as the Triangle of Care developed by the Carers Trust and the Royal College of Nursing. When asked about the level of support they received or were offered as a carer, only a small proportion (10%) felt their own needs were recognised and met to the best of the hospital's ability. In addition, while each of the following is recognised by the Care Quality Commission as good practice only:	

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				- 25 respondents (11%) were able to book appointments to meet with the nursing or medical staff caring for their loved one; - 5 respondents (2%) reported that staff showed them around the ward and explained the hospital routine; and - 10 respondents (5%) were offered the chance to complete a carer's survey	
National Institute for Health research Clinical Research Network	Short	8	21	Insert prompt for healthcare professionals to refer patients and their carers to Join Dementia Research, which will enable them to be informed about opportunities to participate in relevant research and to be matched to relevant studies. Join Dementia Research is an initiative funded by the Department for Health and Social Care to help meet the Prime Minister's Challenge objectives on dementia for 2020. It is provided by the National Institute for Health Research, the research arm of the NHS. Diagnosis is a key moment in the course of someone's illness, where an invitation to participate in research is particularly important and most likely to generate a referral into a study. Feedback from patients	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				and carers has been positive in suggesting that participating in research has helped some patients develop a sense of independence, control, hope and wellbeing, as well as making a positive contribution to clinical research.	
National Institute for Health research Clinical Research Network	Short	15	15	Insert a prompt for healthcare professionals to consider appropriate research opportunities and support for patients and their carers to Join Dementia Research. Feedback from patients and carers has been positive in suggesting that participating in research has helped some patients develop a sense of independence, control, hope and wellbeing, as well as making a positive contribution to clinical research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to “tell people living with dementia (at all stages of the condition) about research studies they could participate in.”
National Institute for Health research Clinical Research Network	Short	25	28	Insert a prompt for healthcare professionals to consider appropriate research opportunities and support for patients and their carers to Join Dementia Research. Feedback from patients and carers has been positive in suggesting that participating in research has helped some patients develop a sense of independence, control, hope and wellbeing, as well as making a positive contribution to clinical research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to “tell people living with dementia (at all stages of the condition) about research studies they could participate in.”

Dementia: assessment, management and support for people living with dementia and their carers

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National Mental Capacity Forum Leadership Group	Short	General	General	Overall it is of great concern that the empowering and protective framework of the MCA is almost invisible within this draft. Examples are given below. This is inexplicable given the nature of the population being considered here: the deprivation of liberty safeguards, for example, are used far more to protect the rights of people with dementia than for any other group of people, yet restriction/restraint and deprivation of liberty are nowhere mentioned.	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to both the Mental Capacity Act and the Care Act within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
National Mental Capacity Forum Leadership Group	Short	9	3	**Advance care planning** This should explain that the MCA provides the way to make LPAs and ADRTs and the advantages.	Thank you for your comment. The committee agreed that the relevant legislation and how this impacted on decisions should be included as part of these discussions.
National Mental Capacity Forum Leadership Group	Short	12	25	**1.2.23 (clinical trials**) might add reference to the legal framework for research using people who lack capacity to consent to inclusion, see MCA code of practice chapter 11).	Thank you for your comment. The committee agreed the appropriate way to address these issues was via a cross-reference to the Mental Capacity Act and the Code of Practice, which are included in the guideline.
National Mental Capacity Forum Leadership Group	Short	13	22	**Care co-ordination**: this says 'give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the Mental Capacity Act 2005'. This is insufficient: MCA s.4 (best interests) outlines a mandatory checklist of factors to consider, which is far stronger than	Thank you for your comment. The committee agreed these issues were best addressed by the cross-reference in the guideline to the Mental Capacity Act and its accompanying Code of Practice, as well as a cross-reference to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).

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				implied here. Reference to IMCA service should include a reference to further information since some professionals may not know when an IMCA **must be instructed** by an NHS body or local authority decision-maker (rather than just 'be available').	
National Mental Capacity Forum Leadership Group	Short	19	Footnotes	**all footnotes** say 'informed consent should be obtained and documented.' Given the relevant population (people with Lewy Body dementia) this should add information on how to proceed within the MCA in the absence of capacity to consent. This kind of instruction, seemingly suggesting that only 'informed consent' has validity for authorising practice, leads to the unlawful practice of asking individuals who consider themselves to be 'next of kin' to sign authorising treatment	Thank you for your comment. The committee noted that throughout this guideline, issues around consent always interacted with those on capacity, and there was nothing unique in this respect about the situation of using medicines off-license. The guideline already contains a reference to the Mental Capacity Act (and the accompanying Code of Practice) to cover these issues.
National Mental Capacity Forum Leadership Group	Short	20	Footnote 6	See comment 5 above	Thank you for your comment. The committee noted that throughout this guideline, issues around consent always interacted with those on capacity, and there was nothing unique in this respect about the situation of using medicines off-license. The guideline already contains a reference to the Mental Capacity Act (and the accompanying Code of Practice) to cover these issues.

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National Mental Capacity Forum Leadership Group	Short	24	9	**1.10.2** should refer to best interests (plural) decision-making in accordance with the statutory checklist in MCA s.4, and the statutory guidance in the MCA code of practice chapter 5.	Thank you for your comment. The committee agreed these issues were best addressed by the cross-reference in the guideline to the Mental Capacity Act and its accompanying Code of Practice, as well as a cross-reference to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
National Mental Capacity Forum Leadership Group	Short	27	3	Staff in general require more than just training on the principles of the MCA: they have a statutory duty to 'have regard to' the MCA code of practice and work within the MCA e.g. in how they assess capacity and work out best interests. Additionally they must know how to recognise restraint as defined within the MCA, how to recognise and respond to situations where someone may be deprived of their liberty. These issues of restraint and deprivation of liberty apply overwhelmingly to older people with dementia (see most recent annual report on the deprivation of liberty safeguards by NHS digital; also the most recent annual CQC State of Care report.)	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to the Mental Capacity Act (and the accompanying Code of Practice) within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
National Mental Capacity Forum Leadership Group	Short	31	6	See comment 3: **1.2.23 (clinical trials**) might add reference to the legal framework for research using people who	Thank you for your comment. The committee agreed the Mental Capacity Act was a relevant issue in all situations where people do not have the capacity to consent to research, and that the appropriate way to address all issues around capacity

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				lack capacity to consent to inclusion, see MCA code of practice chapter 11).	was via a cross reference to the Mental Capacity Act and its accompanying Code of Practice within the guideline.
NHS England	Short			Might the committee consider saying that signing up to initiatives such as "Join Dementia Research" (https://www.joindementiaresearch.nihr.ac.uk/) would be a good way to encourage people into reseach.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
NHS England	Short	General	General	I would like to congratulate NICE and the committee for all their hard word into producing such an excellent guideline.	Thank you for your comment and your support for the guideline.
NHS England	Short	3-5		In the background it might be worth mentioning the numbers of people diagnosed with dementia and it seems a shame to simply infer this from a publication now 6 years old that dealt primarily with antipsychotic prescribing. The last figures from NHS Digital is that in December 2017 there were 456,739 people on GP registers as having a formal diagnosis of dementia, of whom 441,782 were over the age of 65. The estimated prevalence in that age group of 647,013 gives a national diagnosis rate of 68.3%. This compares to 2009/10 where there were some 290,000 people on the register with an estimated diagnosis rate of around 40%.	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years. Specifically: "Finally, in December 2017, there were 456,739 people on GP registers with a formal diagnosis on dementia, up from approximately 290,000 people in 2009/10, with the majority of this difference accounted for by an increase in diagnosis rates."

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				It would be good to reflect this to, I think, recognise the huge amount of work that has gone in to dementia from everyone around the country, not least members of the committee.	
NHS England	Short	3		A lot is talked about staff training – I think many people would regard this as a paternalistic and rather outdated way of describing "learning and education". It might be worth a note of explanation with regard to the devolved nations. Scotland, Northern Ireland and Wales have their own dementia plans and although the Prime Minister's Challenge 2020 is on behalf of the Prime Minister of the UK, and is certainly used as guidance for the devolved nations, it might be helpful to clarify this. Also, NICE Guidelines are used nationally and internationally, but there other guidelines used in the devolved nations that might be appropriate to make reference to this.	Thank you for your comment. The committee agreed to amend the heading of this section to training and education to address this point, but believed it was important to retain the word training as a key part of the recommendations. In common with all NICE guidance, decisions about whether and how to apply these recommendations in the developed regions are matters to be decided locally, as the guidelines are written solely for England.
NHS England	Short	6		The section on person centred care is very welcome and extremely important. As the committee knows the Alzheimer's Society /	Thank you for your comment, and for this information.

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				Dementia Action Alliance have produced a set of "We" statements which are an update of the original "I" statements and reference to these might be useful. The majority of practitioners are aware of these and they simply articulate good practice and recognise the rights and responsibilities of individuals.	
NHS England	Short	7	1.1.2	I think the use of the term "simplify" text is somewhat patronising in that it suggests that people with dementia need things produced in a simple way – in many ways this is the antithesis to person centred care and I am sure the committee will find, if they are minded, a better and less patronising word for this.	Thank you for your comment. The committee discussed this wording and agreed that the current wording is clear and unambiguous, and should therefore be retained. They agreed that the use of clear and simple text was not patronising, but a basic part of good information provision that should be applied more widely across the healthcare system.
NHS England	Short	9	1.1.11	It is open to debate as to when is the right time to offer advice on advance care planning and guidance. I think perhaps the word "timely" rather than "early" would be better as most practitioners would agree that it can sometimes be too early to provide information on advance care planning e.g. at the first clinic appointment.	Thank you for your comment. The committee discussed this issue and agreed there was an important balance between early opportunities to discuss advance care planning, and not introducing it at an inappropriate stage. The committee stressed that early did not necessarily mean at the first opportunity or first appointment. However, they did also note the evidence showed staff were often reluctant to initiate these discussions, and people often wanted to have these conversation before they are currently offered them. They therefore agreed "early" was the

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					appropriate word to use, and noted that since the recommendation was phrased as "offer", there would be nothing to stop an individual deciding it was earlier than they wanted to start these conversations, and that it would then be appropriate to offer additional opportunities to discuss at a later date.
NHS England	Short	9	1.2.2	Probably one of the commonest diagnostic tests is the GP Cog and it would be appropriate to mention this. The committee make reference to case finding and PHE's screening committee have said, quite rightly, that screening is not appropriate and yet, three of the six tests suggest that it is a screen. Also, it may be that practitioners are not used the three of the six tests and the test your memory is a self-administered rather than a clinician administered test.	Thank you for your comment. The committee were aware of the use of the GPCOG in practice. However, they noted that the GPCOG has only been tested as a screening test, and no evidence currently exists on the accuracy of the test in a population of people with suspected dementia. The committee noted that studies are likely to find better diagnostic accuracy in an unselected population than one with suspected dementia (as many people in the study will have no cognitive impairment, and therefore will be easily classified by the test), and therefore agreed it was appropriate to recommend only those tests shown to have sufficiently good properties in the relevant population. The committee noted that although there were differences between the six tests recommended (whether or not they were initially designed as screening tests, self-administered versus clinician-administered) they all showed sufficiently good diagnostic accuracy to be useful tools in guiding referral decisions in primary care.
NHS England	Short	10	1.2.6	I think it is an important point to make that not everybody with suspected dementia needs to be	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft

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				referred to a specialist dementia diagnostic service. There are very good examples where the diagnosis can be made in primary care by a GP who knows the person well. For example, an elderly person who has been a long-time resident of a care home who has developed some cognitive impairment in whom the GP has done all the various tests is a situation where it would be clinically inappropriate for that person to be removed and taken to a memory service and subjected to an MRI scan. I have sent examples of this to Harry Allen some time ago. This would be counter to good clinical practice. Many colleagues in Primary Care are able to make a diagnosis and can use the advice of support of specialist memory services without a formal referral being made – perhaps it is the word "refer" that could be amended to reflect the breaking down of barriers between primary and secondary care which is to the benefit of people with dementia and their families.	guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
NHS England	Short	10	1.2.8	Many people reading the guidance will not know what a verbal episodic memory test is – giving an example would be helpful.	Thank you for your comment. The committee agreed it was appropriate to keep the phrase "verbal episodic memory" as the most specific and accurate term available, but agreed the evidence was not sufficient to recommend one specific test over the others. However, they did agree it was appropriate to

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					add a definition of this to the guideline to ensure there was no misunderstanding of what was meant.
NHS England	Short	10	1.2.9	In previous NICE guidance it has been suggested that a brain scan is not necessarily in established disease and reflecting this here +would be useful.	Thank you for your comment. The committee agreed with this suggestion and an additional note has been added to the recommendation to "be aware that structural imaging is not always needed, if dementia is well established and the subtype diagnosis is clear."
NHS England	Short	11	1.2.11	I would have thought reference to the generally approved diagnostic criteria such as the International Classification of Diseases (ICD) might be more useful for clinicians rather than going into the very specialist diagnostic criteria, which are often used for research.	Thank you for your comment. The committee noted the ICD codes for dementia where now out of date in a number of areas, and agreed it was important to reference more up to date criteria to guide diagnosis. However, they did agree it may well be appropriate to consider adding reference to the ICD11 criteria in future updates of the guidance, when these are finalised.
NHS England	Short	11	1.2.12	Going straight to detailed Cerebrospinal Fluid (CSF) examination or a PET scan seems clinically very inappropriate and the remarkable statement that "if one does not work try the other one" will, in untutored hands, cause a great deal of unnecessary upset for patients and their families. Someone reading this might think that a person in their mid-eighties who has mild loss of memory and in whom the diagnosis of Alzheimer's disease or mild cognitive impairment is uncertain should have a CSF examination and, if this does not give	Thank you for your comment. The committee noted that the 'consider' recommendations for CSF examination and imaging came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF and imaging earlier in the diagnostic pathway, and to counter that conception agreed it

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				a diagnosis should then have a PET scan, I would have thought some sort of phrase covering this would be important and I suspect that the use of the work "consider" gives this much more traction than is justified. To have the same number of pages talking in great detail about brain scans as it does for the section on person centred care, gives the wrong impression.	was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed this should address any concerns about the guideline advocating a sudden expansion in the use of complex diagnostic tests, or their use in determining if someone has dementia at all, rather than to support subtyping.
NHS England	Short	12	1.2.2 3	It is important to note that national initiatives for raising awareness of dementia care	Thank you for your comment. The committee noted that this recommendation focused solely on case finding in a population with no clinical suspicion of dementia, and agreed that generally raising awareness of dementia among health and social care professionals was a fundamentally different and important issue. The committee were also aware of specific policy initiatives (such as the dementia CQUIN) and it has been made clear within the guideline that this recommendation is not meant to affect the interpretation of that pre-existing policy.
NHS England	Short	13	1.2.2 7	Using some less traditional language of "refer" "and multidisciplinary" phrases feels outdated and taking advice from dementia advisors who can be based at primary care seems to be appropriate. Reference should be made to the current review of the Mental Health Act and the	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in

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				implications that will have in terms of capacity would be important.	dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment." A cross-reference has now also been added to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018), which the committee agreed was the appropriate place for issues around the Mental Health Act to be considered.
NHS England	Short	14	1.3.6	I would have thought some reference for marginalised group would be appropriate.	Thank you for your comment. The committee agreed there were particular issues around a number of marginalised groups, both in terms of the general difficulties these groups

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					have in accessing healthcare, and specific issues in relation to care from dementia. The committee noted that no specific evidence was found to enable recommendations on how care should be tailored to best meet the needs of this group, but agreed the recommendations on making care accessible to as many groups as possible and tailoring information and interventions to the individuals needs and preferences were relevant to this issue, as were the references in the guideline to relevant pieces of legislation, including the Equality Act. The committee agreed that it was not appropriate to try and write an exhaustive list of all the groups who special attention would be needed for, as this risked making it seem that any group not mentioned did not have these needs, but noted that all groups covered by the Equality Act would necessarily have to be considered to see if additional or modified support was required.
NHS England	Short	15	1.4	It is very helpful to have clear guidance on the things not to give - reference to aromatherapy would be helpful.	Thank you for your comment. The committee agreed it was appropriate to make “do not offer” recommendations in areas where there was no evidence of benefit from interventions. For aromatherapy, whilst the evidence base was limited, there was some evidence of potential benefits on agitation in people with severe dementia. The committee agreed this evidence was not sufficient to make a positive recommendation, but also that it was not appropriate to make a negative

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					recommendation when there is some evidence there may be potential benefits.
NHS England	Short	15	1.4.7	A definition of interpersonal therapies would be useful as there is some evidence that psychotherapy can help people with early Alzheimer's disease.	Thank you for your comment. A definition has been added to the guideline, and the committee were keen to stress this was a recommendation not to use interpersonal therapy to treat the cognitive symptoms of Alzheimer's disease. If people living with dementia had another condition for which interpersonal therapy were indicated, the committee agreed it would be correct to offer them to people living with dementia in the same way as those without.
NHS England	Short	16	1.5.4	It is a great advance to say that one of the anti-Alzheimer drugs can be prescribed by people other than specialists.	Thank you for your comment and your support for this recommendation.
NHS England	Short	27	1.13	It might be helpful to refer to the core competencies for dementia care enshrined in the Health Education England documentation. https://www.hee.nhs.uk/sites/default/files/documents/Care%20Navigation%20Competency%20Framework_FINAL.pdf	Thank you for your comment. The committee noted the existence of tis (and other) HEE framework documents that could be useful in dementia, but agreed it would not be appropriate to pick out 1 or 2 of these to refer to over and above other advice on training and competencies.
NHS Leeds North CCG	Short	20-22	all of 1.7	There's no reference to other medication that may be used in distress & agitation, eg. benzodiazepines.	Thank you for your comment. The committee noted that no evidence was identified on the use of these other medicines for managing non-cognitive symptoms, and therefore it was not possible to include them in the recommendations.
NHS Leeds North CCG	Short	31-33	all	Recommendations for Research. Suggest we add management of Type 1 diabetes in dementia (see Comment 19)	Thank you for your comment. The committee noted the guideline does contain a research recommendation around the

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					management of diabetes (both type 1 and type 2) in people living with dementia.
NHS Leeds North CCG	Short	31-33	all	Recommendations for Research. Suggest we add "advance care planning - developing and evaluating approaches which enable meaningful conversations with people with dementia, and effective recording and decision-making as a result. Ref. comment 7 above.	Thank you for your comment. The committee noted this suggestion, but agreed it was not as high a priority for future research as those recommendations contained in the guideline.
NHS Leeds North CCG	Short	31-33	all	Recommendations for research: Experience of memory clinics run by specialists in community and primary care settings: local experience, and reports on Gnosall model, suggests high satisfaction and low rates of "did not attend" when people can come to eg. a local GP rather than a specialist outpatient setting.	Thank you for your comment. The committee noted this suggestion, but agreed it was not as high a priority for future research as those recommendations contained in the guideline.
NHS Leeds North CCG	Short	27-28	all of 1.13	Health Education England and Skills For Care both explicitly reference "Leadership In Dementia Care" as an important area for training. Propose that we consider including this.	Thank you for your comment. The committee agreed the guideline did contain a substantial section on staff training, and that because of the large number of people and consequent high cost of staff training in dementia, it was important to keep these recommendations focused on things for which there was clear evidence of benefit.
NHS Leeds North CCG	Short	5-6	28ff	Surely the Human Rights Act should be on the list ?	Thank you for your comment. The committee agreed with this suggestion and the Human Rights Act has been added to the list of relevant legislation in the introduction to the recommendations.

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NHS Leeds North CCG	Short	3	13-14	The Alzheimers Society estimates of the numbers of people with dementia are different to NHS England estimates. The concern is that the Alzheimers Society use an inaccurate methodology, in that constant estimates of dementia risk for each age group are applied to ONS population projections. Whereas research evidence all points to dementia risk decreasing over time, therefore dementia prevalence is likely to increase more slowly than suggested by population projections. See eg. http://www.bmj.com/content/358/bmj.j2856 Although this is preamble rather than recommendation, it seems important to apply the evidence base critically from the start, for the credibility of the guideline.	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years. The committee agreed that in a condition where there is still considerable under-diagnosis, accurate prevalence estimates were hard to achieve.
NHS Leeds North CCG	Short	3	16-17	The evidence about new diagnoses in 2011 and the increase in new diagnoses reflects success at improving diagnosis. However, in the context of the preceding lines we seem to be conflating this with demographic increase.	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years.
NHS Leeds North CCG	Short	6	8ff	Two sets of guidance applicable in England: Dementia: Good Care Planning (NHS England, 2016) Implementation Guide and Resource Pack for Dementia (NHS England, 2016)	Thank you for your comment. These resources have been linked to as suggested, since they were agreed by the committee to be relevant to a large number of people involved in delivering care and support for people living dementia.

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NHS Leeds North CCG	Short	7	7ff	Concern that involvement in decisions and attempts at person-centred care often lead carers and staff to fire questions at people, which can be stressful for people with dementia and cause agitation. The basis of SPECAL and other communication training is to avoid direct questions and use open conversation methods instead. Would the evidence base support advice on this point ?	Thank you for your comment. The committee noted this concern, and agreed appropriate training was key to managing these interactions well. In response to this and other feedback, the committee agreed to add training in "adapting communication styles" to the section of the guideline on staff training and education.
NHS Leeds North CCG	Short	8	27-29	Surely this is a matter of professional skill and practice, include a best-interests judgement, about how to maintain some form of contact with a vulnerable person who at that moment may be struggling with the diagnosis. The draft reads as a very black-and-white matter that seems to allow us to let people go who really need support.	Thank you for your comment. The committee agreed that whilst the situation would be different in people lacking capacity, those with capacity had the right to decline services and follow-up if they so wished, and therefore the important issues were that people were offered future follow-up and contacts, and that there was a clear route for people back in to services when they wanted/needed it.
NHS Leeds North CCG	Short	9	3ff	I like the idea, but I don't think we've got to the heart of how to approach this honestly and sympathetically with people, or how to capture and record the things people say when they want to talk. The concern is that this list will encourage a 'checklist' approach to care reviews.	Thank you for your comment. The committee noted this concern, and agreed it was not possible at present to provide specific recommendations on how these conversation can best be conducted. However, they did note the evidence was clear that many people living with dementia wanted to have these conversations at an early stage in the process.
NHS Leeds North CCG	Short	10	25-26	a) Structural imaging can inform diagnosis of sub-type, not just rule out other causes. Imaging may also find tumours / lesions as well as reversible causes ?	Thank you for your comment. The committee agreed with this suggestion, and the recommendation on structural imaging has been changed to "rule out reversible causes of cognitive decline and to assist with subtype diagnosis"

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NHS Leeds North CCG	Short	12	20-21	In Leeds, we ask GPs referring to Memory Service to request a CT head scan (unless contra-indicated); the CT scan is cheaper than MRI, short and well-tolerated (MRI is longer and more stressful going in a noisy tunnel). We have a Dept of Health mandate to the NHS of 6 weeks from referral to treatment, and the concern is that this draft guidance introduces additional waiting steps after the referral to Memory Service, if scan type isn't decided until afterwards. This guidance has been produced by clinicians in the Yorkshire & Humber region and recommends a CT scan is requested at an early stage, and that it can be used in Alzheimers Disease as well as vascular dementia. http://www.yhscn.nhs.uk/media/PDFs/mhdn/NeuroimagingGuidance2015.pdf	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
NHS Leeds North CCG	Short	12	24ff	I agree that there is no case for whole-population 'case-finding', but are we also ruling out case-finding within an at-risk cohort ? Eg. people over 75 with an acute hospital admission ? The term seems ambiguous.	Thank you for your comment. A definition of case finding has been added to the guideline to address this confusion.

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NHS Leeds North CCG	Short	13	12-21	I disagree with the approach of specialist services for the review of dementia after diagnosis, and I'm doubtful what the actual evidence is for this approach – I see a study from the Netherlands compares specialist review v primary care, but surely this depends on the quality offered by primary care ? Most people with dementia have comorbid long-term conditions, and a specialist service detracts from a holistic approach to living well with the various challenges. Specialist care is also more stigmatising. Please note also that the NHS England guidance, "Dementia: Good Care Planning" locates the responsibility for review very much with primary care. We have to be careful how evidence is interpreted, and consider the make up of the NICE committee who quite rightly are dementia-focused, and balance this against the holistic approach to long-term conditions which I believe also has an emerging evidence base ? Of course timely access to specialists is important.	Thank you for your comment. The committee agreed that review could be carried out in primary care, and noted this was included as an option in the recommendation. However, they noted that if this was to be the case, it would be important for the primary care service to include/have access to the appropriate multidisciplinary support that people living with dementia are likely to need.
NHS Leeds North CCG	Short	13	22ff	We should not use the term "care co-ordination" or "care co-ordinator" at this stage because it is ambiguous. To mental health services it suggests the role which is allocated under the Care	Thank you for your comment. The committee agreed that both terms were currently in use, but that at the moment "care coordinator" was the more commonly understood term, and

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				Programme Approach, which is not needed universally, but in complex, riskier, instances. "Care Navigator" is much more relevant as a universal post-diagnosis provision. We introduced the 'care co-ordinator' term in Quality Standard QS1, it was a mistake then and we can put it right now.	therefore agreed this was the one that should be used in the guideline.
NHS Leeds North CCG	Short	14	25ff	Accessibility to services should include: people who do not have a recorded diagnosis because eg. they are reluctant to seek it, but nevertheless would benefit from services and may be supported towards seeking diagnosis. Any exclusion criteria based on a requirement for recorded diagnosis should have clear, specific justification.	Thank you for your comment. The committee agreed that there was no evidence identified within the guideline that would enable them to make recommendations, but agreed this was a relevant issue. As noted within the committee's discussion of the evidence for the diagnostic section; "the committee commented that it was also important to consider situations where a patient may not want a referral for an assessment/diagnosis, and the potential disadvantageous outcomes that might result from this choice (e.g. problems with obtaining support, care and treatment)."
NHS Leeds North CCG	Short	17	18-27	There is huge variation in prescribing costs for special preparations of AChEIs and memantine, and advice could be included along the lines of a document (link below) prepared by colleagues in Yorkshire and Humber region. Some of the variations are illogical / inexplicable, eg. orodispersible Donepezil in the sugar-free version was one-tenth the price of the sugary version, at	Thank you for your comment. The committee agreed that it was a matter for local areas to ensure they obtained necessary medicines at the lowest possible price, and did not feel it appropriate to reference specific pricing material within the guideline, due to the risk of it quickly becoming out of date.

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				the time my colleagues wrote the advice: www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/DES/Cost%20of%20drugs%20for%20treatment%20of%20Alzheimers%20Disease%2010.7.16.pdf	
NHS Leeds North CCG	Short	17	14-17	Local policy in Leeds on AChEIs is more explicit than this, that the medications do not require specialist review. Previous NICE guidance has required specialist review and looked to discontinue prescribing as dementia progressed. This has led to Memory Services capacity being used for medication reviews rather than timely diagnosis; and other more holistic elements of support going disproportionately to people with dementia medication (and people with eg. vascular dementia being discharged quickly from follow-up). Therefore please consider making a more explicit recommendation, that review and ongoing prescribing can in primary care without specilaist advice.	Thank you for your comment. The committee noted that once the first prescription of cholinesterase inhibitor or memantine has been made in primary care, monitoring would also take place within that setting.
NHS Leeds North CCG	Short	20	21-23	I agree in principle with para 1.7.1, that the first questions must always be around possible causes of behaviour, and not assuming it is a 'symptom of dementia'. However, it doesn't address in practice the need for carers / care staff to be able to protect the person with dementia and those around them, whilst a difficult situation with	Thank you for your comment. The committee noted that no evidence was identified around the use of interventions to manage severe and urgent non-cognitive symptoms, and therefore agreed they were not able to make recommendations on this in the guideline.

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				agitation and aggression is managed. Could any further recommendations be offered to explicitly addresses the situation where prescribing is being considered as an urgent & interim step ?	
NHS Leeds North CCG	Short	20	21-23	Anecdotally, I have been told of incidents where a dementia specialist clinician (correctly) identified delirium as a possible cause of agitation & distress that had to be investigated; but, they did not go about this in a helpful way. Instead of discussing with the GP and working up an MDT approach, they told the carer to ring the GP. Would it be helpful to clarify that investigating clinical causes should be done in parallel with managing the presenting situation and requires a multi-disciplinary approach and not 'handing off' ?	Thank you for your comment. The committee noted these concerns, but agreed that in the absence of evidence, it was not possible to make any more detailed recommendations than those currently included in the guideline.
NHS Leeds North CCG	Short	22	4-9	In one engagement / consultation exercise, the CCG found one carer who was unhappy that 'their' person with dementia had been given electro-convulsive therapy; and a further example where the carer sought a second opinion after a doctor had recommended ECT. They were concerned that there had been misdiagnosis and inappropriate treatment. Neither this draft guideline, nor the NICE guideline on depression, covers the use of ECT in dementia – though the depression guideline does cover the monitoring	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified for elector-convulsive therapy, it was not possible to make recommendations on this topic within the guideline.

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				of cognitive impairment which may be caused by ECT. Therefore proposed that this issue should be explicitly covered in a way that gives consistency and appropriate cross-referencing between the two guidelines.	
NHS Leeds North CCG	Short	23	20-22	There is no guidance re. dementia and management of Type 1 diabetes. I appreciate that not every co-morbidity can be covered, but this is likely to be a prevalent one given progress in diabetes care, survival into old age and risk of long-term vascular complications. People with Type 1 will typically have many decades experience of self-management with a lot of nuance and individual understanding re. early warnings of hypoglycaemia, what and when to snack, managing exercise and activity and so on. Continuous glucose monitoring is getting cheaper and offers a way of promoting positive risk-taking, if a carer knows that eg. a hypo would set off an alert. If nothing else, this could be included as an area for research ?	Thank you for your comment. The committee agreed that in the absence of evidence that people living with dementia should be treated differently for type 1 diabetes, this would be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." The committee noted the guideline did include a research recommendation on the management of diabetes (both type 1 and type 2) in people living with dementia.

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NHS Leeds North CCG	Short	24	2-4	risks on admission to hospital also include the risks of a prolonged length of stay and severe decline in functioning. Recommendations could include: awareness of disorientation and busy environment causing distress; need to promote meaningful activity and assess needs for support with eating, drinking and medication; reference to John's Campaign; consideration of high quality holistic assessment to enable discharge planning.	Thank you for your comment. The committee noted that the list of factors given here were only examples, and there were many other factors that would need to be taken in to account in individual cases. The specific examples on the list were chosen by the committee as those they agreed were likely to be the most common problems encountered.
NHS Leeds North CCG	Short	26	1-9	Propose that support for carers should include "steps to avoid taking over the life of the person with dementia, and enabling the independence of the person as much as possible". This is anecdotal, but I've been really struck by Wendy Mitchell's approach in her new book ("Somebody I Used To Know") to carry on living alone and what she feels are the advantages of not taking up her daughters' offers to live with them.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included this as a defined aspect of training.
NHS Leeds North CCG	Short	27	4-12	Could we explicitly include *communication skills* to work with people with dementia, as something that all staff should have training on.	Thank you for your comment. The committee agreed with this suggestion, and training in "adapting communication styles" has been added to this section.
NHS Leeds North CCG	General	general	general	in response to the above question: "Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why ?"	Thank you for our comment. The committee noted all the challenges mentioned, and had the following comments: 1) Recommendations for particular diagnostic test were based on the evidence for their accuracy, and the committee agreed it was for local areas to decide how to organise their particular

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				- The recommendations at 1.2 seem at odds with the NHS England guidance "Implementation Guide and Resource Pack for Dementia". If GPs should wait for blood test results to come back to rule out reversible causes (1.2.6), and structural imaging / scans should be requested after the person is seen in specialist clinic (pp10-12) then we won't be able to diagnose within 6 weeks, without investment in / development of very quick turnarounds to blood tests and scans. - Bringing the social care workforce up to the training and skills standards is both costly and complex, given the low pay and turnover in the sector, and local authority standard fees not covering staff time to be released for training. Putting the guideline into practice for post-diagnosis review will be challenging. I believe this should be in primary care (comment above), but regardless of which service carries it out it will be	pathway. In particular, they noted the 6 week time was from referral to diagnosis, and not from initial presentation to diagnosis, so timings around blood tests, if carried out in primary care before a referral, should not affect those timescales. 2) The committee agreed there would be costs around staff training, but noted the evidence was clear this was a highly effective intervention for improving the care and experience of people living with dementia. 3) The committee agreed it could not make specific recommendations around how or where post-diagnostic support should be organised, but that it was important people had access to a multidisciplinary team who can provide appropriate information and support.

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				a challenge for cost and current recruitment situation.	
NHS Leeds North CCG	General	general	general	in response to the above question: "Would implementation of any of the draft recommendations have significant cost implications ?" - Care co-ordination: this would be very expensive as a universal post-diagnosis offer if it implies a qualified practitioner equivalent to Care Programme Approach. A "care navigator" would be appropriate, combined with ready access to specialist clinician, and still have significant cost implications, depending on the extent to which each locality has developed this. - See above re. response times for blood tests and scans. I really don't think we can justify treating requests for tests / scans for dementia on an "urgent" timescale, but a 1-2 week timescale would make sense. Current non-urgent standard is 6 weeks. - Bringing the social care workforce up to the training and skills standards is both costly and complex, given the low pay and turnover in the sector, and local	Thank you for your comment. The committee noted there would be costs associated with care coordination, but that there was clear evidence this was an effective intervention to improve care for people living with dementia. The committee agreed there would be costs around staff training, but noted the evidence was clear this was a highly effective intervention for improving the care and experience of people living with dementia. The committee agreed it could not make specific recommendations around how or where post-diagnostic support should be organised, but that it was important people had access to a multidisciplinary team who can provide appropriate information and support.

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				authority standard fees not covering staff time to be released for training. Putting the guideline into practice for post-diagnosis review will be challenging. I believe this should be in primary care (comment above), but regardless of which service carries it out it will be a challenge for cost and current recruitment situation.	
NHS Leeds North CCG	General	general	general	in response to the above question: "What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)" - "Users" is ambiguous given the habits of professionals in referring to people - I assume that here, it means people using this guideline, rather than people with dementia using services ? - Consider avoiding / reducing the recommendations about who should provide particular services – specialist or primary care. This is an emerging area for practice and research and the main thing is what happens in the service, not who is providing it.	Thank you for your comment. The committee agreed there was considerable change currently ongoing around who should provide which services and in what settings, and agreed that it was only appropriate to make reference to particular settings or providers when there was clear evidence that was the most appropriate approach.

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NHS South Gloucestershire CCG	Full	General	general	My main comment is that the guidelines appear out of touch with what is happening on the ground, and in particular do not acknowledge that primary care diagnosis can be safe and appropriate in the frail elderly. This is a very disappointing missed opportunity which will lead to these updated guidelines being as widely ignored as the previous one was. A Primary care focus would have made the updated guidelines hugely more relevant (eg a reference to DiADeM, endorsed by AS) I support the work NICE does but this trend makes its advice increasingly irrelevant to professionals.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
NIHR Nottingham Biomedical Research Centre	Short	7	10	As above. Please specify that devices such as hearing aids, remote microphones and other assistive listening devices, would provide a means to modify communication by making speech	Thank you for your comment. The committee agreed that the appropriate management of identified hearing loss should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics,

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				audible. See Ferguson et al 2017 Cochrane review on hearing aids.	treatments and care services for comorbidities to people who do not have dementia."
NIHR Nottingham Biomedical Research Centre	Short	9	17	Hearing loss is a significant co-morbidity of dementia and can affect diagnosis of Pwd. More than 70% of PwD have hearing loss. A number of the recommendations regarding diagnosis will require the PwD to be able to hear (e.g. 1.2.1 to 1.2.4, 1.2.8). For example taking a history or filling in a questionnaire. There should be some note that if the PwD has a hearing loss, then the hearing loss should be managed with a device (eg. hearing aid, remote microphone, assistive listening devices). In addition, it should be stated that effective communication strategies are used by the person speaking to the PwD (see examples https://www.chs.ca/communication-tips-0).	Thank you for your comment. The committee noted this point, and agreed it was appropriate to include a cross-reference to the NICE guideline on hearing loss to address these issues.
NIHR Nottingham Biomedical Research Centre	Short	15	9	Hearing loss is a significant co-morbidity of dementia and can affect management of PwD. Here, group activities are recommended. However, if the PwD cannot hear what is going on during the group activity they will not be able to fully participate. The result will be withdrawing from the situation, which can lead to psychosocial consequences and mental health problems (see Heffernan et al Int J Audiol 2016). Appropriate management of hearing loss (e.g. hearing aids)	Thank you for your comment. The committee noted this point, and agreed it was appropriate to include a cross-reference to the NICE guideline on hearing loss to address these issues.

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				will help improve audibility. Although the one study on hearing loss in PwAD did not show any effect of hearing aids to improve cognition per se, the patient's hearing will have been improved. A recent Cochrane Review on Hearing Aids has shown that hearing aids are effective at improving listening, hearing- and health-related quality of life (Ferguson et al, Cochrane, 2017). Furthermore, hearing loss is significantly related to dementia (see Lin et al JAMA 2011).	
NIHR Nottingham Biomedical Research Centre	Short	22	17	Any reason why hearing loss is not listed as a long-term condition in PwD? NICE guidelines for hearing loss are currently under development, and will be published in May 2018. In these guidelines there are numerous places where dementia is listed and one of the research recommendations is to assess prevalence in people who under-present for Hearing loss (Appendix Q pg 482, Q1); and use of hearing aids in dementia (appendix Q pg 483 Q2). Given there are NICE guidelines on hearing loss that refer to dementia, it would seem appropriate for these dementia guidelines to refer to hearing loss. https://www.nice.org.uk/guidance/gid-cgwave0833/documents/guideline-appendices-2	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics,

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					treatments and care services for comorbidities to people who do not have dementia"
NIHR Nottingham Biomedical Research Centre	Short	28	3	It would be appropriate hear to specifically mention hearing loss and how this can be managed with devices. This is not mentioned in the full guidelines or the LETRs when referring to MSS (e.g. hearing aids, remote microphones and other assistive listening devices).	Thank you for your comment. The committee discussed this issue but agreed that, in the absence of any evidence, it was not possible to include this within the recommendations.
NIHR Nottingham Biomedical Research Centre	Full	General	general	Communication is mentioned 61 times and within the second line of the Context. Clearly communication is important. However, these guidelines fail to address how communication can be improved by improving audibility of speech of others talking to PwD through the use of device or effective communication strategies. This is a clear omission. Furthermore, training healthcare staff to be more aware of hearing loss and its effects and how to manage hearing loss would have a significant impact on patient outcomes. In my own experience as a hearing researcher and clinician of talking to a several hundred HCPs who work with PwD, their knowledge of the impact that hearing loss has on communication and therefore many facets of PwD's lives, is often poor. However, just raising awareness of the impact of hearing loss can result in a real	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia"

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				improvement in understanding how important hearing is on communication. These guidelines could serve to do just this (i.e raising awareness of the impact of hearing loss). The benefits to PwD and their family members and carers could be substantial.	
NIHR Nottingham Biomedical Research Centre	Full	10	3	Communication is listed as one of the main symptoms of dementia in the initial setting of the context. To be able to communicate well it is important for the PwD to be able to hear others who are talking to them. However, ability to hear or the management of hearing loss is rarely mentioned (hearing as part of 'hearing loss' or 'hearing aids' is mentioned only 13 times in the whole document). Has the committee considered the impact of hearing loss more broadly in the treatment and management of PwD? We suggest that the role of hearing on communication receives some attention. This would include healthcare professionals as well as family members and carers.	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia"
NIHR Nottingham Biomedical Research Centre	Full	43	20	In the diagnosis of dementia (section 5) it is encouraging to see that the guidelines recognise that dementia may mimic hearing loss. However,	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss,

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				there is no indication anywhere as to how PwD should be rerferred to specialist audiology services or how and when HCPs can or should test/screen for hearing loss. This should be included in the guidelines.	which makes recommendations on hearing assessments for people with suspected and diagnosed dementia.
Norfolk and Suffolk NHS Foundation Trust	Short	15	9, 10, 11	This recommendation shows a significant shift in language from the previous NICE guidelines, despite further evidence since the previous guidance for the effectiveness of Cognitive Stimulation Therapy (CST). Also, there is no evidence to suggest that "elements" of cognitive stimulation and reminiscence therapy is effective. The vast majority of positive evidence is for structured CST, following a manualised approach. The wording in the draft guidelines is going to lead to increased difficulty with offering our patients alternatives to medication and undermine attempts to advocate for non-pharmacological approaches alongside medication and is very concerning. It seems to be based on a misunderstanding and misinterpretation of the evidence base for CST. Furthermore, the manualised CST programme works very well in community services, where staff are keen to have structured guidance in	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				delivering groups, rather than needing to create their own interventions from scratch.	
Norfolk and Suffolk NHS Foundation Trust	Full	277	37	This section considers the economic analysis of CST, but uses a base case model, rather than published health economic studies. There have been 2 key papers published considering the cost effectiveness of manualised CST (Knapp et al, 2006 which considered CST; D'Amico et al, 2015 which considered maintenance CST). Both are listed in the references in Appendix J, but only D'Amico et al (2015) has been considered in the evidence. These papers show strong evidence for the cost effectiveness of manualised CST and it is important for the Knapp paper to be used, rather than a base case model (see comments 3 and 4 for further discussion of this). These papers look at the cost of the delivery, as well as the changes in use of health and social care services for those in receipt of the intervention. Furthermore, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-	Thank you for your comment. The Knapp (2006) paper was not a cost-utility study and therefore did was not consistent with the reference case. As a result, it is inaccurate to state that this analysis showed that CST is cost effective, as no threshold value has been established for the effectiveness instruments used against which gains could be assessed. The D'Amico (2015) paper however, was a cost-utility study and was eligible for inclusion as part of the economic review. Please note that the effectiveness evidence used in Knapp (2006) was based on Spector (2003), and has been considered by this guideline by the way of inclusion in our quantitative synthesis of parameters for the model developed by NICE.

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				content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually. **References** D'Amico F, Rehill A, Knapp M, Aguirre E, Donovan H, Hoare Z, Hoe J, Russell I, Spector A, Streater A, Whitaker C, Woods RT, Orrell M (2015) Maintenance cognitive stimulation therapy: an economic evaluation within a randomised controlled trial. *Journal of the American Medical Directors Association,* 16 (1): 63-70. Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *British Journal of Psychiatry*, 188: 574-580.	

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Norfolk and Suffolk NHS Foundation Trust	Full	296	5	"No evidence of benefit was found on outcomes other than cognition (for CST)". This is an incorrect statement. Several studies have shown statistically significant improvements on outcomes in addition to cognition, namely quality of life (Spector et al, 2003; Capotosto et al., 2017; Paddick et al., 2017; Orrell et al., 2014); mood (Yamanaka et al., 2013; Niu et al., 2010); behavioural symptoms (Paddick et al., 2017); activities of daily living (Orrell et al., 2014). A Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects as well as showing evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis. **References** Capotosto E, Belacchi C, Gardini S, Faggian S, Piras F, Mantoan V, Salvalaio E, Pradelli S, Borella E (2017). Cognitive Stimulation Therapy in the	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life but the rest of studies included in the meta-analysis could not

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				Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry,32:331-340 Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Russell I, (2014) Maintenance cognitive stimulation therapy (CST) for dementia: single-blind, multicentre, pragmatic randomized controlled trial. *British Journal of Psychiatry* 2014 (204): 1-8*.* Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, *29*(6), 979-989. Spector, A., Thorgrimsen,L., Woods, B., et al (2003) Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. British Journal of Psychiatry, 183, 248-254	differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the meta-analysis could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

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				Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562. Yamanaka K, Kawano Y, Noguchi D, Nakaaki S, Watanabe N, Amano T, Spector A (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, 17:579-586.	
Norfolk and Suffolk NHS Foundation Trust	Full	296	5	"the committee… noted it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity". This statement is not supported by the evidence, which shows that manualised CST is much more effective than other interventions, including Reminiscence. A systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation demonstrates the best evidence for improving	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				cognitive functioning amongst all non-pharmacological interventions. Several trials within the Cochrane review compared Cognitive Stimulation with an active, social control group, and the findings were consistently in favour of structured group Cognitive Stimulation over a social control (Woods et al, 2012). **References** Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, Woods B, Beck C, Auer S, Lai C, Spector A, Fazio S, Bond J, Kivipelto M, Brodaty H, Rojo JM, Collins H, Teri L, Mittelman M, Orrell M, Feldman HH, Muñiz R (2010). Non-pharmacological therapies in Alzheimer's disease: A systematic review of efficacy. Dementia and Geriatric Cognitive Disorders;32:161-178 Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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Norfolk and Suffolk NHS Foundation Trust	Full	296	5	"They noted that in practice the two interventions are not mutually exclusive, with cognitive stimulation and reminiscence both forming part of the activities included within those groups". Whilst the committee are correct that CST does incorporate some aspects of reminiscence, the statement above shows a misunderstanding of CST (2006). One of the key focuses of CST is on generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills and enable new semantic connections to be made. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). **References** Spector A, Thorgrimsen L, Woods B, Orrell M (2006) Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				(CST) to people with dementia. Hawker Publications, UK.	
Norfolk and Suffolk NHS Foundation Trust	Full	296	5	"The committee agreed the most appropriate recommendation was for people to be provided with access to structured group activities, with cognitive stimulation and reminiscence both forming part of the activities included within those groups…. This was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" These recommendations are problematic for several reasons. As stated in the comments above, there is a far stronger evidence base for CST than for reminiscence. Additionally, the evidence is for CST when used as a manualised intervention. There is no evidence for any benefits if just elements of the programme are used, and there is no evidence in general for structured group activities. Therefore it is puzzling to see why NICE would recommend something which is not evidence based.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				In the Trust where I work (NSFT), CST is viewed favourably by staff as having a clear manual, which can be followed by a range of health and social workers at all levels of expertise eases implementation and minimises preparation time, providing a highly cost-effective intervention. This change in wording will create ambiguity and my fear is that it is likely to be interpreted that any type of structured group is sufficient, leading to a lack of clinical governance, and a lack of adherence to any sort of standardisation. The conclusion in the report that "this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according to important key principles which fit with the underlying theoretical models. I would encourage NICE to argue for more adherence to protocol and evidence base, rather than less.	

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Norfolk and Suffolk NHS Foundation Trust	Full	300	4	*"Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them"* This recommendation, as stated in comment 1, is concerning for all the reasons given in the above comments. CST, unlike AChEs and memantine, is suitable for all different types of dementia, it also shows improvement on measures such as quality of life and mood, as well as cognition. There is a risk that the wording "consider" will imply this is not an important recommendation. Additionally, "who are not already accessing them" may imply any sort of group activity will suffice. Given my comments, I would suggest the wording is changed to be more similar to the 2006 guidelines *"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia"*.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				As no recommendations were made for pre- and peri-diagnostic counselling and support for people with dementia and their families (evidence statement 13.1.4 full guidelines, p.263, line 14), or for post diagnostic interventions (evidence statement 13.1.6 full guidelines, p.266, line 2), there is a real danger that those with dementia will be offered only medication, and it will be even harder for people to access non-pharmacological interventions.	
Norfolk and Suffolk NHS Foundation Trust	Appendix J	10	10	In our Trust (NSFT), we do not have a Band 6 running the sessions – we have 2 Band 4s. This is typical of most organisations. Therefore the cost analysis is not correct, and the Knapp paper (referenced in comment 2) needs to be consulted	Thank you for your comment. In order to best reflect the level of expertise in a typical provision of a course of group CST, members of the GC were consulted with regard to the number and seniority of staff that would be required. The committee recognised that there is variation in the seniority of staff used to deliver CST across CCGs, ranging from two band 6s to two band 4s, and therefore advised that a band 6 and band 4 were an appropriate combination to serve as the baseline for modelling CST. It was important that the combination of number and seniority of staff selected for the base-case model closely reflected the profile of staff used to deliver group CST in studies from which the effectiveness data used in the model were drawn. It is not clear that the intervention would have identical effectiveness if delivered by more or less senior staff.

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					However, for all interventions in our model, we provide as estimate of ceiling cost for the magnitude of benefit observed. That is, if providers are able to deliver the benefit provided by group CST as per our model for an amount less than the value specified, this is likely to be reasonable use of NHS/PSS resources. This information can be used to estimate the value for money provided by alternative configurations (although, as noted above, this would only be valid if the effectiveness of the intervention is assumed to be unaltered). The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations,

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					a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Norfolk and Suffolk NHS Foundation Trust	Appendix J	10	11	All our CST groups are run from our base, so there is no staff travel time per session. This is typical for most organisations, so it is not correct to assume that the intervention takes place at an external venue. Again, therefore the cost analysis is not correct, and the Knapp paper (referenced in comment 2) needs to be consulted. It is not clear to me why patient travel is included, as presumably this is not a cost to the NHS, as we rarely provide cost of transport. Additionally, unlike for CST, many of our memory medication nurses do make significant journeys across rural Norfolk to see people at their homes, and the cost of their travel does appear to have been included in NICE's economic analyses of memory medication.	Thank you for your comment. Our analyses aim to be representative of what we understand to be typical practice in the NHS, of which there is often variation to differing degrees. In Knapp (2006), the cost of preparing the CST intervention was borne by the research project, and this included travel expenses. The guideline committee was consulted regarding this and indicated that costs for patient travel are sometimes borne by the organisation running the programmes. We are aware that some organisations have facilities available to them for which they do not have to pay, and accordingly a sensitivity analysis was conducted where these costs were excluded. The results of this sensitivity analysis in the base case produced an ICER of £17,111/QALY, making CST cost-effective if QALYs are valued at £20,000 each.

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					The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Norfolk and Suffolk NHS Foundation Trust	Appendix J	10	14	We have approximately 8 patients in the group – the recommendations are 5-8 in each group which is typical in most organisations (not 5, as stated in the table). Therefore the cost analysis is not correct, and the Knapp paper (referenced in comment 2) needs to be consulted.	Thank you for your comment. Economic models produced by NICE are based on the best available evidence along with the committee's judgement about the quality and applicability of that evidence to current practice across the whole of the NHS. The parameter in question has been tested in a one-way sensitivity analysis in the model and was found not to alter the

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					committees' conclusion about the cost-effectiveness of the intervention. The parameter in question incorporated data from D'Amico (2015), which used a group size of 5 patients. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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Norfolk and Suffolk NHS Foundation Trust	Appendix J	10	14	The total cost per session is calculated as £233.19. The Knapp (2006) paper calculated the cost per session as £90. Even the Knapp (2009) paper may be an overestimate, as noted above, we tend to have lower staff salary and travel costs, and less preparation time per session. Using the Knapp cost per session calculation, even with just 5 people in each group, the total cost per patient per CST course (14 sessions) is £252, compared to NICE's estimate of £652.94.	Thank you for your comment. Economic models produced by NICE are based on the best available evidence along with the committee's judgement about the quality and applicability of that evidence to current practice across the whole of the NHS. The parameters in question have been tested in a one-way sensitivity analysis in the model and were found not to alter the committees' conclusion about the cost-effectiveness of the intervention. Our analysis uses up to date costing for staff, and unlike the Knapp (2006) analysis, assumed that the researchers were not skilled in delivering CST and therefore incurred training costs. Furthermore, our analysis assumed that there were external venue costs, and costs associated with the transportation of patients to receive CST. These assumptions were ratified by the guideline committee for use in our economic analysis. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations,

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					a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Norfolk County Council	Short	28-29	general	Staff training – Whilst Norfolk County Council expects its own social care practitioners to have relevant experience of dealing with adults suffering from dementia and to understand person-centred outcomes, Norfolk County Council already has 'Dementia awareness' training available for its own staff. It may be that this becomes a mandatory requirement which would have a minor impact on financial resources. Norfolk County Council would be more concerned of the necessity to provide training to all of those involved with providing care (including care providers, informal carers and families) which would create a further financial burden on the local authority.	Thank you for your comment. The committee agreed there could be costs associated with the recommendations in the guideline for both carer support and staff training. However, the committee agreed there was robust evidence that both of these were effective and cost-effective interventions, and therefore were confident to make strong recommendations that they should be implemented.
Norfolk County Council	Short	9	general	• Advanced Care planning – This is the biggest single proposed change to current practice in Norfolk. Currently, if an adult	Thank you for your comment. The committee noted that providing ongoing opportunities to discuss advance care planning may be a change in practice for some areas, but that

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				makes their views known in respect of advanced care planning, Adult Social Services will record those wishes however, this is not a practice which is currently promoted. Advanced care planning decisions could be formally recorded in 'Advance Decisions to Refuse Treatments' or with 'Lasting Power of Attorneys'. The Care and Compassion website has a very good guide on detailing advance care planning decisions to be taken into account at a later date (should an adult be unable to express their wishes). There is a concern however about the impartiality of social work practitioners being involved in these decisions however regular care reviews should remove the need to spend time and resources on specific assessments related to advance care planning. The local authority would certainly expect practitioners to provide advice to people on where they can get more information/obtain documents should they wish to set up LPAs/ADRTs.	this was an important way to ensure that the wishes and preferences of people living with dementia are respected for the entirety of their lives. The committee acknowledged there are likely to be short-term resource implications in implementing this recommendation, both in ensuring information is appropriately shared, and training of staff so that they are able to carry out these tasks However, the committee were confident this would be a worthwhile use of resources that would improve care for both people living with dementia and their carers.

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				• If implemented on a wider scale, we would be concerned that current computer technology and software programmes may need some adjustment for specific advanced care planning so that advance wishes were accurately recorded in a way that is easily accessible by all of those to whom this information relates. Active promotion of this is likely to increase the length of time taken to complete Care Act Assessments and place additional burdens on social care budgets. There would also be concerns about a need to review advanced care planning decisions so that this information was kept up to date. That is to say not only would practitioners be reviewing current care needs under the Care Act but may also end up reviewing future needs. There are also implications where family members have not been told of advanced care planning decisions, leaving the local authority vulnerable to potential legal challenges and potential criticism of workers with regard to impartiality (as mentioned above).	
Norfolk County Council	Short	13	26	• Face to face assessments for adults with dementia where possible – In Norfolk,	Thank you for your comment. The committee agreed it may not be practical (or necessary) for assessment to take place

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				most Care Act assessments are completed face to face with social work practitioners for those suffering with dementia. There are occasions where carers and family are involved with the provision of care to the adult with dementia and where Norfolk County Council feels that care assessments can be accurately completed by telephone or other means although these cases are rare. The Council is concerned that any increase in the number of adults requiring face to face assessments would lead to additional financial pressures on the local authority. All care assessments require regular reviews. Although Norfolk County Council completes nearly all Care Act assessments on a face to face basis for those suffering with dementia, a larger number of reviews are undertaken through other media with those involved with caring for the person as well as family members. The draft guidance does not make it clear whether all reviews must be completed face to face but if so, then this would again have an impact on resources required.	face to face in all cases, and it was for this reason the words "where possible" are included in the recommendation. The committee agreed that in the absence of any evidence, it was not possible for them to make recommendations on whether reviews needed to take place face to face or not.

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Norfolk County Council	Short	15	13	Cognitive rehabilitation – Norfolk already offers this to all those receiving NHS services. With ongoing integration between health and social care in Norfolk, it is anticipated that cognitive rehabilitation will be offered to all of those suffering from mild to moderate dementia whose needs become apparent through social care routes. This is part of the local authority's dementia strategy and it is hoped that this will be in place within the next 6 - 12 months.	Thank you for your comment. The committee agreed this was a useful intervention to have available and were pleased to hear it is being rolled out in practice already.
Norfolk County Council	Short	30	5	Dementia Lead – Norfolk does not currently have a dementia lead post however, it does work with jointly with the NHS in the provision of services to those with dementia. Whilst the financial impact of having a dementia lead in place would not be huge, Norfolk County Council is concerned that this is again another additional cost at a time of financial pressures.	Thank you for your comment. The points listed here are merely suggestions for how recommendations could be implemented, and local areas would need to make their own decisions about how best to convert the guideline in to practice.
Northumberland Tyne and Wear NHS Foundation Trust	Full	36	17	Summary of recommendations, point 75 We are concerned that the current NICE guidance which states (*"People with mild / moderate dementia of all types **should** be given the opportunity to participate in a structured group cognitive stimulation programme") is proposed to change to the following guidance ("**Consider** providing structured group activities (including*	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both

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				elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them"). *Based on our knowledge and experience of caring for patients with dementia both in a memory clinic setting and in a specialised Day Hospital for those with complex care needs we find this proposed change very concerning.* *The suggested wording 'consider providing' rather than 'should' is very concerning to us. In this resource-limited times, the wording of guidelines such as NICE are important to commissioners and our worry is that a change to 'consider' will result in CST not being funded. We feel strongly that CST is very beneficial to patients with mild-moderate dementia, and this change may result in their being denied effective treatment. We have detailed recent real life anonymised examples of the benefits of CST observed in our service in our response to point 2 below. Therefore this new dementia guidance may result in patients with dementia being denied effective intervention and*	in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				as advocates for our patients we feel we need to make a representation to the committee on their behalf to prevent this from happening. *Overall, our suggestion would be to make the benefits or otherwise of CST a named priority for future research. The overwhelming majority of research efforts and research funding currently are focussed on pharmacological interventions, which unfortunately thus far have been unsuccessful.* *The shortcomings of outcome measures in dementia (cognitive and non-cognitive) are well known. Furthermore the relative lack of research into CST outcomes when compared particularly to pharmacological interventions is not evidence that CST is ineffective, it simply reflects the underfunding of non-pharmacological interventions research for dementia currently.* *We note that the new proposed guidance suggests providing '**selected elements'** of CST only. This is unlikely to be successful in clinical practice. Our experience, based on having delivered CST to numerous groups of patients since 2013 (alongside other interventions we have available such as reminiscence) is that the*	

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				manualised highly structured programme together with carefully designed activities and social interaction has greatly improved the quality of life of a number of our patients. It would be difficult if not impossible to provide the same intervention without the structure of the manualised programme.	
Northumberland Tyne and Wear NHS Foundation Trust	Full	296	5	The statement in the draft guidance regarding the evidence base for CST states "...no evidence of benefit was found on outcomes other than cognition." (section 13.2.5). Based on our own experience, this is unlikely to be correct. As described above, a relative lack of research evidence in this context simply illustrates the under-funding of non-pharmacological research into dementia interventions.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger

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				Reviewing our clinical records of patients with dementia who have completed CST, the primary benefits have been greatly improved communication abilities (therefore importantly reducing agitation and distress), increasing engagement with the clinical team therefore allowing therapeutic alliances (in patients where all other attempts and therapies had failed) and peer support in a way that is not seen in other therapy modalities in our experience. Here is a summary of the benefits recorded in the clinical notes for recent CST participants attending the day hospital 1. The discussion of challenging issues and current affairs in a familiar group during CST provides a mechanism for peer support. Sessions result in patients giving one another peer support. Last week one participant talked about her son's alcohol misuse and the effect of this on her. The group tried to give practical advice and support-**(of note, this patient had not disclosed this issue to**	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD, but the pooled result of the meta-analysis including other relevant studies could not detect clinically meaningful differences in quality of life between people living with mild/moderate

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				medical staff or in any one to one therapy sessions). Another participant with a severe dementia became upset during CST and the group rallied around her giving practical advice and trying to highlight that she was not alone. 2. CST improves confidence in our patients. This is really important as most participants have insight at some level into their deficits. A fundamental aspect of CST is to focus on the skills that people have. A member of our team gave the following clinical example 'I have seen a lady with significant word finding difficulties blossom in the group solely due to comfort and confidence in her surroundings and contemporaries: I had to visit this lady at home to persuade her to attend the unit and she sat during that visit holding my hand and crying. 3. We generally see an improvement in mood and animation in our patients attending CST. This is because the	dementia offered cognitive stimulation therapy versus usual care. Stewart (2017) would have been excluded because they used a before-after study design. This type of study design was excluded because there was enough evidence on randomised controlled trials (RCTs). Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

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				sessions are varied and there is always a topic that someone will respond to: This highlights to families how they can engage their loved one in similar activities at home. For example, we have a patient with an MMSE of 14. His wife had been reluctant to allow him to attend due the severity of his impairment because she did not feel he would get anything out of it. Prior to CST he had not engaged with any other therapeutic activities and would sit and scratch his head. However during a poetry-based discussion he clapped after each example and laughed appropriately at the amusing ones. 4. CST helps clinicians with a holistic assessment of patients strengths and likes and dislikes. We can use this when building up formulations and devising interventions for the family to use at home. Interventions and formulations help us address the needs of the patient, reducing the need for pharmacological	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				intervention. This has its own benefits. One of the CST sessions is about emotions and helps us to identify how the participant understand emotions. This massively impacts on our approaches. For example with one patient, I knew to wear a really exaggerated smile in my interactions with him otherwise he took my expression for anger. 5. **As a team, we feel that CST benefits CST facilitators as it reminds us that each patient has a strength no matter how impaired they are cognitively, that each patient is an individual and to look at individual needs holistically!** Furthermore, although not directly related to UK practice, one member of our team has substantial experience of use of CST in resource limited settings in low and middle income countries. In sub-Saharan Africa improvements in behavioural symptoms, quality of life, anxiety and depression symptoms were found (1) (plus unpublished	

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				Nigerian data) Other recent studies have reported findings supporting non-cognitive effects of CST.(2-5) A relatively recent Cochrane review found evidence supported improvements in quality of life and communication (6). As such we feel that this statement is misleading and is not supported by current evidence. Sometimes, benefits of an intervention such as CST are difficult to quantify. As such, existing assessment scales and outcome measures simply may not capture the benefits seen by participants, clinicians and carers, This is an area where as described in our answer to point one above, further work on appropriate outcome measures, particularly those devised with patient and public involvement should be encouraged. To illustrate this, here is a poem that was created (with a facilitator) but with input from all members of our most recent CST group most of whom have complex needs. The sea That definite smell, the waves splashing against the rocks.	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				I could never wait to take off my shoes and socks. The way it changes colours, the waves rolling into shore. Never tire of watching the sea, it leaves you wanting more As a mistress it can be cruel, show it some respect Walk along the coastline, shells we would collect The coast was a special holiday, even just to Tynemouth Seagulls pinching chips, dogs chasing them back south As a child we never got farther than seahouses in a caravan But travelled a little further, to Minorca as a man Snorkelling, bitten by jellyfish, a far cry from Whitley Bay A double decker to the coast made for a special day The sea also takes us back to war time, the beaches and no mans land Getting back to family, the north east is all we had planned The sea holds lots of memories, it takes us on our travels It can bring us peace and calm, as the fast pace of life unravels	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Here is a summary of feedback from our most recent CST group based at our Memory Service. I would like to spend more time with group members – more sessions Every session was useful Theres no doubt its helped with my memory Everyone is lovely I enjoyed the company and will miss the group For myself as a carer I found the introductory session extremely informative, lots of little tips as to how to deal with issues that memory loss causes I would like to thank the staff for the work they have put in I liked to be with other people and everyone is approachable Staff are warm and friendly and very welcoming I would just like to say thank you to the team who have been caring and kind. ,Mum will miss coming **1.** Paddick SM, Mkenda S, Mbowe G, et al. Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				efficacy using a stepped-wedge design. *Int Psychogeriatr.* Jun 2017;29(6):979-989. **2.** Yamanaka K, Kawano Y, Noguchi D, et al. Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial. *Aging Ment Health.* 2013;17(5):579-586. **3.** Orrell M, Aguirre E, Spector A, et al. Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *Br J Psychiatry.* Jun 2014;204(6):454-461. **4.** Stewart DB, Berg-Weger M, Tebb S, et al. Making a Difference: A Study of Cognitive Stimulation Therapy for Persons with Dementia. *J Gerontol Soc Work.* Apr 14 2017:1-13. **5.** Capotosto E, Belacchi C, Gardini S, et al. Cognitive stimulation therapy in the Italian context: its efficacy in cognitive and non-cognitive measures in older adults with dementia. *Int J Geriatr Psychiatry.* Mar 2017;32(3):331-340.	

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				6. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev.* 2012;2:CD005562.	
Northumberland Tyne and Wear NHS Foundation Trust	Full	296	5	The guidance notes that "...it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity." (13.2.5). This statement does not correspond with our anecdotal experience, because particularly at our Day Hospital, patients have other opportunities to take part in groups, but do not show the substantial individual benefits of CST described in our answer to point 2 above. Therefore simply being part of a group would not be sufficient to see the peer support, communication and engagement benefits described in our answer to point 2 above. It may be that the combination of social interaction, mental stimulation and familiar reliable structure produce these benefits together by providing sufficient challenge to patients.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				In terms of research evidence, a relatively recent Cochrane review (1) notes the benefit of CST when compared to a social/group activity control group. Simply being part of a trial often leads to improved outcomes in pharmacological and other trials for dementia, and the fact that CST has been compared to non-CST group activities is an advantage lacking in some other therapeutic trials in dementia. 1. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev.* 2012;2:CD005562.	
Northumberland Tyne and Wear NHS Foundation Trust	Full	296	5	The 2018 draft dementia guidelines state "...there would be **no difference in cost of delivery** between providing an intervention with a more varied range of components, and this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model." (13.2.5). This statement is not accompanies by any specific evidence or costings and therefore does not	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this

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				appear evidence-based. CST does in fact have a strong evidence base, particularly when compared to other non-pharmacological interventions such as reminiscence therapy. The cost of CST, at least in our service (likely to be representative of other services) is likely to be low, as it is carried out by clinical staff during normal clinical sessions and forms part of assessment and treatment (which might otherwise result in more individual sessions). The use of a manual allows less experienced staff to deliver the intervention, again likely to reduce the cost. Design of an alternative intervention programme, including elements of CST and other therapies would require specialised input from highly experienced and trained staff and would be therefore likely to cost more. There is no evidence that replacing CST with such an alternative programme would be of benefit to patients so it seems difficult to understand how such a statement has been made in the guidance. These of course are opinions based on our experience rather than research evidence, but the statement made by the committee similarly appears to be opinion-based.	into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				As mentioned earlier, one member of our team (S-M P) has previously evaluated CST for use in resource limited settings (1) and health economic analysis found costs of CST to be low, and to be recommended. Although those settings were different to those of the UK, notably because of the lack of accessible cholinesterase inhibitors, CST was delivered by trained staff (nurses and occupational therapists) in a similar manner to that usually seen in the UK. Paddick SM, Mkenda S, Mbowe G, et al. Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. Int Psychogeriatr. Jun 2017;29(6):979-989.	
Northumbria Healthcare NHS Foundation Trust	Full	36	17	Summary of recommendations, point 75 We note the change in the language used from the 2006 guidance (*"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme"*) to the proposed 2018 text (*"Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia*	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-

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				who are not already accessing them"). Based on our own knowledge and experience, we cannot agree with this change in language surrounding CST. The evidence base around CST appears to be growing rapidly and there have been some notable additions to the scientific literature that support the use of CST during this time, including our own work.[1-6] As such, the wording, "Consider providing..." seems rather weak and the change seems hard to justify based on both the evidence presented in the draft guidance and the wider literature. Likewise, the suggestion that only "...elements..." of CST should be considered appears to be out of step with the literature. Our anecdotal experience strongly supports the use of CST as a manualised package. Having a clear framework for the intervention is helpful with regard to training of healthcare workers, but also for patients and their families, who can build on session themes outside of the group. CST was adapted by our group for Tanzania and Nigeria by local healthcare workers[7] and we feel that it would have been impossible to deliver such an intervention effectively in this setting, in the absence of an overarching framework, such as	effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you have cited: Yamanaka (2013), Orrell (2014) and Woods (2012) were already included as evidence for CST. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Stewart (2017) would have been excluded because they used a before-after study design. This type of study design was excluded because there was enough evidence on randomised controlled trials (RCTs).

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				that provided by CST as a manualised intervention. 1. Paddick SM, Mkenda S, Mbowe G, et al. Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *Int Psychogeriatr.* Jun 2017;29(6):979-989. 2. Yamanaka K, Kawano Y, Noguchi D, et al. Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial. *Aging Ment Health.* 2013;17(5):579-586. 3. Orrell M, Aguirre E, Spector A, et al. Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *Br J Psychiatry.* Jun 2014;204(6):454-461. 4. Stewart DB, Berg-Weger M, Tebb S, et al. Making a Difference: A Study of Cognitive Stimulation Therapy for Persons with Dementia. *J Gerontol Soc Work.* Apr 14 2017:1-13.	Mkenda (2016) would have been excluded because the aim of the study was an adaptation of CST to use in a specific context.

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				5. Capotosto E, Belacchi C, Gardini S, et al. Cognitive stimulation therapy in the Italian context: its efficacy in cognitive and non-cognitive measures in older adults with dementia. *Int J Geriatr Psychiatry.* Mar 2017;32(3):331-340. 6. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev.* 2012;2:CD005562. 7. Mkenda S, Olakehinde O, Mbowe G, et al. Cognitive stimulation therapy as a low-resource intervention for dementia in sub-Saharan Africa (CST-SSA): Adaptation for rural Tanzania and Nigeria. *Dementia (London).* Jun 21 2016.	
Northumbria Healthcare NHS Foundation Trust	Full	296	5	The draft guidance relating to this is "...no evidence of benefit was found on outcomes other than cognition." (13.2.5). Our own studies in Tanzania and Nigeria have found evidence of effectiveness with regard to improvement in quality of life, anxiety and depression and behavioural symptoms (Nigeria results	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				unpublished).[1] These findings are supported by work from other researchers.[2-6] Most notably the Cochrane Collaboration systematic review by Woods et al found evidence supporting improvements in quality of life and communication. As such we feel that this statement is misleading and is not supported by current evidence. On a clinical level, this statement also seems implausible. We are unaware of any plausible mechanism whereby a psychosocial intervention would only act to improve cognition in isolation. Rather, improved cognition is likely to occur in tandem with improvements in mood, communication and social and physical function. This in turn is likely to impact positively on quality of life. **1.** Paddick SM, Mkenda S, Mbowe G, et al. Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *Int Psychogeriatr.* Jun 2017;29(6):979-989. **2.** Yamanaka K, Kawano Y, Noguchi D, et al. Effects of cognitive stimulation therapy Japanese version (CST-J) for people with	manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Stewart (2017) would have been excluded because they used a before-after study design. This type of study design was

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				dementia: a single-blind, controlled clinical trial. *Aging Ment Health.* 2013;17(5):579-586. **3.** Orrell M, Aguirre E, Spector A, et al. Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *Br J Psychiatry.* Jun 2014;204(6):454-461. **4.** Stewart DB, Berg-Weger M, Tebb S, et al. Making a Difference: A Study of Cognitive Stimulation Therapy for Persons with Dementia. *J Gerontol Soc Work.* Apr 14 2017:1-13. **5.** Capotosto E, Belacchi C, Gardini S, et al. Cognitive stimulation therapy in the Italian context: its efficacy in cognitive and non-cognitive measures in older adults with dementia. *Int J Geriatr Psychiatry.* Mar 2017;32(3):331-340. **6.** Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev.* 2012;2:CD005562.	excluded because there was enough evidence on randomised controlled trials (RCTs). Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST. Orrell (2014) and Yamanaka (2013) were already included as evidence for CST.

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Northumbria Healthcare NHS Foundation Trust	Full	296	5	The guidance notes that "...it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity." (13.2.5). Although we agree that it is not yet clear what the key 'active ingredients' of CST are, there is evidence to support the conclusion that it involves more than just being part of a group. In our rural African setting, multigenerational living is the norm and older people will generally have much higher levels of social interaction, particularly with children, than typically seen in the UK and other high-income countries. Village life has a large communal element and village committees have a responsibility to ensure older people are provided for. As such, social isolation in later life is very rare. In our study, although socialisation within a group was clearly important, we did not perceive it to be a major component in the intervention and it is very unlikely to have resulted in the marked improvement in cognition we observed. As such, the statement made seems at odds with our anecdotal experience and, more importantly, with the growing evidence base for CST. Woods et al[6] noted that the effect of a social control group was notably	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				less than that of CST and the limited evidence base to support the use of reminiscence therapy also suggests that group activity alone is not the main active ingredient in CST. 6. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev.* 2012;2:CD005562.	
Northumbria Healthcare NHS Foundation Trust	Full	296	5	The guidance notes that "...there would be no difference in cost of delivery between providing an intervention with a more varied range of components, and this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model." (13.2.5). This statements appears to lack any scientific basis and we feel it must be omitted. There is a strong evidence base regarding CST and a very limited evidence base supporting the use of other psychosocial interventions, such as reminiscence therapy. There is no evidence that we are aware of that would allow one to draw the conclusion that a more varied range of components would lead to	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				better outcomes. Indeed, a more accurate statement would be that inclusion of a more varied range of components would be likely to increase cost (at least to some extent), with absolutely no evidence that this would lead to better outcomes.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Nuffield Council on Bioethics	Short			We welcome the recommendations set out in section 1.1. While dementia is a harmful disorder, a good quality of life is possible if the person with dementia is seen and respected as a person with values and interests to whom we have the same duties as any other fellow human beings. Amongst the key values underpinning our approach to dementia, should be concern for the autonomy and well-being of the person with dementia, coupled with an attitude of solidarity based on the belief that we are all 'fellow-travellers' and dependent, to various degrees at different times in our lives, on each other. We recognise that it is not always possible to provide services, or support individuals, in a way	Thank you for your comment and your support for these recommendations.

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				which fully respects all these values, because at times they may come into conflict (for example sometimes it may be impossible to promote wellbeing and at the same time maximise autonomy). It is also sometimes necessary to balance the interests of the person with dementia with the interests of carers (see diagram on page 39). However, we emphasised that involving the person with dementia in 'small' things or 'micro' aspects of their life and their effects is of considerable significance to making the person feel valued and in control.[49] The importance of information, support and access to services immediately after diagnosis was evident in the responses from our public consultation. The needs of any person with dementia and those close to them will vary significantly, depending on individual preference and on the nature and progress of their dementia at the point of diagnosis.[50] It isn't just the access to information, but also the importance of communication itself. A key aspect of recognising and relating to the person with dementia is to	

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[49] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.3 – 3.5.

[50] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.25.

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				find appropriate forms of communication through which they may be reached, however advanced the dementia.	
Nuffield Council on Bioethics	Short	6	13-24	We welcome NICE's principles of person-centred care set out in this section. This largely aligns with the components of the ethical framework in our dementia report, particularly components 4 – 6: • **Component 4** **The importance of promoting the interests both of the person with dementia and of those who care for them:** People with dementia have interests, both in their autonomy and their wellbeing. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values. Autonomy is not simply to be equated with the ability to make rational decisions. A person's well-being includes both their	Thank you for your comment and your support for this section.

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				moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning. The separate interests of carers must be recognised and promoted. • **Component 5** **The requirement to act in accordance with solidarity:** The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole. • **Component 6** **Recognising personhood, identity and value:** The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.	

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Nuffield Council on Bioethics	Short	9	3	We welcome the emphasis on offering "early and ongoing opportunities" for people to be involved in planning care in the future, including lasting powers of attorney (health and welfare), advance statements about wishes, and advance decisions to refuse treatment. Welfare powers of attorney are a very good way of promoting a person's autonomy interests. Indeed, they have many advantages over an advance decision as they permit decisions to be made in the light of up-to-date knowledge both of the person's clinical needs and the care options available.[51]	Thank you for your comment and your support for this recommendation.
Nuffield Council on Bioethics	Short	13	22	We welcome the emphasis on a 'single named health or social care professional' responsible for co-ordinating care. In our report, we found that people need help accessing what is inevitably a fragmented support system, given the wide range of services available. We welcomed the use of professionals whose role would be to help people diagnosed with dementia access appropriate services in the UK and suggested that there is a	Thank you for your comment and your support for this recommendation.

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[51] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 5.55.

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				strong ethical justification for these to be introduced throughout the whole of the UK.[52]	
Nuffield Council on Bioethics	Short	15	5	We very much welcome the recommendations set out in this section, particularly the emphasis on the importance of offering "a range of activities to promote wellbeing that are tailored to the person's preferences." We welcome the emphasis on services or activities which are flexible and appropriate to the individual.[53] How things are done, so that people with dementia feel like valued individuals, will often be far more important than the particular structure or format of services. If care is to be of appropriately high ethical standard, the support provided needs to promote the autonomy and wellbeing of the person with dementia and recognise their individuality and value as a person.	Thank you for your comment and your support for these recommendations.
Nuffield Council on Bioethics	Short	20	19	We welcome the emphasis on the importance of identifying clinical and environmental causes of agitation; offering psychosocial and environmental interventions to reduce distress;	Thank you for your comment and your support for these recommendations.

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[52] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.27.

[53] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 3.31.

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				and only offering antipsychotics as a last resort for those who are at risk of harming themselves or others or experience agitation, hallucinations or delusions that are causing them severe distress. Support such as information and advice, psychological therapies to improve confidence, practical help in the home, and assistive technologies have an important role to play in improving the quality of life and promoting independence for people with dementia.	
Nuffield Council on Bioethics	Short	25	14	We welcome the recommendations in this section of the NICE guidelines. It is important that carers are supported financially, emotionally and practically. Service providers have a responsibility to inform carers, openly and systematically, of the social and financial support to which they are entitled.[54] Carers should also have access to ongoing education to help them respond to ethical problems.[55]	Thank you for your comment and your support for these recommendations.
Nuffield Council on Bioethics	Short	27	3	We welcome the guidance in this section, particularly for all staff to have "training in	Thank you for your comment, and your support for these recommendations.

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[54] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 7.30.
[55] Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, paragraph 6.3.

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				person-centred care." Professionals and care workers providing care to people with dementia should also have access to ongoing education to help them respond to ethical problems.[56]	
Optical Confederation	Short	General	general	The overarching theme for optical professionals within this consultation is communication and access to data. Optical practices should be provided with access to relevant data for patients via the summary care record or similar. This will enable quicker and better decision making regarding patient care and reduce unnecessary stress for patients. Trying to elicit complex information from patients with dementia can be stressful for all involved and this information should be easily available to all who have need to access it.	Thank you for your comment. The committee agreed that sharing of appropriate information is a key aspect of improving care for people living with dementia, and included a specific recommendation on ensuring relevant information is shared.
Optical Confederation	Short	General	general	We cannot see anywhere in the consultation, where the importance of regular sight tests for patients with dementia has been addressed. This should include increasing awareness of domiciliary optical services to help patients maintain their independence and maximise their quality of life. Often people with dementia are less able to verbalise their deteriorating sight,	Thank you for your comment. The committee noted this concern, and agreed it was appropriate to add a new recommendation to the guideline to: "Encourage people living with dementia to have eye tests every 2 years. Consider referring people who cannot organise appointments themselves."

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[56] Ibid.

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				which in turn reduces their ability to engage in the world around them. This withdrawal is often attributed to increased dementia by carers. This may actually be significantly helped with an up-to-date prescription, maximising their opportunity to re-engage in the world around them. NICE have previously found in guidance CG161 that whilst there is insufficient evidence that single interventions targeting vision impairment are effective in reducing falls, referral for visual correction as part of a multifactorial intervention has a significant impact on falls reduction. The Alzheimer's society amongst others have been very clear on the importance of regular sight tests for those with dementia, due to the increased impact that increased sensory deprivation can have on these patients https://www.alzheimers.org.uk/info/20064/symptoms/213/sight_and_hearing_loss	
Optical Confederation	Short	7	10	We are supportive of the aims of this, but it is imperative that optical professionals also have access to the relevant information on choices made by patients.	Thank you for your comment. The committee agreed with the importance of sharing information with relevant professionals (including optical professionals), and this led them to make several recommendations on this point. These include recommendation 1.1.7 (asking for consent to share

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					information at diagnosis) and recommendation 1.3.4 (on sharing the information contained in care and support plans).
Optical Confederation	Short	8	19-20	It is important that the question includes optical professionals to avoid eye care being excluded from information sharing agreements.	Thank you for your comment. The committee noted that the list of relevant services would be different for different individuals, depending on their individual needs, including any comorbidities. Due to these complexities the committee agreed that it was not appropriate to construct a specific list of services.
Optical Confederation	Short	9	3-15	It is important that any management or treatment plans are made available to all clinicians so that optical professionals can make informed management and referral decisions.	Thank you for your comment. The committee agreed with the importance of sharing care and support plans with relevant services, where consent has been obtained.
Optical Confederation	Short	13	23-24	It is important that this person is easily identified, so that optical professionals know who to contact with regard to care decisions.	Thank you for your comment. The committee agreed it was important this information was shared appropriately so all relevant service know who the correct individual to contact is.
Optical Confederation	Short	14	18-21	Optical professionals see patients in a variety of settings. It is therefore important that the transfer of patient data is quick and smooth.	Thank you for your comment. The committee agreed this recommendation was relevant for all settings in which people would be seen, and that efficient transfers of information were an important part of high quality care.
Optical Confederation	Short	27	4	For clarity we presume this training requirement is intended for care staff not as an additional requirement for optical professionals. If it is not, then care and support providers should provide staff with training proportionate to the respective needs of individual staff, in person-centred and	Thank you for your comment. The committee agreed the training provided should be proportionate to the level of contact and interaction the staff members have with people living with dementia.

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				outcome-focused care for people living with dementia…	
Optical Confederation	Short	14 & 15	14 (26-29 & 15(1-4)	Optical practices already provide accessible services via home visits and domiciliary care. While we welcome collaboration in future service design, we are wary of overly onerous requirements. Unfortunately, there are currently technical restrictions on a number of tests that may be conducted by optical professionals. This is due to the requirement for patients to maintain steady fixation to use imaging equipment and visual field screening equipment. In patients with dementia this is not always possible with the current technology.	Thank you for your comment. The committee agreed it was important that services be made accessible to as wide a range of people living with dementia as possible, but agreed there was not sufficient evidence to say how these services should be organised in practice.
Otsuka Pharmaceuticals	Short	13 of 33	19	**Review after diagnosis:** **1.2.29:** there are cognitive, behavioural and functional symptoms for dementia and Alzheimer's Dementia and it is important to make these explicit as part of post diagnosis review. NICE CG42 , "*Dementia: supporting people with dementia and their carers in health and social care"* makes this clear by stating "**A behavioural and functional analysis should be conducted by health and social care professionals with specific skills, in conjunction with carers and care**	Thank you for your comment. The committee agreed that, in the absence of evidence, it was not possible to include a recommendation along these lines in the section of the guideline on post-diagnostic review. However, references to a structured assessment are included in both the section on developing care and support plans, and the section on managing non-cognitive symptoms in people living with dementia.

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				workers, and an individually tailored care plan should be developed to address the issues." **Recommendation:** ensure that functional and behavioural needs are referred to explicitly in this section to facilitate care planning.	
Otsuka Pharmaceuticals	Short	15 of 33	Line 5, Section 1.4	**1.4 Interventions to promote cognition, independence and wellbeing:** the challenges of dementia and Alzheimer's Disease are multifaceted – cognition, behaviour and functional symptoms – all of which have an impact on an individual's wellbeing and independence. It states that a range of activities should be offered but focusses on only those that promote cognitive stimulation, rehabilitation and training. This is in contrast to the content of the full guidelines, which acknowledge the impact of behavioural and functional symptoms, including and not limited to agitation, sleep disorders and mobility difficulties, and goes on to advocate the provision of services to help manage these symptoms. **Recommendation**: include explicit reference to services and support to promote wellbeing and	Thank you for your comment. The committee agreed that the recommendations in the guideline included all those non-pharmacological interventions for which there was robust evidence of effectiveness and cost-effectiveness. The current quality standards for dementia will be updated after this guideline is published.

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				independence as per NICE Quality Standard Q30 *"Dementia: independence and wellbeing"* and NICE CG42, "*Dementia: supporting people with dementia and their carers in health and social care"*. These include the importance of access to leisure facilities, peer support and engagement.	
Otsuka Pharmaceuticals	Short	20 of 33	20	**1.7 Managing non-cognitive symptoms. Agitation, aggression and distress:** Given the evidence and challenges set out in the full guidance this section lacks the detail needed to provide clear, helpful guidance for professionals on detection and diagnosis, and the need for ongoing review as part of a patient's care plan. The J Cummings et al paper, Int Psychogeriatr. 2015 Jan; 27(1): 7–17, describes a consensus for the definition of agitation in cognitively impaired patients. **Recommendation:** Expand this section to include where and how patients may present; who might be involved in the diagnosis and treatment decision; and include examples of non-pharmacological interventions; ensure consistency of language (noting terminology	Thank you for your comment. The committee agreed that the recommendations in the guideline included all those pharmacological and non-pharmacological interventions for managing non-cognitive symptoms for which there was robust evidence of effectiveness and cost-effectiveness. The current quality standards for dementia will be updated after this guideline is published.

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				above) and references to delirium. There needs to be consistency with the NICE Q30 and in the Dementia flow chart https://pathways.nice.org.uk/pathways/dementia#content=view-index&path=view%3A/pathways/dementia/dementia-interventions.xml	
Otsuka Pharmaceuticals	Short	25 of 33	8	Paragraph 1.10.8 Insert Delirium, **agitation, aggression and distress** to be consistent.	Thank you for your comment. The committee agreed these symptoms were covered by other bullet points within this list, and the incidence of delirium in hospitalised people living with severe dementia to be worth an explicit mention by itself.
Otsuka Pharmaceuticals	Full and short	General	General	**Behavioural and functional symptoms:** the full guideline sets out clearly the challenges of diagnosing and treating these symptoms, recognising the qualitative and quantitative burden on individuals, families and health and social care systems. It is disappointing to note that this information and guidance is not incorporated into the short guideline to an extent that would be helpful for professionals. The short guideline does not provide adequate information on definitions, support for detection, diagnosis and care for behavioural and functional symptoms.	Thank you for your comment. The committee agreed that the recommendations included in the short guideline were as specific as possible given the evidence available, and noted that a number of recommendations for future research had been made in areas with a lack of evidence. The committee noted that a number of different terminologies were used to describe non-cognitive symptoms for people living with dementia, but agreed the current wording in the guideline should be clear and familiar to most people working in the area.

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				Recommendation: In reference to symptoms use the term **cognitive, behavioural and functional** in all guidance and supporting documentation.	
Oxford Project to Investigate Memory and Ageing (OPTIMA)	Short	15	17	Same comment as above in 1.	Thank you for your comment. Stratification by median baseline MMSE was not a subgroup analysis specified by the committee in the protocol for this question, and therefore this evidence was not included in the guideline. The committee noted this evidence and agreed that, with the mixed results from the only study available in people with a diagnosis of dementia (negative overall, but positive for a specific subgroup), it was not possible to make positive recommendations for this intervention in the guideline. However, they did agree that, because of these promising results for a particular subgroup, it was appropriate to remove "vitamin B and folic acid supplements" from the 'do not' recommendation in the guideline. The committee noted that neither the prevention of dementia nor the management of MCI were within the scope of the guideline, and therefore it was not possible to make recommendations on these topics.
Oxford Project to Investigate Memory and Ageing (OPTIMA)	Full	36	25	We would like to discuss the recommendation 'Do not offer…vitamin B or folic acid supplements… to treat dementia. The only	Thank you for your comment. Stratification by median baseline MMSE was not a subgroup analysis specified by the committee in the protocol for this question, and therefore this evidence

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				evidence in Appendix E to support this recommendation is the paper by Aisen (JAMA, 2008) cited under the heading 'Other nutritional interventions'. This paper reported a trial over 18 months of folic acid, vitamins B12 and B6 to lower homocysteine in patients with mild to moderate AD. The summarised results in the Table relate to the whole group of patients which did not show any benefit of the B vitamins treatment. However, on page 1781 of the paper the authors report a subgroup analysis which was not described in the Table in Appendix E. This pre-specified subgroup analysis divided the patients into two subgroups, those with baseline MMSE above the median and those with MMSE below the median. Using the ADAS-cog score, the authors found a significant (P<0.001) beneficial effect of B vitamin treatment after 15 months in those with baseline MMSE above the median, i.e. those with milder AD. The interaction between baseline MMSE and active treatment was also significant in General Estimating Equation analysis (P=0.02). The authors have made available additional data from this trial, which is shown in the Figure below:	was not included in the guideline. The committee noted this evidence and agreed that, with the mixed results from the only study available in people with a diagnosis of dementia (negative overall, but positive for a specific subgroup), it was not possible to make positive recommendations for this intervention in the guideline. However, they did agree that, because of these promising results for a particular subgroup, it was appropriate to remove "vitamin B and folic acid supplements" from the 'do not' recommendation in the guideline. The committee noted that neither the prevention of dementia nor the management of MCI were within the scope of the guideline, and therefore it was not possible to make recommendations on these topics.

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				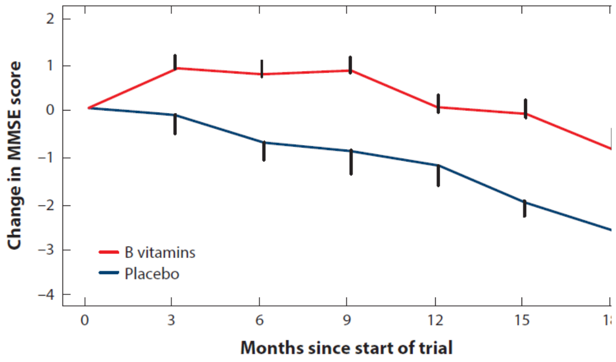 **Figure.** AD patients with a Clinical Dementia Rating score of 0.5 at baseline (i.e. mild AD) were treated with placebo (black) or a mixture of folic acid, vitamins B12 and B6 (red) for 18 months. The B vitamin treatment significantly slowed cognitive decline assessed by MMSE over an 18-month period (P=0.017). (published as Figure 7 in the review by Smith & Refsum, '*Homocysteine, B vitamins and cognitive impairment'* (Annu Rev Nutr, 2016, 36:211). Following their results, which suggest that the stage of the disease is an important determinant of the response to B vitamins, Aisen et al (2008) proposed "studies in more narrowly defined groups of individuals with AD, or perhaps	

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				amnestic mild cognitive impairment (MCI), may be warranted." This is exactly what was done in the VITACOG trial which recruited 271 people with MCI. Treatment was for 2 y with placebo, or with B vitamins to lower homocysteine, and a highly significant slowing of whole and regional brain atrophy and a slowing of cognitive decline was found in those on active treatment who had high homocysteine at baseline (Douaud et al. *Prevention of Alzheimer's disease-related gray matter atrophy by B vitamin treatment*, PNAS, 2013, 110:9523). This trial has been reviewed in Smith & Refsum 2016, cited above, and in Smith & Refsum, '*Dementia prevention by disease-modification through nutrition'*, J Prev Alz Dis 2017, 4:138. A consensus statement on homocysteine and dementia is in press: Smith et al. '*Homocysteine and dementia: an international consensus statement'* J Alz Dis 2018, in press. A cost-benefit analysis of screening elderly for raised homocysteine and treating them with B vitamins shows that such a policy would be highly cost-effective: Tsiachristas & Smith *'B-vitamins are potentially a cost-effective population health strategy to tackle dementia: Too good to be true?'* Alzheimer's and Dementia (NY) 2016 2:156.	

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				We would like to ask NICE to reconsider their recommendation not to offer B vitamins to those with dementia but, on the contrary, consider suggesting that those with early stage dementia and moderately raised homocysteine might benefit from this very safe intervention. This is current practice in memory clinics in Sweden (reference cited in Smith & Refsum 2017). Of course, more trials are needed to see whether lowering homocysteine will slow, or prevent, conversion from MCI to dementia, but pending the outcome of such trials it would seem prudent to offer a safe treatment to slow down cognitive decline in those with MCI who have raised homocysteine.	
Parkinson's Disease Nurse Specialist Association	Short	8	23	Document decisions in patients notes – are you referring to psychiatry or main hospital notes, as in many areas, as the 2 services are joined up in many areas, general and psychiatry cannot view each other's notes, and are often in different trusts in the same locality	Thank you for your comment. The committee agreed some confusion has been introduced in this recommendation by the statement to "tell all relevant services what the person has decided", which has now been deleted. The committee noted the importance of having information contained in a single record so it was accessible to multiple services, but agreed that in the absence of evidence, they could not give specific guidance on how this system should be organised.
Parkinson's Disease Nurse Specialist Association	short	8	27	Should written information about being contacted and this discussion particularly about future appointments and documented.	Thank you for your comment. The committee agreed it would be important to document if people took up the option to be contacted at a future date, to ensure this took place.

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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Parkinson's Disease Nurse Specialist Association	Short	9	4	It does not say who is doing this should be identified, which professional or team… eg Parkinson's team for Parkinson's Disease Dementia	Thank you for your comment. The committee noted that the appropriate individual to do this would be different for each individual (based, for examples, on their dementia subtype and any comorbidities), and therefore agreed it was not possible to be prescriptive on this is the recommendations.
Parkinson's Disease Nurse Specialist Association	Short	11	12	Movement disorder society link it questionable as it directs to a dated article referring to an algorithm (level 1), using MMSE which in 2007 was more frequently used. The Montreal Cognitive assessment is the most commonly used measure in clinical practice. Refer to movement disorder society systematic review September 2015, movement disorders vol 3, issue 1, jan/feb 2016, pages 9 – 18, SK Holden et al.	Thank you for your comment. The committee noted this was the most up to date reference available for the relevant diagnostic criteria.
Parkinson's Disease Nurse Specialist Association	Short	12		Omits to mention diagnosing Parkinson's Disease Dementia, there should be a section on this after diagnosing DLB	Thank you for your comment. No reliable evidence was identified on tests for the diagnosis of Parkinson's disease dementia, and therefore the committee agreed it was not possible to make recommendations on this topic.
Parkinson's Disease Nurse Specialist Association	Short	17	6	Recognition of advanced nurses practitioners with specialist expertise, to initiate and titrate AChE inhibitor is a welcome addition. Potential to commence appropriate cholinesterase inhibitor in primary care will benefit patients who ae unable to access specialist memory team. This helps to address inequity in accessing specialist memory	Thank you for your comment and your support for this recommendation.

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				teams memory, and reduce the delay in accessing timely medication.	
Parkinson's Disease Nurse Specialist Association	Short	20	5	This section is comprehensive however, should be inserts here a sentence here…. Add and liaise with Parkinson's team	Thank you for your comment. An additional recommendation has now been added to the guideline cross-referring to the Parkinson's disease guideline for the management of non-cognitive symptoms of Parkinson's disease.
Parkinson's Disease Nurse Specialist Association	Short	21	8	In Parkinson's Disease refer to PD Nice guidance 2017, re preferred option of quetiapine.	Thank you for your comment. An additional recommendation has now been added to the guideline cross-referring to the Parkinson's disease guideline for the management of non-cognitive symptoms of Parkinson's disease.
Parkinson's Disease Nurse Specialist Association	Short	22	11	PD Nice guidance 2017 recommends melatonin for RBD but does not exclude dementia.	Thank you for your comment. The committee noted this and the fact that the majority of the evidence from the trials was in Alzheimer's disease, and therefore agreed it was appropriate to amend this recommendation to "do not offer melatonin to manage insomnia in people living with Alzheimer's disease."
Parkinson's Disease Nurse Specialist Association	Short	28	1	Staff and family members are likely to have different requirements and needs, and learning maybe affected by emotional perspective of carer / family member	Thank you for your comment. The committee noted this concern, and this was part of the reason why this recommendation was only made at the weaker 'consider' level.
Parkinson's UK	Short	General	General	Given the prevalence of Lewy Body Dementia (10-15%) (NICE Clinical Knowledge Summaries; Dementia; Causes. https://cks.nice.org.uk/dementia#!topicsummary accessed 8/2/18) and Parkinson's Disease Dementia (2%) (Alzheimer's Society (2014) 'Dementia UK second edition') we would	Thank you for your comment. The committee agreed with this suggestion, and a reference to the NICE Parkinson's disease guideline has been added.

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				recommend the guidance is strengthened by referencing the NICE guidance on Parkinson's to ensure people with Parkinson's and dementia receive a holistic person-centred approach to their care.	
Parkinson's UK	Short	General	General	We believe that the guidance does not adequately address the care of people with dementia with comorbidities. This is particularly important for people with Parkinson's and dementia where the management of symptoms of one condition impacts the other. For example, the need for considering the impact of a person's Parkinson's medication on a person's dementia symptoms as referred to in comment 6 below. People with Parkinson's and dementia will be required to attend multiple appointments from multiple agencies, an issue highlighted in All-Party Parliamentary Group on Dementia's (2016) report 'Dementia rarely travels alone: living with dementia and other health conditions', and so therefore requiring a more holistic person-centred approach. There is a need for condition specific comorbidities guidance as opposed to more general guidance as it does in section 1.8.1.	Thank you for your comment. Evidence was looked for on the management of comorbidities in people living with dementia, but only very limited evidence was identified, and in particular no evidence on the management of Parkinson's disease in people living with dementia. Since consultation, an additional recommendation has been added to the section on care and support plans, stating that care coordinators should "ensure it contains information on the management of any comorbidities the person has."
Parkinson's UK	Short	General	General	We feel that there is a lack of guidance focused on specific care settings, in particular in hospital,	Thank you for your comment. The committee noted that in many areas the evidence base only covered people in a

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				in care homes and in the home. Since 70% of people living in care homes, 60% of people in receipt of homecare have dementia, and 25% of hospital beds at any one time, it would suggest that guidance specific to these settings would be of value (Prince M, Knapp M et al (2014). Dementia UK: Update, Alzheimer's Society and (UKHCA, 2013); Lakey, L (2009) Counting the cost: Caring for people with dementia on hospital wards published by the Alzheimer's Society). We believe it would be beneficial for people with Parkinson's with dementia for health and social care professionals to receive guidance specific to care in these settings.	particular setting (e.g. the majority of the evidence on staff training came from people living in care homes). The committee agreed that wherever possible it was appropriate to try and extrapolate this evidence to the more general population of people living with dementia, as otherwise there was a risk of particular groups not being covered, solely because studies happened not to have been done in those populations.
Parkinson's UK	Short	General	General	Parkinson's UK believes that people with dementia (including people with mild cognitive impairment) should be given the opportunity to take part in research. Through our own work we have supported people with Parkinson's dementias to be involved in four research projects, this was done at an early stage, helping to shape study design and consider the priorities for people with Parkinson's dementias in their research.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				However, with only 5% of people with dementia being involved in research (National Institute for Health Research (NIHR) 2015 statistics), there is an opportunity for the guidance to ask health professionals to sign post to people with dementia to NIHR's 'Join Dementia Research'.	
Parkinson's UK	Short	8	6-7	We are concerned that people with Parkinson's with dementia risk getting 'lost' between their dementia teams and their Parkinson's teams, leading to a negative impact on their continuity of care. We recommend that the guidance is altered to include 'shared care' so that information is included on health and social care professionals involved in their dementia care and their Parkinson's care to ensure there is continuity in a person's care across both conditions.	Thank you for your comment. The committee noted this concern and agreed it was appropriate to add an extra point to the section around care and support plans, to "ensure it contains information on the management of any comorbidities the person has."
Parkinson's UK	Short	10	27	The progression of different subsets of dementia differs, as well as the prevalence of certain symptoms of dementia between different subsets. This means the subset of dementia a person has will affect the type of care, treatment and support they need for this to be effective.	Thank you for your comment. The committee agreed that diagnosis of a dementia subtype was important to optimise care and support, and this was why a number of additional diagnostic tests are recommended in this section to ensure people receive an accurate subtype diagnosis.

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				For example, Dementia with Lewy Bodies affects visual function, attention and spatial awareness as opposed to memory associated more commonly with other types of dementia such as Alzheimer's (Mueller, Christoph et al (2017) 'The prognosis of dementia with Lewy bodies' The Lancet Neurology, Volume 16 , Issue 5 , 390 – 398). Some symptoms such as severe hallucinations and sleep disturbance tend to be experienced early on, whereas dizziness, difficulty standing and fluctuating consciousness can present at any stage of the condition. Parkinson's UK recognises the importance of diagnosis of dementia subtypes so that the most appropriate and effective care and support can be put in place. We believe therefore that the guidance 1.2.10 needs to be strengthened and the words "(if possible)" removed.	
Parkinson's UK	Short	13	8-11	Parkinson's UK welcomes the inclusion of 'treat for delirium first' (in 1.2.26) when it is not possible to tell whether a person has delirium, dementia, or delirium superimposed on dementia. Delirium is a symptom often experienced by people with Parkinson's (Vardy	Thank you for your comment and your support for this recommendation.

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				ER, Teodorczuk A, Yarnall AJ (2015) 'Review of delirium in patients with Parkinson's disease. Journal of Neurology Nov;262(11):2401-10). It is also difficult to distinguish Lewy Body Dementia from delirium due to the fact that hallucinations, attention difficulties, fluctuations, and arousal problems are associated with both conditions (Morandi, Alessandro et al. (2017) The Diagnosis of Delirium Superimposed on Dementia: An Emerging Challenge Journal of the American Medical Directors Association , Volume 18 , Issue 1 , 12 – 18) We therefore recommend 'treat for delirium first' must stay in the guideline.	
Parkinson's UK	Short	14	9-13	As per NICE guidance on Parkinson's Disease in adults NG71, people with Parkinson's should have a comprehensive care plan in place. For a holistic, person-centred approach to care it is important that a person's Parkinson's care plan and their dementia care plan are integrated so that their needs are looked at as a whole.	Thank you for your comment. The committee noted this concern and agreed it was appropriate to add an extra point to the section around care and support plans, to "ensure it contains information on the management of any comorbidities the person has."

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				Medicines management is of particular importance to people with Parkinson's, as we know some of the side effects of Parkinson's medication can exacerbate the symptoms of dementia (Varanese, S., Birnbaum, Z., Rossi, R., & Di Rocco, A. (2010). Treatment of Advanced Parkinson's Disease. Parkinson's Disease, 2010, 480260). We also know that some anti-psychotic medication can have a harmful effect on people with Lewy Body Dementia (Ballard C, Grace J, McKeith I, Holmes C. (1998) 'Neuroleptic sensitivity in dementia with Lewy bodies and Alzheimer's disease.' Lancet. 1998 Apr 4;351(9108):1032-3.) We therefore recommend that a further bullet point be added under 'develop a care and support plan, and:' in section 1.3.2 that reads "- Care and support plans should be integrated with existing care and support plans for other pre-existing health conditions"	
Parkinson's UK	Short	20	3-5	We welcome the reference to the NICE Parkinson's guidelines for pharmacological management of Parkinson's Disease Dementia.	Thank you for your comment and your support for this recommendation.

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Parkinson's UK	Short	20	3-5	We are concerned there is no reference to the management of some symptoms of Lewy Body Dementia that are not covered in the NICE Parkinson's guidelines, namely REM sleep behaviour disorder, drooling, parkinsonism and autonomic symptoms. We recommend reference is made to the McKeith, I et al. (2017) 'Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium.' for management of symptoms.as well as for diagnosis.	Thank you for your comment. The committee noted that only very limited evidence was found on managing non-cognitive symptoms in people with Parkinson's disease dementia or dementia with Lewy bodies, and therefore agreed it was appropriate to cross-refer to the advice in the NICE Parkinson's disease guideline. However, the committee noted these interventions may need to be modified to be appropriate or a population of people living with dementia, and agreed it was important to highlight this within the recommendation
Parkinson's UK	Short	21	1-7	We are concerned that there is no reference in the guidance to the potential harmful effects, in regard to neuroleptic sensitivity, of anti-psychotic medication has on people with Lewy Body Dementia (Ballard C, Grace J, McKeith I, Holmes C. (1998) 'Neuroleptic sensitivity in dementia with Lewy bodies and Alzheimer's disease.' Lancet. 1998 Apr 4;351(9108):1032-3.) In the guidance 1.7.3 it advises the use of anti-psychotics in people with dementia experiencing hallucinations and agitation and so this is potentially harmful for people with Lewy Body Dementia.	Thank you for your comment. The committee noted the specific concerns around the risks of antipsychotics in people with dementia associated with Parkinson's disease, and therefore agreed to add an extra recommendation to this section, stating to "be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in NICE guideline on Parkinson's disease. Be aware that interventions may need to be modified for people living with dementia."

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				We recommend the guideline is revised to reflect this risk to people with Lewy Body Dementia.	
Parkinson's UK	Short	22	11	There is evidence, and experience from clinical practice that melatonin has been found to be beneficial for people with Lewy Body dementia with REM behavioural sleep disorder (Zhang W, Chen XY, Su SW, Jia QZ, Ding T, Zhu ZN, Zhang T. (2016) 'Exogenous melatonin for sleep disorders in neurodegenerative diseases: a meta-analysis of randomized clinical trials.' Neurological Sciences (2016) 37: 57). Parkinson's UK therefore recommends the addition of a recommendation to 'consider' the use of melatonin for people with Lewy Body dementia with REM behavioural sleep disorder.	Thank you for your comment. The committee noted this and the fact that the majority of the evidence from the trials was in Alzheimer's disease, and therefore agreed it was appropriate to amend this recommendation to "do not offer melatonin to manage insomnia in people living with Alzheimer's disease." The committee also agreed it was appropriate to add a cross-reference to the Parkinson's disease guideline for the management of non-cognitive symptoms (included RBD) covered there, as no evidence was identified specifically in people with PDD or DLB to allow recommendations to be made in this guideline.
Parkinson's UK	Short	24	9-13	We are concerned by the introducing of an anticipatory planning process when people with dementia are 'approaching the end of life' (1.10.2) because whilst recognising people in the later stages of the condition can still have capacity to make decisions (Hegde, S., & Ellajosyula, R. (2016). Capacity issues and	Thank you for your comment. The committee agreed that anticipatory healthcare planning may also be appropriate earlier than when someone is approaching the end of life, and a cross-reference has been added from this recommendation to the section on advance care planning to improve the clarity of this recommendation.

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				decision-making in dementia. Annals of Indian Academy of Neurology, 19(Suppl 1), S34–S39), factors affecting capacity such as cognitive impairment are more prevalent. We therefore recommend 1.10.2 is changed to "From diagnosis, introduce the anticipatory care planning process for people living with dementia. Involve the person and their family members or carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care. "	
Pennine Care NHS Foundation Trust	Full	179		Modifying risk factors for Dementia progress mentions a list of risk factors but does not mention hearing loss. In recent Lancet report (Vol 390 No. 10113) Dementia, Prevention, Intervention and Care, reports that uncorrected hearing loss between 45-65 years of age increased risk of developing Dementia at 9% higher than any of the risk factors listed in this Nice Guideline.	Thank you for your comment. The guideline only contained a section on modifying risk factors to slow the progression of established dementia. The guideline did not contain a section on risk factors for the development of dementia, and therefore it was not possible to consider this evidence within the review. However, the committee noted that the recently published NICE guideline on hearing loss did contain a research recommendation on this issue; specifically: "In adults with hearing loss, does the use of hearing aids reduce the incidence of dementia?" The committee agreed this was a relevant question to be addressed, the results of which could inform an update of either this guideline or the hearing loss guideline.

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Royal College of General Practitioners	short	8	18-24	Whose role is it to document this – secondary care, primary care? How will the information be shared to 'all relevant services'?	Thank you for your comment. The committee noted the concerns around how this recommendation was phrased, and it has therefore been amended simply to "document these decisions in the person's records," which would then be the responsibility of the service who have gathered this information.
Royal College of General Practitioners	short	8	27-29	How will this work in practice? Already, people are being discharged from dementia services with no mechanism for annual review or self-referral back into the system. For a degenerative condition, an annual review should be built in as standard, not necessarily an appointment, maybe a telephone call and/or 'paper clinic' when data like numbers of GP/A&E visits/social service contacts is examined to see if there's an escalation of need.	Thank you for your comment. The committee agreed that whilst the situation would be different in people lacking capacity, those with capacity had the right to decline services and follow-up if they so wished, and therefore the important issues were that people were offered future follow-up and contacts, and that there was a clear route for people back in to services when they wanted/needed it.
Royal College of General Practitioners	short	8	6-7	This would require a lot more long-term commitment of both health and social care teams to individual patients than currently exists	Thank you for your comment. The committee agreed that implementing these recommendations required good integration of health and social care services, but this was an important aspect of good care and one that should be encouraged throughout the guideline.
Royal College of General Practitioners	short	9	1-2	This is crucial, but requires an accessible and responsive service – not currently common.	Thank you for your comment. The committee agreed that services are not always currently arranged in a way that makes this possible, and therefore this was an important recommendation to make to drive services to be set up in a way to make it possible.

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Royal College of General Practitioners	short	10	12-14	This needs more emphasis e.g. a separate step in the guidelines 'reduce the anticholinergic burden of medication' – and more detail, if you stop a medication how much time does it typically take for any cognitive impairment it may have caused to recover? When to re-assess?	Thank you for your comment. The committee noted the guideline did already contain a recommendation to "consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives when assessing whether to refer a person with suspected dementia for diagnosis." The committee agreed that the limited nature of the evidence available meant this was as much detail as they were able to include in the recommendation.
Royal College of General Practitioners	short	10	27-28	What is the benefit of diagnosing specific subtypes of dementia – how much of the resources should go on potentially expensive tests compared to provision of care? Need clearer guidance on the 'if possible' aspect of this suggestion, especially if diagnostic tests are less accurate in certain age groups.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer

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					without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Royal College of General Practitioners	short	13	23-4	Massive resource implications, but this is the single most worthwhile intervention.	Thank you for your comment. The committee agreed both that there would be resource implications for this recommendation, but that the evidence clearly demonstrated it was an effective and worthwhile intervention.
Royal College of General Practitioners	short	14	18-21	In London, the Co-ordinate My Care website provides a way of doing this – used mainly for terminally ill patients. Can residential home/social services access this which would obviously be key for a similar tool in dementia?	Thank you for your response. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
Royal College of General Practitioners	Short	4 and 10		The guideline focuses on areas where "enough evidence is available to identify what works best". Recommendation 1.2.6 states that a referral is required to a dementia diagnostic service if "dementia is still suspected". There is no evidence that such a service provides better outcomes than a diagnosis made by a general practitioner. It may be argued that a GP is better able to diagnose dementia as they may have known the patient for several years and noted the cognitive decline. Using standard NICE language (page 5) this recommendation should be graded as "consider	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been

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				referral" and qualified with "if diagnostic uncertainty or there is a need to access services only available through secondary care". Dementia is a condition in which GPs have gained considerable experience due to its increasing prevalence. If the NHS is to cope with the increasing demand the model of care needs to shift from hospital to the more cost-effective primary care. The model in this guideline has failed to recognise this need and has not moved on from the earlier hospital based guideline.	added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Royal College of General Practitioners	Short	17	3	There are already huge capacity issues in diagnosing memory problems and dementia. We need to sort the bottleneck of specialist assessment. In practice, even GPs with a lot of experience are not recognised by social care or medicines management in being able to initiate medication or make care recommendations. If a GPwSI is meant attached to secondary care then the guideline should state this. It is important to increase near patient testing and more GPs being given authority to make the diagnosis which can authorise further care and intervention.	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been

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					added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Royal College of General Practitioners	short	18	15-17	Need guidance on whether cognition/memory tests delivered by interpreter are valid – if no research based evidence then please make this a recommendation for research as this will be a growing problem in the next 10-20 years. This should be included in the diagnosis section as well.	Thank you for your comment. Unfortunately, this recommendation comes from a section of NICE technology appraisal 217 that has not been updated as part of this guideline, and therefore it is not possible to make changes to this wording as part of the guideline update.
Royal College of General Practitioners	short	18	21-23	Need more detail – what other appropriate methods, is this referring to functional activity questionnaire etc	Thank you for your comment. Unfortunately, this recommendation comes from a section of NICE technology appraisal 217 that has not been updated as part of this guideline, and therefore it is not possible to make changes to this wording as part of the guideline update.
Royal College of General Practitioners	Short	18	27	It is not clear that if people are already being treated for diabetes or hypertension or ischaemic heart disease, then they need to stay on	Thank you for your comment. The committee agreed this point was covered by the part of the recommendation to "not offer the following to slow the progress of Alzheimer's disease." The

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				appropriate doses but these medications should not be used otherwise to slow the progress of dementia.	phrase "specifically to slow the progression of Alzheimer's disease" has now been used to make clear they should still be offered for relevant comorbidities. Treatment of the comorbidity itself would be covered by the alternative recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Royal College of General Practitioners	short	21	11-12	Is there a tool available to measure distress/risk of harm objectively?	Thank you for your comment. The committee agreed that no evidence was identified which enabled them to recommend a specific tool for this purpose.
Royal College of General Practitioners	Short	25	23	Please include "spiritual" with physical, mental, emotional needs.	Thank you for your comment. This has been changed as suggested.
Royal College of General Practitioners	Short	28	23	Otherwise very good and comprehensive. It is good to see examples of participatory groups being organised for carers and those with a dementia diagnosis, such as run by the National Museum of Scotland.	Thank you for your comment and your support for these recommendations.
Royal College of General Practitioners	Short	16 and 17		Recommendation 1.5.4 states that prescribing of dementia drugs should only be initiated by, amongst others, a GP with specialised expertise. There is no evidence that initiation is beyond the competence of a standard GP. GPs initiate many long-term medications with potentially serious	Thank you for your comment. The committee agreed the current guidance represented a shift towards more prescription of cholinesterase inhibitors and memantine in primary care, and this change was generally welcomed by stakeholders of the guideline. In particular, they noted the importance of establishing a clear diagnosis of Alzheimer's

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				side-effects. With the increasing prevalence of dementia GPs as a whole have developed increasing skills in this area and the management of dementia is now part of standard general practice. This recommendation is not based on the technology appraisal 127.	disease before starting treatment, as these treatments are not effective in many other dementia subtypes.
Royal College of General Practitioners	General	General	general	A helpful and wide-ranging document involving the main areas and problems and admitting gaps in knowledge. There is no mention of people with intellectual (learning) disabilities particularly people with Down's syndrome. The care pathways are considerably different in diagnosing, treatment and end of life care. Patients with intellectual disabilities are likely to already have a high treatment load and be on psychotropic medication before the onset of dementia. Annual screening of people with Down's syndrome from Dementia should be considered from at least the age of 40 years. The epidemiology of the condition-age, sex, race, social class, religion and how different cultures cope is valuable as well as the life expectancy and	Thank you for your comment. The committee noted that evidence on people with learning disabilities and dementia was looked for throughout the guideline, but little evidence was identified from which to make recommendations. However, the committee agreed it was appropriate to add a specific reference to learning disabilities in the section of the guideline on making services accessible to specific groups. The committee noted that neither screening nor prevention of dementia were within the scope of the guideline, and therefore it was not possible to make recommendations on these topics. Evidence on the effectiveness of various forms of respite care was looked for within the guideline, but only very limited evidence was identified, and therefore the committee did not feel able to make stronger recommendations than those currently included in the guideline.

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				changing morbidity needs to be outlined despite uncertainties The evidence on Prevention is patchy but would be worth discussing. The need to give relief to carers, by intermittent admission, day centres and a "sitting service" is important Given the very high prevalence of Dementia in the population, It would useful to contain evidence and recommendations from NICE about the model of dementia care within a system. Much of this guidance is about the social model of care rather than an over-focus on the biomedical but much an individual can do is dependent on the system in which they work	
Royal College of Nursing	Full	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop guidelines for the assessment, management and support for people living with dementia and their carers. The RCN invited comments from professionals who work with people living with dementia. The comments below represent the views of our reviewers.	Thank you for this, and the individual comments have been responded to where they appear.

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Royal College of Nursing	Full	General	General	The RCN have done some really helpful work with DAA (Dementia Action Alliance) during 2017 specifically on dementia and prisoners and dementia and learning disability. We feel that these are key areas of activity that require support and attention.	Thank you for your comment. The committee agreed there were a number of subgroups of people living with dementia (including those with learning disabilities) who have particularly complex needs. The committee noted there was currently a lack of evidence on how these individuals should be managed differently which made writing specific recommendations difficult, but they agreed it would be important to consider in future updates of the guideline if such evidence became available. This information has been passed onto NICE's surveillance and commissioning team for future consideration.
Royal College of Nursing	Full	General	General	Guidance is also needed regarding sexual intimacy in people living with dementia, particularly those in care settings. Our intimacy in care homes guidance is currently being refreshed and will be published shortly.	Thank you for your comment. The committee agreed this was an important issue and, whilst the evidence identified did not enable them to make specific recommendations within this guideline, they would welcome the publication of other guidance to cover this important area.
Royal College of Nursing	Full	General	General	The guidelines represent an excellent attempt to implement the ideals of assessment and management of people potentially living with dementia. There are good pockets of practice nationally for specialist diagnosis and it would be reasonably easy to build on these. However there is already conflicting guidance from the Royal College of General Practitioners which could potentially lead to misinterpretation by some	Thank you for your comment. The committee noted that some confusion had been caused by the wording of the draft guideline, in that people interpreted it as saying everyone need to attend an appointment at a secondary care service. The committee agreed the key issue was that everyone with suspected dementia had input from someone with expertise in dementia, both to ensure a correct diagnosis and ensure access to appropriate post-diagnostic support and treatment, but this did not mean the person necessarily had to travel to a

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				practitioners. To save confusion it may be sensible to include any additional or supportive guidance for diagnosis of people with dementia who will not attend a specialist service within the NICE guidance.	physical appointment at that service. To ensure this is clear in the final version of the guideline, an explanation has been added to this section of the guideline, giving the following explanation around the term 'refer': "A referral to a diagnostic service does not require that the person be asked to attend a clinic appointment. It can also involve people being seen in community settings (such as their home or a care home), or advice being provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment."
Royal College of Nursing	Full	General	General	Although services providing diagnosis are widespread there appears to be a shortage of specialist dementia services to provide follow up and ongoing support. In order to provide the standards set out in the guidance, we expect that there would be a large financial burden for many organisations to create these. For example in Dorset there are few services that specialise in dementia care after diagnosis. Most of the work is expected to be actioned by General Practices who may not have any specialist knowledge for dementia care.	Thank you for your comment. The committee noted that there are financial implications in providing post-diagnostic support for the large population of people living with dementia. However, they also agreed that appropriate follow-up and support was essential to ensuring good care for people after a diagnosis. They noted the recommendations made were deliberately not prescriptive about what form that follow-up should take, "a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service", as models of care vary considerably around the country, and the evidence did not enable them to identify which is the most appropriate.
Royal College of Nursing	Full	General	General	We have heard from our reviewers, that in some areas, the knowledge of dementia is poor outside	Thank you for your comment. The committee agreed with the importance of staff training for people working with people

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				those who work older people's specialist care services and therefore, potentially, the need to provide suitable training for many clinicians to skill them up in order to meet the recommendations set out in these guidelines would be high.	living with dementia. They noted that the recommendations for staff training made in this guideline would be relevant for all healthcare staff that provide services for people living with dementia.
Royal College of Nursing	Full	General	General	The 'person centred care' element and the need to include people living with dementia in decision making are key to the effective implementation of these guidelines. We consider that this would have the biggest impact on care. As these are fundamentals of all healthcare, we anticipate that they should be very easy to implement and in reality should be cost neutral.	Thank you for your comment and your support for these recommendations.
Royal College of Occupational Therapists	glossary	420		Abbreviation for General Health Questionnaire should read GHQ (not GDQ)	Thank you for pointing this out – it has now been corrected.
Royal College of Occupational Therapists	General	General	general	There is reference throughout to a lack of evidence of improvement being sustained at long-term follow-up: how realistic an aim is this in a degenerative condition?	Thank you for your comment. Whilst it may be unrealistic to expect people to improve from their baseline in absolute terms at long-term follow-up, the committee agreed it was reasonable to hope that interventions might show sustained benefit compared to the control group in the long-term. The absence of evidence for these long-term improvements was agreed to be a limitation in the evidence base that reduced the committee's confidence in the effectiveness of a number of interventions.

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Royal College of Occupational Therapists	Full	General comment		There is a theme of personalised activities, but no specific reference to the role that occupational therapists have in identifying, analysing, adapting and grading activities to meet this goal; either in direct service provision to people living with dementia and their carers (both formal and informal); or in advisory, training, consultative roles.	Thank you for your comment. NICE guidelines do not routinely comment on which specialists should be performing which roles in implementing recommendations unless there is clear evidence to do so. However, the committee did agree that occupational therapists would clearly be a key constituency in implementing these recommendations in practice.
Royal College of Occupational Therapists	Full	36	20-23	Clarity needed for recommendation 76: *Recommendation number 76.* "Consider providing a needs-based reablement programme (including elements of cognitive rehabilitation and/or occupational therapy) to people living with mild to moderate dementia who are not already accessing them." It seems to suggest that occupational therapy and cognitive rehabilitation are interchangeable- they are separate, albeit complementary interventions.	Thank you for your comment. The committee agreed it was not appropriate to suggest these interventions are interchangeable, and to clarify this the recommendation has been reworded as "consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia."
Royal College of Occupational Therapists	Full	36	17-19	*Recommendation number 75* "Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them."	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The

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				Appears to suggest that CST and reminiscence therapy are interchangeable, which is not correct. The recommendation on using Cognitive Stimulation Therapy appears to have been downgraded from the 2006 edition despite more evidence and a range of manualised CST programmes having been published since. Reference the UKOTRF funded study of OT-CSTdem (attached) re: added value of occupational therapist provided CST in terms of occupational focus.	committee agreed the evidence base was stronger for CST than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Royal College of Occupational Therapists	Full	291	20-23	Section 13.2.4.5 Reminiscence therapy Includes the term occupational therapy in this section that refers to reminiscence therapy – is this correct?	Thank you for pointing this out. This was an error (it should have send reminiscence therapy) and this has now been corrected.
Royal College of Occupational Therapists	Full	291	38	Should say occupational, not occupation.	Thank you for pointing this out, and this has now been corrected.
Royal College of Occupational Therapists	Full	297		Cognitive rehabilitation and occupational therapy "The committee noted that both the large studies of cognitive rehabilitation showed improvements in activities of daily living, with particularly large	Thank you for your comment and this correction. These recommendations have now been rewritten to separate out occupational therapy and cognitive rehabilitation as two

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				benefits shown in the recent UK HTA study. Benefits for depression and quality of life were also shown with occupational therapy, although a difference in activities of daily living could not be demonstrated here, as a number of the trials did not measure this as an outcome. However, the committee agreed that since the primary focus of occupational therapy interventions was on ADL, the impairments in quality of life seen were highly likely to be mediated through improvements in ADL. Again, the committee noted the benefits of occupational therapy were primarily found in group interventions, and noted that both elements of cognitive rehabilitation and occupational therapy incorporated could be incorporated within the same programme to help maximise the number of people who could benefit. The committee also agreed it was important to stress access to these interventions be needs-based, as they would be unlikely to be effective for people without problems with activities of daily living at baseline." The College finds this statement surprising. The four occupational therapy studies included were all dyadic, not group interventions.	separate and alternative approaches to improving functional ability in people living with dementia.

Dementia: assessment, management and support for people living with dementia and their carers

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Royal College of Occupational Therapists	Appendix F – excluded studies			**Section F11 – Supporting informal carers** 9.1 The explanation given for excluding both Graff papers (page 149) is that the Community Occupational Therapy intervention (COTiD) is "aimed at the person living with dementia, rather than their carer". This is not correct. The COTiD intervention is a dyadic intervention aimed at both the person living with dementia and their family carer. WHEDA, the translated version provided within the subsequent German study (page 157) is also a dyadic intervention. The Valuing Active Lifein Dementia (VALID) research programme has developed a UK version of the intervention and just completing a RCT with 468 pairs of people with dementia and their family carers, and again, the intervention is aimed at BOTH parties equally. **Graff (2006)** *Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial *Intervention primarily aimed at the person living with dementia, rather than their carer **Graff (2007)**	Thank you for your comment. The committee noted there many interventions in the guideline that contained elements aimed at both the person living with dementia and their carer, but for the purpose of the guideline it was necessary to divide these interventions in to categories. The committee decided that interventions would only be included in the section of the guideline on supporting carers if they were primarily aimed at the carer, whilst dyadic interventions would be included in the section on interventions for the person living with dementia. Since the interventions were dyadic aiming at both the person living with dementia and their carer in these papers (Graff 2006, Graff 2007, Voigt-Radloff 2009, Woods 2016), the committee agreed that these interventions were not primarily aimed at the carer of the person living with dementia, and therefore were not included in this section (although they were still included within the guideline). The text in the excluded studies section has been updated to make this clearer.

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				*Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial *Intervention primarily aimed at the person living with dementia, rather than their carer **Voigt-Radloff (2009)** *WHEDA study: effectiveness of occupational therapy at home for older people with dementia and their caregivers--the design of a pragmatic randomised controlled trial evaluating a Dutch programme in seven German centres *Intervention primarily aimed at the person living with dementia, rather than their carer 9.2 Likewise, the Remembering Yesterday, Caring Today (RYCT) reminiscence programme is designed for both the person living with dementia and their family carer to participate in together, indeed, there is a specific carer support and education strand within the programme. Hence, it does not make sense to exclude the REMCARE study (page 158) for this reason. (I know because I ran 15 rounds of the programme for two major research studies, including REMCARE!).	

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				Woods (2016) *REMCARE: Pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: Effectiveness and economic analysis *Intervention primarily aimed at the person living with dementia, rather than their carer	
Royal College of Ophthalmologists	Full	general	general	We are concerned that the use of the phrase 'sensory impairment' may prove confusing and non-specific and would be better replaced with 'vision and hearing impairment'. This is particularly relevant to this document as sensory interventions are quoted which are not the same but easy to confuse.	Thank you for your comment. For clarity, this has now been changed to "sensory impairment (such as sight or hearing loss)"
Royal College of Ophthalmologists	Full	general	general	We are in agreement with the responses on the draft guidelines made by the Alzheimer's Society and VisionUK.	Thank you for your comment. The comments from these other stakeholders have been responded to where they appear in this document.
Royal College of Ophthalmologists	Full	389	31	The PrOVIDe study demonstrated that 1/3 of patients have visual impairment which is related to falls. This is already part of the Falls NICE guidance but due to the increased prevalence of visual morbidity in this group special provision should be made. We recommend that special attention is made for visual assessment and rehabilitation is made for patients with dementia	Thank you for your comment. The committee noted this evidence and concern, but agreed that in the absence of specific evidence on how this should be managed differently in people living with dementia, this should be covered by a cross-reference to the NICE falls guideline, and by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care

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				suffering falls and that they have a vision check as part of their post-fall assessment. https://www.college-optometrists.org/the-college/research/research-projects/provide-dementia.html	services for comorbidities to people who do not have dementia." They also agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years"
Royal College of Ophthalmologists	Full	394	21	We are concerned that no reference has been made to visual impairment. The PrOVIDe study recently demonstrated that there is an increased level of visual impairment compared to the non-dementia population with 1/3 of people with dementia suffering from visual impairment. The RCOphth, College of Optoms and VISION UK recommend yearly optometry checks in people with dementia. https://www.visionuk.org.uk/vision-uk-dementia-sight-loss-committee-statement-dementia-eye-examinations/	Thank you for your comment. The committee noted this evidence and agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years", in line with the recommendations for hearing tests for people living with dementia in the NICE guideline on hearing loss. The committee agreed that once someone was identified as having visual impairment, they should then be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."

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Royal College of Physicians	Short	General	General	The RCP is grateful for the opportunity to respond to the above consultation, We have liaised with The British Association of Audiovestibular Physicians (BAAP) and with our Hearing loss Guideline Committee, and would like to make the following comments.	Thank you for taking the time to comment on the guideline. Individual comments have been responded to where they appear.
Royal College of Physicians	Short	20-21	19	Managing non-cognitive symptoms. Our experts note that there is no mention of managing sensory impairment in this section but stress that this is a very worthwhile and easily treatable option in this group of people being both cost effective and clinically effective. Managing the hearing loss in someone with hearing difficulties and cognitive impairment can make a huge difference in their understanding of the world around them. Being able to hear speech is fundamental to being able to understand speech. Being able to hear can reduce confusion and anger, improve depression and alleviate feelings of isolation. This is so important in this group and it is such a shame that sensory impairment, and in particular, hearing loss, has been ignored as a treatable option in view of its prevalence in this population.	Thank you for your comment. The committee noted this point, and agreed it was appropriate to include a cross-reference to the NICE guideline on hearing loss to address these issues.

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				Please refer to the NICE Guidelines on Adult Hearing Loss in preparation. Also: Amieva H, Ouvrard C, Giulioli C, Meillon C, Rullier L, Dartigues JF. Self-reported hearing loss, hearing aids, and cognitive decline in elderly adults: a 25-Year Study. *J Am Geriatr Soc* 2015; **63:** 2099–104., Livingston G. (2017). Dementia prevention, intervention, and care. The Lancet. doi: 10.1016/S0140-6736(17)31363-6	
Royal College of Physicians	Short	9	23	Our experts believe that an important step has been omitted from the guideline. It is important that before you carry out tests listed subsequently you ensure the individual is hearing you adequately. Any test that relies on oral communication could not be viewed as a valid test of cognition unless you have previously ensured that the individual can hear. This is important because there is a strong association between hearing loss and dementia (Lin et al 2011, Gurgel et al 2014, Thomson et al 2017). Hearing impairment will affect a person's ability to understand a verbal test and not everyone with hearing loss is aware of their disability, particularly if they have concomitant cognitive	Thank you for your comment. The committee agreed with the point made and hearing loss has been added to the recommendation on reversible causes of cognitive decline that should be investigated in primary care.

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				impairment (Livingston 2017). Non-verbal testing of cognitive function is important before going further down the assessment route. Lin FR, Metter EJ, O'Brien RJ, Resnick SM, Zonderman AB, Ferrucci L. Hearing loss and incident dementia. Archives of Neurology. 2011; 68(2):214-220, Thomson et al Hearing Loss as a Risk Factor for Dementia: A Systematic Review Laryngoscope Investigative Otolaryngology 2: April 2017 69-79 Livingston G. (2017). Dementia prevention, intervention, and care. The Lancet. doi: 10.1016/S0140-6736(17)31363-6	
Royal College of Physicians	Short	10	12	**Could you include hearing loss or depression as reversible causes of cognitive decline?** Hearing aids have been found to attenuate cognitive decline. (Amieva 2014, Livingston 2017) Certainly, if your initial impression was reliant on an oral test then reassessing after management of hearing loss may be valuable. Amieva H, Ouvrard C, Giulioli C, Meillon C, Rullier L, Dartigues JF. Self-reported hearing loss, hearing	Thank you for your comment. The committee agreed with this suggestion and both depression and hearing loss have been added to the list of reversible causes of cognitive decline which should be investigated in primary care.

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				aids, and cognitive decline in elderly adults: a 25-Year Study. *J Am Geriatr Soc* 2015; **63:** 2099–104., Livingston G. (2017). Dementia prevention, intervention, and care. The Lancet. doi: 10.1016/S0140-6736(17)31363-6	
Royal College of Physicians	Short	13	12	It is important at this point to also consider testing hearing formally and providing the individual with hearing loss with hearing aids and other support for hearing loss as that will make a difference to any rehabilitation programme. If the patient can hear what is said to them they will find it easier to understand. The earlier this happens the better.	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed that once a person was identified as having hearing loss, they would be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Royal College of Physicians	Short	18	6-14	Our experts note the recognition of hearing loss being an important element to assessing and managing these individuals within this section, but are concerned that in the meantime the patient may have had a series of assessments during which they may not have heard what was expected of them. These may include lumbar puncture and administration of medication. Our	Thank you for your comment. Unfortunately, this recommendation comes from a section of NICE technology appraisal 217 that has not been updated as part of this guideline, and therefore it is not possible to make changes to this wording as part of the guideline update.

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				experts reiterate that a hearing test should supersede other assessments.	
Royal College of Physicians	Full	General	General	People of advancing years are not necessarily aware they have difficulty hearing, some accept it as part of the aging process, others do not have the ability to raise the concern themselves. Carers, whether family or professional, are not trained to consider hearing loss as a factor and many are more inclined to put difficulties in understanding down to cognitive decline rather than hearing loss. The whole can be a vicious cycle with hearing loss leading to limited understanding and then depression which in turn leads to worse difficulties with communication with carers stopping talking to the patient leading to greater depression and isolation. Breaking that dreadful cycle with good management of hearing loss puts the whole thing on a different footing – carers are aware of hearing difficulties, hopefully they will make every attempt to communicate effectively and the patient can hear better, understand better and thus respond more. This alleviates anxiety and can help depression and reduce isolation. Our experts note however that first you have to consider that hearing loss may	Thank you for your comment. The committee agreed the most appropriate way to address issues around hearing loss was by adding a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia. The committee also agreed it was appropriate to add hearing loss to the list of possible dementia mimics which should be investigated in primary care before referral for diagnosis (recommendation 1.2.6 in the short guideline). Finally, the committee agreed that once hearing loss was identified in a person living with dementia, this should be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia"

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				occur and know that it will affect the majority of the elderly population. Even mild hearing loss is associated with twice the risk of dementia while severe hearing loss is associated with 5 times the risk of dementia. (Lin 2011) The only way you will know if your patient has a hearing loss is to get it formally assessed.	
Royal College of Physicians	Full	42	19	**'Common dementia mimics in primary care include depression, side-effects of medicines and sensory impairments such as hearing loss.'** Our experts note that this is not reflected in the recommendations and suggest that hearing assessment should be the first step in investigation.	Thank you for your comment. The committee agreed with this suggestion and both depression and hearing loss have been added to the list of reversible causes of cognitive decline that should be investigated in primary care.
Royal College of Physicians	Full	395	22	Our experts note that this paragraph appears to refer to the paper by Adrait 2017 but the document states 'people living with Alzheimer's disease and mild age related hearing loss.' The inclusion criteria in Adrait's paper was individuals with hearing loss between 21 and 80 dB HL which includes mild, moderate and severe hearing loss. Our experts question whether there is another	Thank you for pointing this out, and this has now been corrected by removing the reference to the population as having mild hearing loss.

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				paper or does the reference to 'mild' indicate bias? Looking at the data in this paper it is stated that hearing levels were between 30.5 and 69 dB HL which implies pure tone averages. The means are around 50 dB HL. Our experts note that this is an extreme loss of hearing. Normal conversational voice is around 50 dB HL and one has to be hearing about 30 dB better than this to hear properly in a quiet environment – these people will just not be able to hear normal conversational voice clearly. Our experts believe that this cannot be called mild. With an average of 69 dB HL and age related deafness the hearing loss in the high frequencies will be profound. These people have significant hearing loss and the 'mild' description mentioned in the paper refers to cognitive function.	
Royal College of Physicians	full	399	27	Our experts note that it is unfortunate that the analysis of Adrait 2017 failed to acknowledge that a significant finding in the paper was improvement in The Alzheimer Disease Related Quality of Life (ADRQL) between the group having	Thank you for your comment. The evidence statements for this study have now been updated to make clear that an improvement in quality of life was found at 12 months. However, the committee agreed the study did not provide sufficient evidence by itself to justify making a positive

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				amplification for 12 months against those with it for 6 months. If one looks at the questionnaires examined in this paper, the ADRQL is the only one that looks in any way at the quality of communication rather than non-auditory function. This then may be an important positive finding that has not been considered. Clearly the good users achieved good scores on this test considering they had diagnosed dementia and advanced age and thus poor neural plasticity. This sort of result encourages one to recommend research looking at the QoL questionnaires that are more applicable to hearing loss and communication to see whether early changes in communication translate into improved quality of life over time. The researchers themselves question whether hearing aids would be of more value in a younger age group. Our experts believe that further research is needed.	recommendation for this intervention, due to the small sample size of the study. The committee noted that only very limited RCT evidence was identified on the use of hearing aids specifically in a population of people living with dementia. The committee agreed therefore that, in the absence of evidence, people living with dementia should receive the same access to interventions for hearing loss as people without dementia. Specifically, they agreed this was covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." The committee also agreed it was appropriate to add a cross-reference to the NICE guideline on hearing loss, which makes recommendations on hearing assessments for people with suspected and diagnosed dementia The committee noted that the recently published NICE guideline on hearing loss did contain a research recommendation on this issue; specifically:

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					"In adults with hearing loss, does the use of hearing aids reduce the incidence of dementia?" The committee agreed this was a relevant question to be addressed, the results of which could inform an update of either this guideline or the hearing loss guideline.
Royal College of Physicians	full	401	No page number	**Sensory impairment. '…but it was felt that the relevant populations were small, and that it was unlikely trials could not conducted of a sufficient size to provide definitive answers to this question.'** Our experts note that this sentence needs to be edited and also question whether the size of the population was considered. Hearing loss affects about 70% of those over 70 years; the figures vary but Davies (1995) in a major epidemiological study found 71.1% of those over 70 had hearing loss and found that 41.7% of those over 50 had measurable hearing loss (reported by Action on Hearing Loss). The Health and Safety Executive report in 2014 (HSE2014) states '31% of adults aged 65 and over had good hearing or only minimal objective hearing loss in both ears at both 1 kHz and 3 kHz. The remainder (69%) had some hearing loss.' Then Lin 2011 has	Thank you for your comment. The committee noted this point, and agreed it was appropriate to remove this statement from the committee's discussion of the evidence in this section.

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				demonstrated that mild hearing loss is associated with double the incidence of dementia and severe hearing loss with nearly 5 times higher incidence. This would mean that a significant majority of patients with dementia would have hearing impairment. Our experts suggest that NICE reconsider the wording in this part of the guideline and note that it would have been beneficial to speak to the guideline centre for adult hearing loss to prevent different messages coming out of NICE at the same time. The need for research into hearing loss and dementia is very important; not only for prevention but from the point of view of management and the value of strategies to minimise the impact of hearing loss. NHS England: Commissioning Services for People with Hearing Loss https://www.england.nhs.uk/wp-content/uploads/2016/07/HLCF.pdf Davis A. Hearing in Adults. London: Whurr; 1995. Reported by Action on Hearing Loss in Hearing Matters Report. HSE2014 http://healthsurvey.hscic.gov.uk/media/33545/H	

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				SE2014-Ch4-Hearing.pdf provides statistic from numerous sources.	
Royal College of Psychiatrists	Short	General	General	We welcome the broadening of the categories of professional staff who can diagnose and prescribe for dementia. It is in keeping with a move to a chronic disease management model of care with secondary expertise becoming more focused upon the more complex or 'risky' presentations. The end of life planning and admission to hospital suggestions are very welcome. The guidance should acknowledge the case for combination therapy as an early and recommended approach. The guidance published by the British Association of Psychopharmacology makes a clear case for the use of combination therapy (https://www.bap.org.uk/pdfs/BAP_Guidelines-AntiDementia.pdf). The suggestions around other psychotropic medication use is clear and welcome.	Thank you for your comments and your support for these recommendations. The committee agreed there was good evidence of benefits from combination therapy in people with moderate to severe Alzheimer's disease, and this led to the recommendation that: "For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor: • consider memantine in addition to an AChE inhibitor if they have moderate disease • offer memantine in addition to an AChE inhibitor if they have severe disease." The committee also made a research recommendation around combination therapy for people with dementia with Lewy bodies, to match that made in the Parkinson's disease guideline for people with Parkinson's disease dementia.
Royal College of Psychiatrists	Short	General	General	Greater clarity would be helpful about which Cognitive Assessment Tests should be used in secondary care Memory Assessment clinics	Thank you for your comment. The committee agreed the evidence available in this area did not enable them to make recommendations around which cognitive test should be sued

Dementia: assessment, management and support for people living with dementia and their carers

Consultation on draft guideline - Stakeholder comments table
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				because international consensus groups such as ICHOMS have recommended MoCA ahead of ACE. Regarding diagnosis of dementia in general hospital: • The long CAM is not a user friendly instrument and is not easily used on busy and noisy general hospital settings • The OSLA is not a readily available tool • There is no mention of the 4AT tool that is recommended in SIGN delirium guidance and can potentially be helpful to differentiate between delirium and dementia	in specialist settings, but did agreed a specific recommendation should be added around neuropsychological testing: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is." The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is covered by the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.

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Royal College of Psychiatrists	Short	16-17		The recommendation that first prescription of CEI and Memantine can be made in primary care is helpful as this may allow us to move away from the bureaucratic use of formal shared care prescribing protocols and improve medicines reconciliation; a stronger statement in this respect would be helpful using the word should rather than may: Instead of *"Once a decision has been made to start an AChE inhibitor or memantine, the first prescription **may** be made in primary care"* it would be better to say "*Once a decision has been made to start an AChE inhibitor or memantine, the first prescription **should** be made in primary care"*	Thank you for your comment. The committee agreed that cholinesterase inhibitors and memantine can be safely prescribed in primary care. However, they also agreed the evidence did not demonstrate there were sufficiently clear benefits from this approach to make an explicit statement they should be prescribed in this way.
Royal College of Psychiatrists	Full	General	General	**Access to research and option to register for Join Dementia Research** People living with dementia and their families have a right to be informed about research, and to choose whether or not to take part. Health and Social care services have a responsibility to provide information about and access to research, which should be included within NICE guidelines.	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."

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				The UK Policy Framework for Health and social care research states that: *"1.1. The Health Research Authority (HRA) and the UK Health Departments are committed to an environment where:* *-patients, service users and the public are given, and take, the opportunity to participate in health and social care research and to get involved in its design, management, conduct and dissemination, and are confident about doing so;* *-commissioners and providers of health and social care appreciate how health and social care research benefits patients, service users, staff and the public, and make their resources available for research"*	
Royal College of Psychiatrists	Full	104/109	12-24	It's unclear from the evidence considered on page 104 how a justification has been reached for a recommendation for CSF analysis given the evidence that most cases presenting to memory clinics would be of an age where CSF testing will most likely be unreliable. The evidence for CSF testing that is most robust is made for rapidly	Thank you for your comment. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that

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				progressing Dementias and CJD but there's little mention of that in the recommendations.	conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee noted that CSF examination would not be appropriate in some cases due to a person's age, and made a specific recommendation to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination." They did agree, however, that there were cases in younger individuals with an unclear diagnosis where CSF examination would provide diagnostic value. The committee agreed there was robust evidence of the value of CSF examination in rapidly progressive dementia, and made a specific recommendation on this point: "If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt-Jakob disease and similar conditions."
Royal College of Psychiatrists	Full	132/133	General	RCPsych agrees with these general recommendations to provide support and involve patients with Dementia and their carers. A noticeable omission in all the recommendations listed is a signpost to capacity assessment and	Thank you for your comment. The committee agreed that it was appropriate to include a link to the NICE guideline on Decision-making and mental capacity (which is due to be published in July 2018) at the start of the recommendations,

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				relevant guidelines (including the imminent NICE guideline on Mental Capacity and Decision making). Again, it's worth noting that many of the recommendations made here are equally relevant for those patients diagnosed with MCI, a significant proportion of which the risk of progressing to Dementia is high, making it necessary to ask the question about MCI, when recommendations such as advance care planning should also be equally, if not more so relevant before capacity issues become a constraint.	and a link to the Mental Capacity Act itself, and the accompanying Code of Practice. Management of mild cognitive impairment was not within the scope of the guideline, and therefore it was not possible to make recommendations on this topic, including in the areas of advance care planning.
Royal College of Psychiatrists	Full	300/301	74-81	The evidence states on page 297 "The committee noted that both the large studies of cognitive rehabilitation showed improvements in activities of daily living, with particularly large benefits shown in the recent UK HTA study. Benefits for depression and quality of life were also shown with occupational therapy, although a difference in activities of daily living could not be demonstrated here, as a number of the trials did not measure this as an outcome. However, the committee agreed that since the primary focus of occupational therapy interventions was on ADL, the impairments in quality of life seen were highly likely to be mediated through improvements in ADL"	Thank you for your comment. Please find below a response for each of the papers you cited. Spector (2003) as an individual study reported an improvement in quality of life, but the pooled result of the meta-analysis when other studies were included could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool

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<tr><td></td><td></td><td></td><td></td><td>This makes the negative recommendations given as well as the “do not offer” recommendations in the face of a lack of evidence of harm as explicitly stated extremely baffling and suggestive of significant bias on the part of the committee. RCPsych also agrees with other views raised by colleagues on Cognitive stimulation therapy (CST) especially and support the evidence stated below.

The research evidence for Cognitive Stimulation has grown enormously since the 2006 guidelines. However, the tables of evidence (Appendix E, p.342 onwards) exclude several <i>essential studies</i> noted below. The full report (p.296), states that ‘no evidence of benefits were found in any outcomes other than cognition’. Table 1 below includes several randomised controlled trials on Cognitive Stimulation, noting a) outcomes (other than cognition) that significantly improved and b)whether or not they were included in the evidence review.
Table 1
<table>
<tr><td>Authors of RCT paper</td><td>Outcomes which <i>significantly</i> improved in</td><td>Included i
evidence,
appendix E</td></tr>
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</td><td>with the other quality of life measures found in other studies, so this data point was not included.

Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis.

Orrell (2014) reported an improvement in QoL-AD, but the pooled result of the meta-analysis when other studies were included could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care.

Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia.

Stewart (2017) would have been excluded because they used a before-after study design. This type of study design was</td></tr>
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<tr><td></td><td>addition to cognition</td><td></td></tr>
<tr><td>Spector et al, 2003</td><td>Quality of life</td><td>Yes</td></tr>
<tr><td>Yamanaka et al, 2013</td><td>Mood</td><td>Yes</td></tr>
<tr><td>Capotosto et al, 2017</td><td>Quality of life</td><td>No</td></tr>
<tr><td>Paddick et al, 2017</td><td>Anxiety, behavioural symptoms, quality of life</td><td>No</td></tr>
<tr><td>Orrell et al, 2014</td><td>Quality of life, Activities of daily living</td><td>Yes</td></tr>
<tr><td>Niu et al, 2010</td><td>Depression, apathy</td><td>No</td></tr>
<tr><td>Stewart et al, 2017</td><td>Depression</td><td>No</td></tr>
</table>

A synthesis of 22 systematic reviews on psychosocial interventions for dementia, including 197 unique studies, has just been published (McDermott et al, 2018). Only two interventions were specifically recommended in the conclusions: group Cognitive Stimulation and</td><td>excluded because there was enough evidence on randomised controlled trials (RCTs).

All included studies in the review by McDermott (2018) had been already considered in Appendix O and the updated search for RCTs would have been found individual studies included in these reviews.

Matsuda (2007) was a non-randomised study excluded by Woods (2012) which was used as the source of RCTs for cognitive stimulation therapy.

Wong (2017) would have been excluded because the aim was to investigate the feasibility and cultural appropriateness of CST in Hong Kong.

Olazaran (2010) was included as a systematic review in Appendix O but data was not extracted because Olazaran (2010) did not report details of the individual studies in included in their systematic review.

Notwithstanding the comments above, the committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The</td></tr>
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				Multi-component exercise. Of the former, they concluded that 'group Cognitive Stimulation improves cognitive function, social interaction and quality of life'. This synthesis is unique in its methodology and offers the most up-to-date information on ALL psychosocial interventions for dementia. Further, a Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects AND that there is evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis. In summary: • There is consistent evidence that Cognitive Stimulation improves other domains in addition to cognition. Much of this data was available within the reviewed studies, suggesting some	committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				misunderstanding or misinterpretation of the results. • The evidence reviewed (listed in Appendix E) omitted several key trials. In addition to those noted above, we spotted other key missing trials including that of Matsuda et al (2007) and Wong et al (2017). All references are provided below. 2) No evidence that the effects of Cognitive Stimulation went away after the intervention stopped We agree with this point, although do not feel that this could be justification for not offering an intervention. Given the degenerative nature of dementia, the same is likely to be true for any pharmacological or non-pharmacological intervention and would argue that there is no intervention which has evidence of long-term benefits in dementia. Since the 2006 guidelines, a trial by Orrell et al (2014) has shown that weekly CST results in continuous benefits to quality of life for up to six months. This work was not commented upon in the conclusions.	

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				3) Unclear whether it was specific content of the interventions or simply being part of a group. We would argue that this is an erroneous conclusion. Whilst the literature on non-pharmacological interventions spans several decades and hundreds of studies, the evidence base for manualised, Cognitive Stimulation is considerably stronger than for other interventions, including Reminiscence. For example, a systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions. Several trials within the Cochrane review compared Cognitive Stimulation with an active, social control group, yet the results were consistently in favour of structured group Cognitive Stimulation over a social control (Woods et al, 2012). 6) The two interventions are not mutually exclusive It is correct that Cognitive Stimulation incorporates some aspects of Reminiscence. However, the key focus of Cognitive Stimulation (more specifically the manualised 'CST' programme which is widely followed) is on	

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				generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills and enable new semantic connections to be made. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). We believe that this provides a different message and thus reduces stigma associated with dementia and old age. • 5) Both interventions forming part of activities There are several issues here. Firstly, the evidence base for Cognitive Stimulation is consistently stronger than for Reminiscence. Secondly, whilst there is strong research and clinical evidence for CST when used as a manualised intervention, *there is NO evidence for any benefits if just elements of the programme are used and no evidence, in general, for structured group activities.* Further, having a clear manual, which can be followed by a range of health and social	

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				workers at all levels of expertise; eases implementation and minimises preparation time, providing a highly cost-effective intervention. This change in wording will create ambiguity and is likely to be interpreted that any type of structured group is sufficient, and there will be a lack of governance and adherence to any sort of standardisation. The conclusion in the report that "this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according to important key principles which fit with the underlying theoretical models. We would encourage NICE to argue for more adherence to protocol and evidence base, rather than less. 7) <u>No difference in cost of delivery</u> The nice report states that "there would be no difference in cost of delivery between providing an intervention with a more varied range of components". We would argue that this	

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				assumption cannot be made without a cost effectiveness analysis. There is strong evidence for the cost effectiveness of manualised CST, with two key papers published since the 2006 guidelines (Knapp et al, 2006; D'Amico et al, 2015). Essentially, the cost of an intervention does not just consider the costs of delivery, but also the changes in use of health and social care services for those in receipt of an intervention. Such complex analysis was completed by health economists as part of two CST trials and cannot be presumed for other interventions. Appendix J (p.10) considers the cost of providing CST. There are several errors in this table. Firstly, it states that band 4 or 6 staff are required to run sessions, when in reality it is often band 2 staff. Secondly, it states that groups are for 5 people, when in fact the key research trials included between 5-10 people in each group and many trusts offer groups for up to ten people. The total cost per session is calculated as £233.19. The Knapp (2006) paper calculated the cost per session as £90. Using the Knapp cost per session calculation, even with just 5 people in each group, the total cost per patient per CST course (14 sessions) is £252, compared to NICE's estimate of £652.94.	

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				Additionally, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually. Other notes 1. ; New proposed wording, which suggests 'elements' of cognitive stimulation and reminiscence therapy and uses the words 'consider' rather than 'recommend'. Given that the evidence base for CST has markedly expanded since the 2006 guidelines, we question why the wording has changed and recommend that NICE revert to their former wording from 2006.	

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				We note that most of the psychosocial interventions are preceded with 'consider', yet many of the pharmacological interventions are 'recommended'; a marked change from the 2006 guidelines. 2) Changes within NHS and beyond since the 2006 guidelines CST is now a required standard for the Memory Services National Accreditation Programme (MSNAP) and an audit in 2017 suggested that around 85% of MSNAP accredited memory services routinely offer group CST to people following a diagnosis of dementia. Approximately x% of all UK memory services are accredited and anecdotal evidence suggests that a similar pattern of CST provision is occurring in non-accredited memory services. This widespread provision is offering hope for people post diagnosis, social support and a structured, evidence-based therapy which maintains cognitive functioning and normalises the experience of dementia. Several other reports have endorsed CST since the 2006 guidelines. For example, the World Alzheimer Report (Alzheimer's Disease International), in 2012 and subsequently; have	

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				stated that CST should routinely be given to people with early stage dementia. <u>References</u> Aguirre E, Spector A, Streater A, Hoe J, Woods B and Orrell M (2012). Making a Difference 2: an evidence based group program to offer maintenance Cognitive Stimulation Therapy (CST) to people with dementia. Hawker Publications, UK. Alves, J., Alves-Costa, F., Magalhães, R., Gonçalves, Ó. F., & Sampaio, A. (2014). Cognitive stimulation for Portuguese older adults with cognitive impairment: a randomized controlled trial of efficacy, comparative duration, feasibility, and experiential relevance. *American Journal of Alzheimer's Disease & Other Dementias®*, *29*(6), 503-512. Capotosto E, Belacchi C, Gardini S, Faggian S, Piras F, Mantoan V, Salvalaio E, Pradelli S, Borella E (2017). Cognitive Stimulation Therapy in the Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry,32:331-340	

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				D'Amico F, Rehill A, Knapp M, Aguirre E, Donovan H, Hoare Z, Hoe J, Russell I, Spector A, Streater A, Whitaker C, Woods RT, Orrell M (2015) Maintenance cognitive stimulation therapy: an economic evaluation within a randomised controlled trial. *Journal of the American Medical Directors Association,* 16 (1): 63-70. Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *British Journal of Psychiatry*, 188: 574-580. Matsuda, O. (2007). Cognitive stimulation therapy for Alzheimer's disease: the effect of cognitive stimulation therapy on the progression of mild Alzheimer's disease in patients treated with donepezil. *International Psychogeriatrics*, *19*(2), 241-252. McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., ... & Orrell, M. (2018). Psychosocial interventions for people with dementia: a synthesis of systematic reviews.	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Aging and Mental Health, DOI 10.1080/13607863.2017.1423031 Niu, Y. X., Tan, J. P., Guan, J. Q., Zhang, Z. Q., & Wang, L. N. (2010). Cognitive stimulation therapy in the treatment of neuropsychiatric symptoms in Alzheimer's disease: a randomized controlled trial. *Clinical rehabilitation*, *24*(12), 1102-1111. Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, Woods B, Beck C, Auer S, Lai C, Spector A, Fazio S, Bond J, Kivipelto M, Brodaty H, Rojo JM, Collins H, Teri L, Mittelman M, Orrell M, Feldman HH, Muñiz R (2010). Non-pharmacological therapies in Alzheimer's disease: A systematic review of efficacy. Dementia and Geriatric Cognitive Disorders;32:161-178 Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Russell I, (2014) Maintenance cognitive stimulation therapy (CST) for dementia: single-blind, multicentre, pragmatic randomized controlled trial. *British Journal of Psychiatry* 2014 (204): 1-8. Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017).	

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				Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, *29*(6), 979-989. Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry*, 183, 248-254. Spector A, Thorgrimsen L, Woods B, Orrell M (2006) Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy (CST) to people with dementia. Hawker Publications, UK. Stewart, D. B., Berg-Weger, M., Tebb, S., Sakamoto, M., Roselle, K., Downing, L., ... & Hayden, D. (2017). Making a Difference: A Study of Cognitive Stimulation Therapy for Persons with Dementia. *Journal of Gerontological Social Work*, 1-13.	

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				Yamanaka K, Kawano Y, Noguchi D, Nakaaki S, Watanabe N, Amano T, Spector A (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, 17:579-586. Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562. Wong, G. H., Yek, O. P., Zhang, A. Y., Lum, T., & Spector, A. (2017). Cultural adaptation of cognitive stimulation therapy (CST) for Chinese people with dementia: multicentre pilot study. *International Journal of Geriatric Psychiatry*. Yamanaka K, Kawano Y, Noguchi D, Nakaaki S, Watanabe N, Amano T, Spector A (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, 17:579-586.	

Dementia: assessment, management and support for people living with dementia and their carers

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Stakeholder	Document	Page No	Line No	Comments	Developer's response
Royal College of Psychiatrists	Full	101	General	RCPsych is concerned that this guideline focuses so narrowly on dementia but excludes dementia screening and Mild Cognitive Impairment (MCI) in particular as "not within the scope of this guideline". This can be problematic for those diagnosed with or suspected of having MCI which can have a substantial overlap with early Dementia. It would be helpful if this distinction and the scope of the guideline is explicitly stated at the outset in both the short and full guideline to ensure readers are aware MCI is not included within this guideline.	Thank you for your comment. As you correctly state, dementia screening and the diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed. The committee noted that the exclusion of these issues is clearly stated within the scope of the guideline.
Royal College of Psychiatrists	Full	101	General	Whilst mention is made of the "challenges of diagnosing Dementia in certain vulnerable groups.", it's surprising that whilst appropriate mention is made of learning disability specialists, no mention, recognition or direction is given towards Old Age Psychiatrists specifically and Old age psychiatric specialist teams who undoubtedly have the necessary specialist training, experience and recognition in assessing and managing patients with all stages and types of Dementia. There is no evidence given of why this omission appears to have been perpetuated throughout this guideline. The statement "specialist diagnostic services" is misleading and of little	Thank you for your comment. The committee agreed that old age psychiatrists are likely to be the most common prescribers, but agreed it was appropriate to be more general in the recommendation to avoid giving the impression that other subtypes of psychiatry (such as learning disabilities psychiatrists) were not appropriate prescribers.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				value. Further mention of "a memory service or equivalent hospital- or primary care-based multidisciplinary dementia service" is generic and fails to take account of the specialist training and expertise of Old age psychiatrists in assessing and managing Dementia.	
Royal College of Psychiatrists	Full	119	23-25	There is surprisingly no mention at all of using the 4AT to distinguish delirium from Dementia. This is now a commonly used test that has high sensitivity and specificity and is easy to use References: O'Sullivan D, Brady N, Manning E, O'Shea E, O'Grady S, O 'Regan N, Timmons S. **Validation of the 6-ItemCognitive Impairment Test and the 4AT test for combined delirium and dementia screening in older Emergency Department attendees.** Age Ageing. 2017; Sep 1:1-7 [Epub ahead of print] Baird L, Spiller JA. **A quality improvement approach to cognitive assessment on hospice admission: could we use the 4AT or Short CAM?** BMJ Open Qual. 2017; 6(2):e000153. Infante MT, Pardini M, Balestrino M, Finocchi C, Malfatto L, Bellelli G, Mancardi GL, Gandolfo C, Serrati C. **Delirium in the acute phase after**	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is include in the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				stroke: comparison between methods of detection. Neurol Sci. 2017; 386:1101-1104 De J, Wand AP, Smerdely PI, Hunt GE. Validating the 4A's test in screening for delirium in a culturally diverse geriatric inpatient population. Int J Geriatr Psychiatry. 2016; Oct 20. [Epub ahead of print] Hendry K, Quinn TJ, Evans J, Scortichini V, Miller H, Burns J, Cunnington A, Stott DJ. Evaluation of delirium screening tools in geriatric medical inpatients: a diagnostic test accuracy study. Age Ageing. 2016; 45:832-837 Kuladee S, Prachason T. Development and validation of the Thai version of the 4 'A's Test for delirium screening in hospitalized elderly patients with acute medical illnesses. Neuropsychiatr Dis Treat. 2016; 12:437-43 Bellelli G, Morandi A, Davis DH, Mazzola P, Turco R, Gentile S, Ryan T, Cash H, Guerini F, Torpilliesi T, Del Santo F, Trabucchi M, Annoni G, MacLullich AM. Validation of the 4AT, a new instrument for rapid delirium screening: a study in 234 hospitalised older people. Age Ageing. 2014; 43:496-502 Lees R, Corbet S, Johnston C, Moffitt E, Shaw G, Quinn TJ. Test accuracy of short screening tests	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				for diagnosis of delirium or cognitive impairment in an acute stroke unit setting. Stroke. 2013; 44:3078-83 **SELECTED STUDIES USING THE 4AT** Morandi A, Di Santo SG, Cherubini A, Mossello E, Meagher D, Mazzone A, Bianchetti A, Ferrara N, Ferrari A, Musicco M, Trabucchi M, Bellelli G; ISGoD Group. Clinical Features Associated with Delirium Motor Subtypes in Older Inpatients: Results of a Multicenter Study. Am J Geriatr Psychiatry. 2017; 25:1064-1071. Bellelli G, Morandi A, Di Santo SG, Mazzone A, Cherubini A, Mossello E, Bo M, Bianchetti A, Rozzini R, Zanetti E, Musicco M, Ferrari A, Ferrara N, Trabucchi M; Italian Study Group on Delirium (ISGoD). "Delirium Day": a nationwide point prevalence study of delirium in older hospitalized patients using an easy standardized diagnostic tool. BMC Med. 2016; 14:106 Morandi A, Han JH, Meagher D, Vasilevskis E, Cerejeira J, Hasemann W, MacLullich AM, Annoni G, Trabucchi M, Bellelli G. Detecting Delirium Superimposed on Dementia: Evaluation of the Diagnostic Performance of the Richmond Agitation and Sedation Scale. J Am Med Dir Assoc. 2016; 17:828-33	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Bo M, Bonetto M, Bottignole G, Porrino P, Coppo E, Tibaldi M, Ceci G, Raspo S, Cappa G, Bellelli G. Length of Stay in the Emergency Department and Occurrence of Delirium in Older Medical Patients. J Am Geriatr Soc. 2016; 64:1114-9 Oliver D. Delirium matters. BMJ. 2016;353:i2886 De J, Wand AP. Delirium Screening: A Systematic Review of Delirium Screening Tools in Hospitalized Patients. Gerontologist. 2015; 55:1079-99 Shenkin SD, Russ TC, Ryan TM, MacLullich AM. Screening for dementia and other causes of cognitive impairment in general hospital in-patients. Age Ageing. 2014; 43:166-8 Jackson TA, Naqvi SH, Sheehan B. Screening for dementia in general hospital inpatients: a systematic review and meta-analysis of available instruments. Age Ageing. 2013; 42:689-95	
Royal College of Psychiatrists	Full	120	6	There is some evidence suggesting benefits of computerised cognitive testing which deserves further research. Aslam R'h W, Bates V, Dundar Y, et al. A systematic review of the diagnostic accuracy of automated tests for cognitive impairment. Int J	Thank you for your comment. The committee agreed there would be value in further research in this area, but did not consider it as high a priority for future research as the specific recommendations included in the guideline. The specific paper you cite was published after the cut-off date for evidence to include within the guideline. However, this

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Geriatr Psychiatry. 2018;1–15. https://doi.org/10.1002/gps.4852	reference has been passed to the NICE surveillance team for consideration in planning future updates of the guideline.
Royal College of Psychiatrists	Full	161	General	It's unsurprising that the only RCT that was used to compare Memory clinics vs GP care which is the same study repeated as evidence across several chapters of this NICE guideline was one Dutch study; as the NICE guidelines on Dementia required specialist treatment and monitoring until the last few years. There are however dozens of non-RCT studies on memory clinics that in effect should offer sufficient weight. Despite the comment about weighting the study using UK utility weights in a scenario analysis. there is a danger in using none UK evidence generally to compare the level, funding, availability and approach of services from another country, where services are country dependent. A Dutch GP service might not offer equivalent services, facilities or approaches as an example, to a UK GP provider. The role of specifically "Old Age Psychiatric services" in managing complex presentations including BPSD is not mentioned.	Thank you for your comment. The committee agreed with all the concerns raised, but noted that this review question did include a broader range of quantitative studies than RCTs (including before and after and cohort studies). However only a very limited amount of evidence was identified. The committee agreed therefore that, in the absence of a robust body of UK applicable data, it was not possible to make specific recommendations around how people living with dementia should be followed up after diagnosis.
Royal College of Psychiatrists	Full	192	21	This is again a very concerning and misleading approach where physicians are categorised as "…psychiatrists including those specialising in learning disability, neurologists, and physicians	Thank you for your comment. The committee agreed that old age psychiatrists were a key population here. The wording of the statement was designed to ensure that other subtypes of psychiatry (such as learning disabilities) were not excluded

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				specialising in the care of older people", deliberately or ignorantly neglecting to mention the specific role of old age psychiatrists who are the main physicians responsible for the diagnosis and management in secondary care within the UK.	from the evidence. To avoid confusion, old age psychiatrists have been added as a specific population of relevance here.
Royal College of Psychiatrists	Full	197	General	This statement of evidence copied from the NICE consultation document s significantly concerning and suggests implicit age discrimination among the committee. "Although, in Aupperle et al. 2003, the authors did not report standard deviation at 2 year follow up the committee noted that, participants who were seen by a geriatric psychiatrist experienced an overall slight improvement in Clinical Dementia Rating (CDR) over 2 years. The committee thought this would be very unusual, as Alzheimer's disease is a degenerative condition."???? Considering that this was a study examining the compliance with ant dementia medication prescribed in secondary care vs primary care where there was a high dropout rate with poor compliance, of anti-dementia drugs, it's very worrying that the committee felt there wouldn't be improvement in CDR in patients compliant	Thank you for your comment. This comment comes from a misinterpretation of the evidence reported from the Aupperle study, and the committee's discussion of it. The committee were not suggesting that it was a priori surprising that people managed by specialists did better than people managed in primary care (indeed, this was precisely the hypothesis this question was trying to address). Rather, the committee were surprised that the study found an improvement in CDR scores in absolute terms for the people managed in specialist care, which they agreed was not representative of their clinical experience.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				with anti-dementia drugs compared to those who weren't. Recent evidence suggests that "when health professionals make decisions and judgments about older adults, they may not be aware that these are affected by implicit ageism or age biases that devalue older patients, and thus will not notice the harmful consequences that follow (Swift 2016). Differences in the treatment options offered to younger and older individuals can also be the result of indirect ageism, particularly if limited resources are distributed based on cost-benefit analysis, which disproportionately disadvantages older adults (Swift 2017, CPA, 2009). These analyses tend to use Quality Adjusted Life Years (QALY) to assess the relative cost effectiveness of treatments and procedures for Alzheimer's disease, osteoarthritis, osteoporosis, or age-related macular degeneration, however, such analyses can be problematic and tend to work against people for whom it is estimated have fewer remaining years (CPA, 2009). This is also supported by warning of evidence of ageism in situations as identified above by the World health organisation (WHO 2015).	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				1. Swift, H. J., Abrams D., Drury, L., & Lamont, R. A. (2016). Briefing paper: The perception of ageing and age discrimination. London: British Medical Association. 2. Swift, H. J., Abrams, D., Lamont, R. A. and Drury, L. (2017), The Risks of Ageism Model: How Ageism and Negative Attitudes toward Age Can Be a Barrier to Active Aging. Social Issues and Policy Review, 11: 195–231. doi:10.1111/sipr.12031 3. Centre for Policy on Ageing. (2009). Ageism and age discrimination in mental health care in the United Kingdom: A review from the literature. Centre for Policy on Ageing: London, UK. Retrieved December 17, 2017 from http://www.cpa.org.uk/information/reviews/reviews.html. 4. WHO. (2015). World report on ageing and health. Geneva: World Health Organisation. Retrieved December 16, 2017 from http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1	
Royal College of Psychiatrists	Full	198	General	Can you clarify how you defined "a clinician with appropriate specialist expertise"?	Thank you for your comment. A definition is given in the short version of the guideline, alongside this recommendation.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
Royal College of Psychiatrists	Full	217	59/60	RCPsych supports these recommendations. Assessing functioning as mentioned in the evidence does raise the question of why no mention is made under the section on diagnosis and also on monitoring of using evidence based occupational therapy (OT) assessment such as the AMPS or LACL if diagnosis is not clear after neuro imaging, as these would help to identify a decline in function. They can also help decide the most appropriate time to offer medication with a view to improving function.	Thank you for your comment. The committee agreed that, in the absence of any evidence being identified for occupational therapy assessment during diagnosis, it was not possible to make recommendations on this topic.
Royal College of Psychiatrists	Full	249	5	RCPsych has concerns the committee extended the recommendation not to use cholinesterase inhibitors in frontotemporal dementia based on the assumption that there is no underlying cholinergic deficit in frontotemporal dementia. There is a group within the Primary Progressive aphasia's, Logopenic variant (LV) which is associated with cholinergic depletion. The cholinergic deficit in LV in the study by Jolien Schaeverbeke et al., 2017 provides a potential rationale for off-label use of AChE inhibitors in LV PPA due to underlying AD pathology. Reference: Jolien Schaeverbeke, Charlotte Evenepoel, Rose Bruffaerts, Koen Van Laere, Guy	Thank you for your comment. The committee agreed it was now common practice to regard logopenic progressive aphasia as an atypical form of Alzheimer's disease, and therefore this would not be covered by the recommendation for frontotemporal dementia.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Bormans, Eva Drries, Thomas Tousseyn, Natalie Neilssen, Ronald Peeters, Mathieu Vandenbulcke, Patrick Dupont, Rik Vndenberghe, Cholinergic depletion and basal forebrain volume in primary progressive aphasia, NeuroImage Clinical 13(2017) 271 – 279 Language regions contain a relatively high density of AChE containing neurons (Hustler and Gazzaniga, 1991), which may suggest a rational basis for cholinergic treatment in PPA. Cholinergic therapy improves language in various disorders affecting the language network (Berthier et al., 2006; Ferris and Farlow, 2013; Tanaka et al., 1997; Yoon et al., 2015) A study with an open-label of 18weeks and a randomised, placebo-controlled phase for eight weeks with galantamine included PPA patients (Ketesz et al., 2008). This study showed the overall language performance showed a trend towards stabilization over a total duration of eight weeks**.**	

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				It would also be useful to add research recommendations in this area specifically looking at treatment options.	
Royal College of Psychiatrists	Full	277	37	This section considers the economic analysis of CST, but uses a base case model, rather than published health economic studies. There have been 2 key papers published considering the cost effectiveness of manualised CST (Knapp et al, 2006 which considered CST; D'Amico et al, 2015 which considered maintenance CST). Both are listed in the references in Appendix J, but only D'Amico et al (2015) has been considered in the evidence. These papers show strong evidence for the cost effectiveness of manualised CST and it is important for the Knapp paper to be used, rather than a base case model (see comments 3 and 4 for further discussion of this). These papers look at the cost of the delivery, as well as the changes in use of health and social care services for those in receipt of the intervention. Furthermore, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by	Thank you for your comment. The Knapp (2006) paper was not a cost-utility study and therefore did was not consistent with the reference case. As a result, it is inaccurate to state that this analysis showed that CST is cost effective, as no threshold value has been established for the effectiveness instruments used against which gains could be assessed. The D'Amico (2015) paper however, was a cost-utility study and was eligible for inclusion as part of the economic review. Please note that the effectiveness evidence used in Knapp (2006) was based on Spector (2003), and has been considered by this guideline by the way of inclusion in our quantitative synthesis of parameters for the model developed by NICE.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually. **References** D'Amico F, Rehill A, Knapp M, Aguirre E, Donovan H, Hoare Z, Hoe J, Russell I, Spector A, Streater A, Whitaker C, Woods RT, Orrell M (2015) Maintenance cognitive stimulation therapy: an economic evaluation within a randomised controlled trial. *Journal of the American Medical Directors Association,* 16 (1): 63-70. Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *British Journal of Psychiatry*, 188: 574-580.	

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Stakeholder	Document	Page No	Line No	Comments	Developer's response
Royal College of Psychiatrists	Full	296	5	"No evidence of benefit was found on outcomes other than cognition (for CST)". This is an incorrect statement. Several studies have shown statistically significant improvements on outcomes in addition to cognition, namely quality of life (Spector et al, 2003; Capotosto et al., 2017; Paddick et al., 2017; Orrell et al., 2014); mood (Yamanaka et al., 2013; Niu et al., 2010); behavioural symptoms (Paddick et al., 2017); activities of daily living (Orrell et al., 2014). A Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects as well as showing evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis. **References** Capotosto E, Belacchi C, Gardini S, Faggian S, Piras F, Mantoan V, Salvalaio E, Pradelli S, Borella E (2017). Cognitive Stimulation Therapy in the	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life but the rest of studies included in the meta-analysis could not

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				Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry,32:331-340 Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Russell I, (2014) Maintenance cognitive stimulation therapy (CST) for dementia: single-blind, multicentre, pragmatic randomized controlled trial. *British Journal of Psychiatry* 2014 (204): 1-8. Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, *29*(6), 979-989. Spector, A., Thorgrimsen,L., Woods, B., et al (2003) Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. British Journal of Psychiatry, 183, 248-254	differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the meta-analysis could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562. Yamanaka K, Kawano Y, Noguchi D, Nakaaki S, Watanabe N, Amano T, Spector A (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, 17:579-586.	
Royal College of Psychiatrists	Full	296	5	"No evidence of benefit was found on outcomes other than cognition (for CST)". This is an incorrect statement. Several studies have shown statistically significant improvements on outcomes in addition to cognition, namely quality of life (Spector et al, 2003; Capotosto et al., 2017; Paddick et al., 2017; Orrell et al., 2014); mood (Yamanaka et al., 2013; Niu et al., 2010); behavioural symptoms (Paddick et al., 2017); activities of daily living (Orrell et al., 2014). A Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger

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				benefits cognition in mild to moderate dementia, over and above any medication effects as well as showing evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis. **References** Capotosto E, Belacchi C, Gardini S, Faggian S, Piras F, Mantoan V, Salvalaio E, Pradelli S, Borella E (2017). Cognitive Stimulation Therapy in the Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry,32:331-340 Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Russell I, (2014) Maintenance cognitive stimulation therapy (CST) for dementia: single-blind, multicentre, pragmatic randomized controlled trial. *British Journal of Psychiatry* 2014 (204): 1-8. Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017).	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life but the pooled result of all the studies included in the meta-analysis could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not

Stakeholder	Document	Page No	Line No	Comments	Developer's response
				Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, *29*(6), 979-989. Spector, A., Thorgrimsen,L., Woods, B., et al (2003) Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. British Journal of Psychiatry, 183, 248-254 Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562	make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the pooled result of the meta-analysis including the other relevant studies could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.
Royal College of Psychiatrists	Full	296	5	"They noted that in practice the two interventions are not mutually exclusive, with cognitive stimulation and reminiscence both forming part of the activities included within those groups". Whilst the committee are correct that CST does incorporate some aspects of reminiscence, the	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both

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				statement above shows a misunderstanding of CST (2006). One of the key focuses of CST is on generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills and enable new semantic connections to be made. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). "The committee agreed the most appropriate recommendation was for people to be provided with access to structured group activities, with cognitive stimulation and reminiscence both forming part of the activities included within those groups…. This was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" These recommendations are problematic for several reasons. As stated in the comments above, there is a far stronger evidence base for	in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				CST than for reminiscence. Additionally, the evidence is for CST when used as a manualised intervention. There is no evidence for any benefits if just elements of the programme are used, and there is no evidence in general for structured group activities. Therefore it is puzzling to see why NICE would recommend something which is not evidence based. The conclusion in the report that "this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according to important key principles which fit with the underlying theoretical models. As no recommendations were made for pre- and peri-diagnostic counselling and support for people with dementia and their families (evidence statement 13.1.4 full guidelines, p.263, line 14), or for post diagnostic interventions (evidence statement 13.1.6 full guidelines, p.266,	

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				line 2), there is a real danger that those with dementia will be offered only medication, and it will be even harder for people to access non-pharmacological interventions. **References** Spector A, Thorgrimsen L, Woods B, Orrell M (2006) Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy (CST) to people with dementia. Hawker Publications, UK.	
Royal College of Psychiatrists	Full	363	1-30	RCPsych supports these recommendations.	Thank you for your comment and your support for these recommendations.
Royal College of Psychiatrists	Full	404	19	"The committee agreed however, that future research in this area would be valuable. It has been recognised for a long time that this is a complex patient group to manage, and yet there are still no randomised controlled trials in this population. It therefore recommended that trials should be conducted, looking at the optimum management strategies for people with an enduring mental health problem who go on to develop dementia" – Although this is a laudable	Thank you for your comment. The committee agreed that other forms of research would also be valuable, but that the population of people with both dementia and a mental health comorbidity was large enough that randomised trials in this area, whilst complex, could be achievable.

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				recommendation, how likely or how useful is this going to be to undertake high quality RCT's on older people with Dementia and a comorbid severe mental health problem. Clearly in complex cases like this RCT's cannot be a realistic gold standard and other forms of research and evidence should be encouraged and considered.	
Royal College of Speech and Language Therapists	Short version	25	1	When people with severe dementia are admitted to hospital their communication needs must be taken into account. Communication problems occur in all forms of dementia and in the later stages these problems become increasingly challenging for both the individual and the staff around them. Hospital staff will need support to be able to understand the best means to communicate with someone and to enable the individual to express their needs, and to consent to care and treatment. If communication is not appropriately supported then, behaviour that challenges can result. This is often an attempt by the person to make sense of the environment or communicate an unmet need. Supporting evidence:	Thank you for your comment. The committee noted that the list of factors given here were only examples, and there were many other factors that would need to be taken in to account in individual cases. The specific examples on the list were chosen by the committee as those they agreed were likely to be the most common problems encountered.

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				Five good communication standards: Reasonable adjustments to communication that individuals should expect in specialist hospital and residential settings https://www.rcslt.org/news/docs/good_comm_standards	
Royal College of Speech and Language Therapists	Short	General	General	The short version of the draft guideline refers frequently to communication problems but there is no reference to the role of speech and language therapy in supporting people with communication needs, through assessment and provision of therapy and training for staff and carers. All people with dementia will experience communication problems during the progression of the condition. Screening and assessment by speech and language therapists will allow these needs to be supported and strategies developed to maximise communication ability. Failure to identify and support communication problems can result in people's needs being unmet, deprivation of dignity and choice, and harm if pain is not identified and managed. Supporting evidence:	Thank you for your comment. The committee agreed that in the absence of evidence, it was not possible to make specific recommendations on the role of speech and language therapists in supporting communication. However, they did agree on the importance on communication, and therefore agreed it was appropriate to add training in "adapting communication styles" to the recommendations on staff training and education.

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				• Jokel et al, 2014: Word retrieval therapies in primary progressive aphasia Carthrey et al, 2012: Nonpharmacological interventions for cognitive impairments following primary progressive aphasia; A systematic review of the literature	
Royal College of Speech and Language Therapists	Short	7	10	The Guideline highlights that people with dementia will need support to express and communicate their wishes on care and treatment but it does not give enough ways to support this. People should be helped to communicate by providing communication support appropriate to their individual needs, for example; communication aids, advocacy support, interpreters, specialist speech and language therapy support and involvement of family members or friends.	Thank you for your comment. The committee agreed that in the absence of evidence, it was not possible to make specific recommendations on the role of speech and language therapists in supporting communication. However, they did agree on the importance on communication, and therefore agreed it was appropriate to add training in “adapting communication styles” to the recommendations on staff training and education.
Royal College of Speech and Language Therapists	Short	14	5	People with limited capacity should be supported via the changes being introduced by NICE guideline “decision making and mental capacity” draft, 2018. It is important that this guideline is referenced.	Thank you for your comment. The committee agreed with this point and a reference to the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018) has now been included in the guideline.
Royal College of Speech and Language Therapists	Short	14	28	It must be recognised that if a person with dementia does not have a family or carer to support them, then their communication	Thank you for your comment. The committee agreed with the importance of communication, and noted that the lack of evidence from the study designs included in the guideline

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				problems will make them more vulnerable and additional support must be provided.	(primarily randomised controlled trials and qualitative studies) made it difficult for them to make specific recommendations on this issue. However, they did agreed that one particularly relevant issue was around staff training, and training on "adapting communication styles" has been added to the section of the guideline on staff training and education.
Royal College of Speech and Language Therapists	Short	15	9	The RCSLT is very concerned that speech and language therapy does not feature in this section on supporting cognition, independence and rehabilitation.	Thank you for your comment. Evidence on speech and language therapy was looked for as part of the evidence review for this section. No RCT evidence was identified for speech and language therapy, and therefore the committee agreed it was not possible to make a recommendation on this topic in this section.
Royal College of Speech and Language Therapists	Short	15	13	The RCSLT is concerned to see occupational therapy highlighted in supporting rehabilitation and reablement but not speech and language therapy, which also has a crucial role to play.	Thank you for your comment. Evidence on speech and language therapy was looked for as part of the evidence review for this section. No RCT evidence was identified for speech and language therapy, and therefore the committee agreed it was not possible to make a recommendation on this topic in this section.
Royal College of Speech and Language Therapists	Short	24	11	Communication problems occur in all forms of dementia and in the later stages, as dementia progresses, these problems become increasingly challenging (Bourgeois, 2010). RCSLT recommends that all health and social care planning is delivered in a manner that supports people's communication abilities and allows them to express their decisions and choices.	Thank you for your comment. The committee agreed with the importance of communication, and noted that the lack of evidence from the study designs included in the guideline (primarily randomised controlled trials and qualitative studies) made it difficult for them to make specific recommendations on this issue. However, they did agreed that one particularly relevant issue was around staff training, and training on

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					"adapting communication styles" has been added to the section of the guideline on staff training and education.
Royal College of Speech and Language Therapists	Short	24	23	The RCSLT is disappointed that this is the only reference to eating and swallowing in the short version despite it being a widely recognised challenge. The RCSLT is concerned that there is no information on the assessment of swallowing ability or the management of dysphagia in the guideline. Difficulties with eating, drinking and swallowing (dysphagia) are a recognised challenge for people with dementia. Dysphagia, if not managed, results in malnutrition and dehydration (Hudson, 2000), and is a causal factor in repeated chest infections and choking risk. Early intervention is crucial to avoid costly hospital admissions.	Thank you for your comment. On the specific issue of dysphagia, the committee agreed it was appropriate to add an extra recommendation to the section on palliative care, to "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."
Royal College of Speech and Language Therapists	Short	24	33	People should be supported to eat and drink if they wish to do so (NICE, 2016). It should be recognised that some people will want to eat and drink despite being unable to do so safely and support from a speech and language therapist will be essential to support risk feeding. The RCP recognises that risk feeding can be achieved through support from a speech and language therapist (RCP, 2010) and this should be added.	Thank you for your comment. The committee agreed with the points raised, both around 'at risk feeding' and the involvement of speech and language therapists, and therefore the recommendations have been amended to address these points. Specifically: "Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs.

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					Consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."
Royal College of Speech and Language Therapists	Short	25	14	The RCSLT recommends that carers need to be supported in effective ways to promote safe swallowing, reduce risk of aspiration and enable nutrition and hydration needs to be met. Eating and swallowing is important for staying healthy, but a poor diet can lead to fatigue, risk of infection and less muscle strength. Dehydration and weight loss can result if people with dementia are unable to communicate their needs. It cannot be assumed that carers will know how to manage challenges with eating and swallowing. The RCSLT recommends that this information is offered to carers. Such advice could include changes to texture and consistency of food.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in these issues.
Royal College of Speech and Language Therapists	Short	25	21	Communication difficulty has been described as one of the most frequent and hardest to cope with experiences for family carers. Optimising the communication skills of both the person with dementia and carer is essential to providing high quality relationship-centred care. One of the crucial roles of speech and language therapists is to support, advise and train carers	Thank you for your comment. The committee agreed that in the absence of evidence, it was not possible to make specific recommendations on the role of speech and language therapists in supporting communication. However, they did agree on the importance on communication, and therefore agreed it was appropriate to add training in "adapting communication styles" to the recommendations on staff training and education.

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				about communication needs in dementia, strategies to support and enhance communication, and management of dementia where the primary symptoms are with language and communication rather than memory, for example, primary progressive aphasia and its variant.	
Royal College of Speech and Language Therapists	Short	26	7	Information needs to be available in a range of formats recognising that carers of people with dementia may have communication needs themselves. All information must be provided in an accessible format and tailored to the needs of the individual. This should be supported by tools such as visual materials, communication aids and hearing aids, as appropriate.	Thank you for your comment. The committee agreed with all these points, and agreed these were covered by the recommendation to provide training in "a format suitable for them (for example individual or group sessions, or online training and support)."
Royal College of Speech and Language Therapists	Short	27	3	The RCSLT recommends that training must be provided to all staff to enable them to understand the communication difficulties experienced by people with dementia, and strategies to support communication exchange, which is especially pertinent for issues around consent to care and treatment. Supporting evidence:	Thank you for your comment. The committee agreed with the importance of communication, and noted that the lack of evidence from the study designs included in the guideline (primarily randomised controlled trials and qualitative studies) made it difficult for them to make specific recommendations on this issue. However, they did agreed that one particularly relevant issue was around staff training, and training on "adapting communication styles" has been added to the section of the guideline on staff training and education.

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				As indicated in the Francis report on the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), people with dementia should receive care from staff appropriately trained in dementia care. The report clearly recommends that dementia care training should include, "the importance and use of communication skills for working with people with dementia".	
Royal College of Speech and Language Therapists	Short	27	3	The RCSLT also recommends that training should be provided to staff in the management of eating and swallowing difficulties. This would support safe swallowing, reduce the risk of aspiration and enable nutrition and hydration needs to be met.	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered staff training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness. On this basis they agreed it was not possible to include more detailed recommendations in this section of the guideline than those currently included.
Royal College of Speech and Language Therapists	Short	28	11	The RCSLT supports the training of health and social care professionals to initiate and maintain difficult or challenging conversations. We would be happy to work with you to develop this training.	Thank you for your comment and your support for this recommendation. The committee would welcome further research on the most appropriate ways to deliver training for staff working with people living with dementia.
Royal College of Speech and Language Therapists	Short	29	05	The RCSLT is concerned at the list of professionals and those that are omitted from the list. The RCSLT believes that speech and language therapist should be included on the list as experts with specialist knowledge and skills to contribute to a diagnostic decision.	Thank you for your comment. The committee were keen to point out that this definition solely referred to the question of who should give advice before pharmacological treatment for Alzheimer's disease is started. It was not intended as a more general statement around who would count as a specialist

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					clinician. The final version of the guidance should make this point clearer.
Royal College of Speech and Language Therapists	Full version	40	11	On admission to hospital the communication needs of an individual must be considered, to enable them to communicate safely with staff and for staff to engage with them. This will allow issues such as pain and other personal issues to be discussed. Support from a speech and language therapist will allow these conversations to take place to maximise communication by both parties.	Thank you for your comment. The committee agreed that in the absence of evidence, it was not possible to make specific recommendations on the role of speech and language therapists in supporting communication. However, they did agree on the importance on communication, and therefore agreed it was appropriate to add training in "adapting communication styles" to the recommendations on staff training and education.
Royal College of Speech and Language Therapists	Full		17	Feedback from carers clearly highlights the problem of communication breakdown and the need for staff to better understand the communication needs of people with dementia and their families.	Thank you for your comment. The committee agreed this was an important issue, and therefore training in "adapting communication styles" has been added to the section of the guideline on staff training and education.
Royal College of Speech and Language Therapists	Full	General		The RCSLT is **very** concerned that the full guideline does not sufficiently highlight the communication and eating, drinking and swallowing needs of people with dementia. This is despite the fact that almost all people with experience these difficulties during the progression of the condition. It is essential that these needs are clearly flagged up	Thank you for your comment. The committee agreed it was appropriate to make two changes to the recommendations to address these concerns. First, training on "adapting communication styles" has been added to the section of the guideline on staff training. Secondly, a specific recommendation on speech and language therapy has been added to the section on eating and drinking: "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."

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				1. Supporting communication is essential to allow people to make decisions but more importantly to consent to care and treatment. And Supporting eating, drinking and swallowing needs (dysphagia) prevents malnutrition, dehydration and the risk of repeated chest infections and life threatening pneumonia.	
Royal College of Speech and Language Therapists	Full	General	General	Additional evidence on the life story and memory wallet literature approach: Supporting evidence: - Bourgeois, M. (1990) Enhancing conversation skills in patients with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behavior Analysis,* 23, 29-42. - Bourgeois, M. (1993) Effects of memory aids on the dyadic conversations of individuals with dementia. *Journal of Applied Behaviour Analysis,* 269, 77-87. - Bourgeois, M., Dijkstra, K., Burgio, L. & Allen-Burge, R. (2001) Memory aids as an augmentative and alternative communication strategy for nursing home residents with	Thank you for your comment. Please find below a response for each of the papers you have cited. Bourgeois (1990), Bourgeois (1993) and Bourgeois (2001) were pilot studies with extremely small sample sizes (around 6 people) and therefore would not provide useful information on which to make recommendations. Both Egan (2010) and Subramaniam (2012) were looked at and excluded because there were more recent systematic reviews available containing the same studies (see Appendix O). Gridley (2016) is a narrative review which does not meet the inclusion criteria for study design. Subramaniam (2014) was included for the evidence review on reminiscence therapy (see Appendices E, H, and I).

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				dementia. Augmentative and Alternative Communication, 17, 196-210. • Egan, M., Berube, D., Racine, G., Leonard, C. & Rochon, E. (2010) Methods to enhance verbal communication between individuals with Alzheimer's Disease and their formal and informal caregivers: A systematic review. International Journal of Alzheimer's Disease. Article ID 906818, 1-12 • Gridley, K., Brooks, J., Carole, B.,, Yvonne F., et al. (2016) Improving Care for People with Dementia : development and initial feasibility study for evaluation of life story work in dementia care (final report). Health Services and Delivery Research. ISSN 2050-4357 • Subramaniamay, P. & Woods, B. (2012) The impact of individual reminisence therapy for people with dementia: Systematic review. Expert Review of Neurotherapeutics, 12, 545-555. Subramaniamay, P., Woods, B. & Whitaker, C. (2014) Life review and life story books for people with mild to moderate dementia: A randomised controlled trial. Aging & Mental Health, 18, 363–375.	

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Royal College of Speech and Language Therapists	Full	32	18 And 20	The Guideline fails to sufficiently highlight that people with dementia will need extra support to express and communicate their views and wishes on care and treatment. Failure to support communication can result in people's needs being left unmet, people being deprived of their dignity and choice, and harm if pain is not identified and managed. People can communicate in a number of different ways and communication support should be provided which is appropriate to individual need. This can include communication aids, advocacy support, specialist speech and language therapy support, involvement of family members or friends. Supporting evidence: • Jokel et al, 2014: Word retrieval therapies in primary progressive aphasia Carthrey et al, 2012: Nonpharmacological interventions for cognitive impairments following primary progressive aphasia; A systematic review of the literature	Thank you for your comment. The committee agreed with the importance of communication, and noted that the lack of evidence from the study designs included in the guideline (primarily randomised controlled trials and qualitative studies) made it difficult for them to make specific recommendations on this issue. However, they did agreed that one particularly relevant issue was around staff training, and training on "adapting communication styles" has been added to the section of the guideline on staff training and education.

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Royal College of Speech and Language Therapists	Full	32	28	The RCSLT supports training health and social care professionals to initiate and maintain difficult or challenging conversations. Where communication ability deteriorates then staff will need to have the tools and strategies to be able to engage in these discussions. The RCSLT has already developed training and support for professionals (https://www.rcsltcpd.org.uk/) and we would be happy to work with you to develop this further training.	Thank you for your comment. Based on feedback from a number of stakeholders, the committee agreed it was appropriate to add training in "adapting communication styles" to the section of the guideline on staff training. The committee welcome all new research and tools developed to help improve the quality of that training in practice.
Royal College of Speech and Language Therapists	Full	33	19	It must be recognised that if a person with dementia does not have a family or carer to support them, then their communication problems will make them more vulnerable and additional support must be provided.	Thank you for your comment. The committee agreed with this point and included a specific recommendation in the guideline about making services accessible to people "who do not have a carer or whose carer cannot support them on their own."
Royal College of Speech and Language Therapists	Full	34	47	Healthcare professionals will want to seek input from a speech and language therapist to help them assess the impact of communication difficulties that the individual faces and this should be highlighted in the guideline.	Thank you for your comment. The committee agreed that speech and language therapists would have a role to play here, in the same way as would be appropriate for people with communication difficulties but without dementia. However, the committee agreed that in the absence of specific evidence in was not possible to make a recommendation, and this was best covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics,

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					treatments and care services for comorbidities to people who do not have dementia."
Royal College of Speech and Language Therapists	Full	36	17	The RCSLT is very concerned that speech and language therapy does not feature in this section on supporting cognition, independence and rehabilitation.	Thank you for your comment. Evidence on the effectiveness of speech and language therapy interventions was looked for as part of the review questions on independence, cognition, functional ability and quality of life. However, no RCT evidence was identified, in contrast to that for other interventions which were included in the guideline, and therefore the committee agreed it was not possible to make any recommendations.
Royal College of Speech and Language Therapists	Full	36	21	The RCSLT is concerned to see occupational therapy highlighted in supporting rehabilitation and reablement but not speech and language therapy.	Thank you for your comment. Evidence on the effectiveness of speech and language therapy interventions was looked for as part of the review questions on independence, cognition, functional ability and quality of life. However, no RCT evidence was identified, in contrast to that for other interventions which were included in the guideline, and therefore the committee agreed it was not possible to make any recommendations.
Royal College of Speech and Language Therapists	Full	37	27	Caring for and caring about people with dementia requires specific communication skills. Carers often receive little information to enable them to meet the communication needs of people with dementia. The RCSLT recommends that carers should receive support and training on communication in dementia. Supporting evidence:	Thank you for your comment. The committee agreed with this point, and noted that communication training was a common feature of many of the effective carer support interventions included in the review, including the START intervention forming the basis of the cost-effectiveness evidence. The recommendation for carer interventions states that it should include "training in adapting communication styles to improve interactions with the person living with dementia."

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				Eggenberger et al (2012) shows that communication skills training in dementia care significantly improves the quality of life and wellbeing of people with dementia and increases positive interactions in various care settings. We recommend that this evidence is considered by NICE.	
Royal College of Speech and Language Therapists	Full	37	95	The RCSLT recommends that carers are supported to promote safe swallowing, reduce risk of aspiration and enable nutrition and hydration needs to be met. Eating and swallowing is important for staying healthy, but a poor diet can lead to fatigue, risk of infection and less muscle strength. Dehydration and weight loss can result if people with dementia are unable to communicate their needs. It cannot be assumed that carers will know how to manage challenges with eating and swallowing. The RCSLT recommends that this information is offered to the support available for carers.	Thank you for your comment. The committee noted a number of suggestions from stakeholders about topics that could be included in training for carers, all of which the committee agreed were potentially relevant. However, they agreed that because of the potentially high cost of delivering training to all carers of people living with dementia, it was important to restrict the recommendations to those areas where there was clear evidence of effectiveness and cost-effectiveness.
Royal College of Speech and Language Therapists	Full	38	18	The RCSLT recommends that all staff are trained in effective communication and strategies to support and enhance communication and promote good care.	Thank you for your comment. As a response to a number of stakeholders raising this issue, the committee agreed it was appropriate to add training in "adapting communication styles" to the section of the guideline on staff training.

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				Supporting evidence: As indicated in the Francis report on the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), people with dementia should receive care from staff appropriately trained in dementia care. The report clearly recommends that dementia care training should include, "the importance and use of communication skills for working with people with dementia".	
Royal College of Speech and Language Therapists	Full	38	27	The RCSLT recommends that training should be offered to staff in the assessment and management of risk associated with dysphagia and in the provision of nutrition that maximises independence. It is crucial that those working with people with dementia understand the implication of dysphagia and safe eating and swallowing and how managing this can prevent costly hospital admission.	Thank you for your comment. The committee noted a number of suggestions from stakeholders about topics that could be included in training for carers, all of which the committee agreed were potentially relevant. However, they agreed that because of the potentially high cost of delivering training to all carers of people living with dementia, it was important to restrict the recommendations to those areas where there was clear evidence of effectiveness and cost-effectiveness.
Royal College of Speech and Language Therapists	Full	39	6	This section highlights that some people will be unable to self-report pain, due to their communication challenges. In such cases it is essential that support is obtained from a speech and language therapist to support communication exchange.	Thank you for your comment. The committee noted that no evidence was found on this issue, and therefore agreed it was not possible to make recommendations around speech and language therapy in this section.

Dementia: assessment, management and support for people living with dementia and their carers

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Royal College of Speech and Language Therapists	Full	39	14	For people with signs of repeat behavioural changes caused by pain, consider seeking alternative methods of communicating with the person to discover the extent of their problems. Input from a speech and language therapist should be sought.	Thank you for your comment. The committee noted that no evidence was found on this issue, and therefore agreed it was not possible to make recommendations around speech and language therapy in this section.
Royal College of Speech and Language Therapists	Full	39	41	As dementia progresses the communication ability of individuals will become more difficult. To involve the person in healthcare planning will require additional communication support to be offered. Speech and language therapy support should be included.	Thank you for your comment. The committee noted that no evidence was found on this issue, and therefore agreed it was not possible to make recommendations around speech and language therapy in this section.
Royal College of Speech and Language Therapists	Full	40	7	It needs to be recognised that some people will want to eat and drink but are unable to do so safely. Support from a speech and language therapist can support choice around risk feeding. Supporting evidence: • Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *Journal of the American Medical Association* 1999; 282:14, 1365-1370. • Palecek EJ, et al. Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons	Thank you for your comment. The committee noted this concern, and agreed it was appropriate to remove the works "can do so safely" from this recommendation to cover the concept of 'at risk feeding'. They also agreed it was appropriate to add a specific recommendation on involving a speech and language therapist at this stage if there are concerns about safety. The new recommendations therefore become: "Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs. Consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."

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				with advanced dementia, *Journal of the American Geriatric Society* 2010; 58:3, 580-584. Sherman FT. Nutrition in advanced dementia. Tube feeding or hand feeding until death? Editorial. *Geriatrics* 2003; 58:11, 10.	
Royal College of Speech and Language Therapists	Full	257		The Guideline says that specialist dietetic support and speech and language therapy for people with dementia will be considered in the non-pharmacological interventions section of this guideline. However, we are concerned that speech and language therapy is not discussed or highlighted in this section.	Thank you for your comment. Evidence on speech and language therapy was looked for as part of the systematic review conducted for non-pharmacological interventions to improve cognition, functional ability, independence and wellbeing for people living with dementia (see appendix O). They therefore agreed that because of the lack of evidence, it was not possible to make recommendations on speech and language therapy in this section of the guideline.
Royal College of Speech and Language Therapists	Full	354		During end of life or palliative care planning, support must be provided to the individual and the family to make decisions. This includes being able to plan and have their wishes met. To enable such discussions to take place, communication must be supported so the views of the individual are heard. At present the section on end of life care is weak and does not offer sufficient information on how this will happen. Supporting communication must be a central theme in end of life care planning for all healthcare professionals to consider.	Thank you for your comment. The committee agreed the recommendations in this section were as specific as possible given the limited evidence available. However, the committee did agree with the importance of communication training for staff working with people living with dementia, and training on "adapting communication styles" has been added to the section of the guideline on staff training and education.

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Royal College of Speech and Language Therapists	Full	411	7, 12, 30, 31	In relation to "carer identified issues": The Royal College of Physicians (RCP) 'Oral Feeding Difficulties and Dilemmas (2010 pg. 13)' state that carers play an extremely important role in carrying out the recommendations prescribed by the speech and language therapists.	Thank you for your comment. The committee agreed that carers could play an important role throughout the care of people living with dementia.
Royal College of Speech and Language Therapists	Full	412	31	The ReSPECT tool would have added value to improve planning. Speech and language therapists and other staff use this working closely with people who are nearing the end of their lives and their carers to discuss future plans and contributing to this national documentation.	Thank you for your comment. The committee agreed that no evidence was found around particular tools in a population of people living with dementia, and therefore it was not possible to make recommendations on this, but did agree that structured tools could have an important role to play in well delivered care.
Royal College of Speech and Language Therapists	Full	413	8	This section clearly highlights the lack of training around communication and the desire of staff to receive more training. The RCSLT would be happy to work with you to support the development of such training. We already develop training on a range of subjects https://www.rcsltcpd.org.uk/ and our experts would be happy to work with you to examine communication skills training in dementia.	Thank you for your comment. The committee noted the stakeholder feedback around the importance of training in communication, and agreed it was appropriate to add training in "adapting communication styles" to the recommendations on staff training and education. The committee would welcome further research on the most appropriate ways to deliver training for staff working with people living with dementia.
Royal College of Speech and Language Therapists	Full	414	40	*Regarding the last paragraph: "The committee also agreed that a palliative care approach is the responsibility of every health and social care professional working with people living with dementia, and therefore the terms 'non-specialist*	Thank you for your comment. The committee agreed with the value of specialist palliative care services, but agreed that in the absence of evidence on specific interventions it was not

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				palliative care' or 'specialist palliative care' were avoided". The RCSLT absolutely agrees that palliative care is the responsibility of every healthcare profession. However our members feel that there is value in the provision of expert specialist care in end of life planning. This is particularly important in the management of dysphagia which can lead to choking, aspiration and pneumonia. The RCP state that "SLTs can advise on strategies to minimise aspiration risk, facilitate eating and drinking, and improve nutritional status…" (pg. 12, 1.65). In relation to nutrition for the person with dementia, best practice includes "assessment by a senior physician in nutrition support and SLT…." (RCP: pages 28, 2.26). Supporting evidence: Lambert (2012) cited by Chadder et al, 2016, highlights the role of speech and language therapists in adult palliative care: "impairment and subsequent facilitation of communication or the placement and maintenance of a tracheostomy/enteral feeding tube (for example), are likely to be addressed to, and by, the SLP	possible to make recommendations on the role of specialist palliative care services. On the specific issue of dysphagia, the committee agreed it was appropriate to add an extra recommendation to the section on palliative care, to "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."

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				(speech language pathologist) throughout palliative care".	
Royal College of Speech and Language Therapists	Full	415		This section includes frequent references to communication, supporting people to "have voice", trying to "find the person inside" and "establishing likes and dislikes". These clearly highlight a role for specialist communication support from a speech and language therapist.	Thank you for your comment. The committee agreed that in the absence of evidence, it was not possible to make specific recommendations on the role of speech and language therapists in supporting communication. However, they did agree on the importance on communication, and therefore agreed it was appropriate to add training in "adapting communication styles" to the recommendations on staff training and education.
Royal College of Speech and Language Therapists	Full	415		The RCSLT agree that people should be supported to eat and swallow for as long as they can safely do so. If people want to continue eating and drinking with unsafe swallowing ability then support from a speech and language therapist must be sought to enable this to happen whilst keeping the person safe. Supporting people's wishes is important for patient choice.	Thank you for your comment. The committee noted this suggestion and agreed it was appropriate to add an extra recommendation to the section on palliative care, to "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."
Royal College of Speech and Language Therapists	Full	415	Final para, line 58	The RCSLT is very concerned that speech and language therapy support will not be provided to people with dementia because the guideline says it is too expensive. This will create a disadvantage, whereby people after a stroke or head injury will receive speech and language therapy but people with dementia will not.	Thank you for your comment. The committee noted this concern and agreed the wording here was unclear, and therefore this section has been removed from the committee's discussion of the evidence on palliative care.

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Royal College of Speech and Language Therapists	Full	415	Final para, line 58	The RCSLT disagrees with this statement "the committee considered the issue of specialist dietetic interventions and speech and language therapy. These services have a high demand from other disease areas and a high cost impact, and there is currently an absence of evidence to justify their use specifically in palliative care for dementia (above other conditions)." In relation to specialist dietetic interventions and speech and language therapy, we would like to highlight a recommendation from NICE Clinical Guideline 42 (2006) which states that "specialist advice concerning swallowing and feeding in dementia should be available", and we do not believe there is any evidence that indicates that this recommendation shouldn't continue to stand.	Thank you for your comment. The committee noted this concern and agreed the wording here was unclear, and therefore this section has been removed from the committee's discussion of the evidence on palliative care.
Royal College of Speech and Language Therapists	Full	415	Final para, line 58	We disagree with this statement that speech and language therapy swallowing assessments present as high cost impact. Appropriate management of eating and swallowing is integral to a comprehensive end of life approach (Smith HA, et al. Swallowing problems and dementia in acute hospital settings: practical guidance for the	Thank you for your comment. The committee noted this concern and agreed the wording here was unclear, and therefore this section has been removed from the committee's discussion of the evidence on palliative care.

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				management of dysphagia. Clinical Medicine 2009; 9: 6, 544–8). People with dysphagia are often admitted to hospital when they reach the stage of severe malnutrition, dehydration or aspiration, timely specialist speech and language therapy intervention can prevent this. A quality report by Sandwell Community Healthcare Services (2009) of their speech and language therapy rapid response dysphagia service highlights a 47% fall in the number of ward referrals for dysphagia related end of life dementia. (Sandwell Community Healthcare Services. Primary care rapid response assessment of dysphagia in end of life care. 2009). http://www.evidence.nhs.uk/qualityandproductivity This statement fails to take into account and weigh up the costs associated with the extensive evidence, of the reason for admission to hospital, and the increased length of stay for people with dementia in hospital. Supporting evidence:	

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				- Sampson et al (2009) cited in the Alzheimer's Society's document 'Counting the Cost (2009)', found that the reason for admission for 43% of people with dementia was caused by pneumonia and UTIs for which admissions could have been prevented or treated in the community. - The Health Foundation Inspiring Improvement document (2011, pg. 8) found that by reducing the hospital length of stay for 7% of people admitted with chest infections/pneumonia by just seven days made an annual estimated saving of £44,438,100. - The British Geriatrics Society Best Practice Guide, relating to Dysphagia Management for Older People Towards the End of Life (2012, pg. 5) states that "Expertise of speech and language therapists and dietitians should be sought and a team decision made which is in the best interest for each individual patient". It goes on to say that an important consideration when deciding on the dysphagia management approach taken is the distress related to eating and drinking, artificial nutrition and hydration, feelings of	

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				hunger/thirst and repeated hospital admissions/changes of environment. "Speech and language therapists can advise on strategies to minimise aspiration risk, facilitate eating and drinking, and improve nutritional status. These are modifications of food and fluids including changes to texture, consistency and quantity; swallowing strategies including manoeuvres and sensory techniques; positioning and postural techniques; external strategies such as carer support, environment and administering food and drink; and behavioural and cognitive techniques." *(Royal College of Physicians and British Society of Gastroenterology. Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life. London: Royal College of Physicians, 2010).*	
Royal College of Speech and Language Therapists	Full	416		The guideline states that support and speech and language therapy for people who live with dementia will be considered in the non-pharmacological interventions section of this guideline. However there is no reference to speech and language therapy in the non-pharmacological interventions section. We are very concerned about this omission.	Thank you for your comment. Evidence on speech and language therapy as looked for as part of the systematic review conducted for non-pharmacological interventions to improve cognition, functional ability, independence and wellbeing for people living with dementia (see appendix O). They therefore agreed it was not possible to make recommendations on speech and language therapy in this section of the guideline.

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Royal College of Speech and Language Therapists	Full	416		The RCSLT is concerned that removing specialists from palliative care underestimates the expertise which is essential at this stage of a person's life. This is particularly important in relation to the management of dysphagia which can cause choking, aspiration and pneumonia. Managing this is crucial to avoid hospital admission. Supporting evidence: • The RCP clearly highlight the role of specialists, "SLTs can advise on strategies to minimise aspiration risk, facilitate eating and drinking, and improve nutritional status…" (pg. 12, 1.65). In relation to nutrition for the person with dementia, best practice includes "assessment by a senior physician in nutrition support and SLT…." (RCP: pages 28, 2.26). Lambert (2012) cited by Chadder et al, 2016 highlights the role of SLT in palliative care. "Impairment and subsequent facilitations of communication or the placement and maintenance of a tracheostomy/enteral feeding tube (for example), are likely to be addressed to, and by, the SLP (speech and language pathologist) throughout palliative care".	Thank you for your comment. The committee agreed with the value of specialist palliative care services, but agreed that in the absence of evidence on specific interventions it was not possible to make recommendations on the role of specialist palliative care services. On the specific issue of dysphagia, the committee agreed it was appropriate to add an extra recommendation to the section on palliative care, to "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."

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Royal College of Speech and Language Therapists	Full	417	19	The RCSLT believes that this statement (118) does not take into consideration those people living with dementia who wish to eat and drink but are unable to do so safely. People should be supported to undertake risky feeding when supported by a specialist speech and language therapist. Pollens (2004) cited in The Role of Speech-Language Pathologists in Adult Palliative Care (2016) that: "In the palliative model, the SLP can assist in developing strategies to maximise the person's ability to enjoy the pleasure of eating/drinking in the safest and most comfortable way possible".	Thank you for your comment. The committee noted this concern, and agreed it was appropriate to remove the works "can do so safely" from this recommendation to cover the concept of 'at risk feeding'. They also agreed it was appropriate to add a specific recommendation on involving a speech and language therapist at this stage if there are concerns about safety. The new recommendations therefore become: "Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs. Consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."
Royal Surgical Aid Society	Full	352	2-27	We are highly encouraged to read these recommendations. We are piloting 3-day Dementia Carer Support Groups during 2018-2019 specifically for groups of up to 16 family /informal carers. The content and structure of the programmes implement all of these recommendations in one event. The Association of Dementia Studies, Worcester University will be evaluating the outcomes for carers who participate.	Thank you for your comment, and your support for these recommendations. NICE would welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies

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				Question 1: Our largely relies on volunteers or unqualified support workers who, whilst being enormously supportive and empathetic to dementia carers, may be unable to provide evidence-based interventions a deep understanding of dementia is required to design and deliver appropriate interventions which uphold the personhood of their person with dementia, build the resilience of carers and persons with dementia. The challenge, therefore, will be in meeting the investment requirements and upskilling of the dementia carers workforce (both paid and volunteer Question 2: Our charity is currently funding the cost of designing, delivering and evaluating the first 12 pilot programmes. The programmes have been designed and are being delivered by experienced practitioners (Speech and language Therapist/Occupational Therapist/Clinical Psychologist). They are 3 days in duration including 2 overnight stays. We aim for carers, by the end of the programme, to be able to manage their own situation more independently and confidently. To this end, the sessions are geared around equipping carers to understand their own needs and the needs of the person they are caring	

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				for and to know where to go to get help in meeting these needs which change over time. The content is split fairly equally between knowledge/skill building and resilience building and based on evidence drawn from literature reviews that we have commissioned from Worcester University (dementia/carers) and Dr Gemima Fitzgerald (resilience). Knowledge and skill building sessions include Understanding Dementia; Responding to challenging behaviour; Legal and Financial Issues; Carers rights; Factual information about the care, health and welfare systems to enable family carers to advocate for themselves and the person with dementia and successfully navigate around the system. More information about the programmes can be found on our website and feedback from carers who have attended the programmes so far can be seen on our Facebook page detailed below. Question 3: Our Charity has experience of implementing these recommendations and in an innovative way, based on available evidence and we are formally evaluating the intervention. We would be willing to submit our experience and our findings to the NICE shared learning database.	

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				PLEASE NOTE THAT WE ARE IN THE PROCESS OF RE-BRANDING AND THE NAME OF OUR CHARITY WILL BE CHANGING WITHIN THE NEXT coming months. . All links provided will automatically re-direct users to our new website and social media sites.	
Shift 8 Limited	Short	15	7,8,9, 10,11	Our organisation has had experience of implementing this approach ("group activities including elements of cognitive stimulation") and would be willing to submit evidence of the benefits of this to the NICE shared learning database. Specifically, we have evidence-based data on the effectiveness of using the Tovertafel. The Tovertafel, which means Magic Table in English, is a game for people with mid-to-late stage dementia, encouraging them to instinctively participate in order to stimulate both physical and social activity. The game consists of interactive light animations which are projected on any table and which motivate the mind and inspire those living with dementia to be active. People living with early, mid and late stage dementia are rarely able enjoy cognitive stimulation, physical activity and social interaction. The Magic Table enables them to enjoy all three. It can be tailored to personal preferences. Our research shows that	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and agreed that such evidence would be considered in future updates of the guideline. NICE would also welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies

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				the Magic Table activity also improves the wellbeing of people living with early, mid and late stage dementia; it improves their happiness and reduces their anger, fear and sadness. It also has huge positive knock-on effects for their loved ones and carers.	
Shift 8 Limited	Short	25	15, 25	Our organisation has experience of implementing this approach ("carers of people with dementia… planning enjoyable and meaningful activities") and would be willing to submit its evidence of the benefits of this to the NICE shared learning database. Specifically, we have evidence-based data on the effectiveness of using the Tovertafel Magic Table activity. It is easy for carers to use and a meaningful activity for people living with early, mid and late stage dementia to enjoy. Our research shows that the Magic Table activity enables people living with early, mid and late stage dementia to experience cognitive stimulation, physical activity and social interaction and that it improves their happiness and reduces their anger, fear and sadness. It also has huge positive knock-on effects on carers.	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and agreed that such evidence would be considered in future updates of the guideline. NICE would also welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies

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Shift 8 Limited	Short	28	3, 4	Our organisation has experience of implementing this approach ("consider training staff to provide multi-sensory stimulation for people with moderate to severe dementia and communication difficulties") and would be willing to submit its evidence of the benefits of this to the NICE shared learning database. Specifically, we have evidence-based data on the effectiveness of using the Tovertafel activity. The Tovertafel, which means Magic Table in English, is a game for people with mid-to-late stage dementia and consists of interactive light animations which are projected on any table and which motivate the mind and inspire those living with dementia to be active. Due to the degenerative nature of the disease, people living with mid-to-late stage dementia are rarely able to enjoy cognitive stimulation, physical activity or social interaction with anyone, let alone loved ones. The Magic Table enables them, and their families, to experience all three once again. Our research shows that it also improves the happiness and reduces the anger, fear and sadness of this group. In turn, this has huge positive knock-on effects for their loved ones and carers.	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and agreed that such evidence would be considered in future updates of the guideline. NICE would also welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies

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Shift 8 Limited	Short	30	5,6,7,	Our organisation has experience of implementing this approach ("identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally") and would be willing to submit its evidence on how to do this and the benefits of this to the NICE shared learning database. Specifically, we have experience of building a "buddy system" with local volunteers.	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and agreed that such evidence would be considered in future updates of the guideline. NICE would also welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies
Shift 8 Limited	Short	30	10,11	Our organisation has experience of implementing this approach ("think about what data you need to measure improvement and plan how you will collect it") and would be willing to submit its evidence on how to do this and the benefits of this to the NICE shared learning database. Specifically, we have experience of how to (robustly but sensitively) design data collection methods to measure the benefits of an activity for people living with mid-to-late stage dementia (a notoriously hard group to collect data on).	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and agreed that such evidence would be considered in future updates of the guideline. NICE would also welcome examples of good practice to be added to its shared learning database, and this can be done using the following link: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies
Shift 8 Limited	Short	30	14, 15	Our organisation has experience of implementing this approach ("develop an action plan, with the steps needed to put the guideline into practice,	Thank you for your comment. The committee would welcome any research published in peer-reviewed journals assessing ways to implement the recommendations in the guideline, and

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				and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases."). Specifically, of getting organisations (e.g. care homes) to add the Magic Table activity to their day-to-day care plans and giving training to ensure it is used optimally.	agreed that such evidence would be considered in future updates of the guideline.
Social Policy Research Unit, University of York	Short	25 26	14 – 29 1-18	Supporting carers. Our recent NIHR-commissioned review of reviews of international evidence on interventions to support carers showed only that interventions that involved contact between carers of people with dementia and other people who know about dementia may improve some aspects of carers' mental health (anxiety, depression) and of their perceptions of burden and stress. Very different types of interventions appeared to be related to these effects and often in comparison to 'usual care' which was otherwise undefined. There is a real danger in this evaluative field of picking up the 'anything is better than nothing' effect, and also of Hawthorne effects from simply being involved in research and therefore having more social interaction than is normal. Our review	Thank you for your comment. The review question on training for carers included an economic evaluation of the START programme, showing a high probability of it being cost effective. This was the reason for the START intervention being the basis of the recommendations produced on this topic. The committee agreed the evidence available, from both subgroup analyses of the RCT data and the meta-regression model, showed that on average, group sessions were more effective than individual, telephone or online sessions, and that interventions containing psychoeducation and skills training were effective, and therefore the committee agreed it was appropriate to recommend this specific intervention type.

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				of reviews did not come to any conclusion about the best way of delivering the contact between carers and others who know about dementia; for example both peer-contact (support group) and psychosocial intervention that was computer mediated had significant impact on both depression and burden. We feel that recommending 'a psychoeducation and skills training intervention' (p.25, lines 15/16) may be over-reaching the evidence. Reference: Thomas S, Dalton J, Harden M, Eastwood A, Parker G. Updated meta-review of evidence on support for carers. *Health Service Delivery and Research*, 5,12, March 2017. See table 12 for best evidence summary.	
Social Policy Research Unit, University of York	Full	134	8	Organisations could consider life story work as a means of supporting people with dementia to communicate their preferences and wishes. University of York research funded by NIHR HS&DR found that some people with dementia find this a useful communication aid and way to connect. However, it should not be assumed that every person with dementia wishes to make a life story and life story documents should not be used *in place* of face to face communication with the	Thank you for your comment. The committee agreed that there were a number of approaches, such as life story work that could be used as tools to support communication and that different approaches would be needed for each individual. However, the committee agreed that at this time there was not sufficient evidence to be able to make recommendations on which of these approaches are the most effective, and therefore that the recommendation should be kept generic until more evidence becomes available.

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				person with dementia, but to support this. Ref: Gridley, K., Brooks, J.C., Birks, Y.F., Baxter, C.R. and Parker, G.M., 2016. Improving Care for People with Dementia. *Health Services and Delivery Research*.	
Social Policy Research Unit, University of York	Full	147	1 - 3	Yes - 'time and opportunities to develop a deeper relationship' with case managers was found to be particularly important in our NIHR HS&DR funded study of support for carers of people with dementia. The final report of this study is not yet available (still in the editorial process) but a summary of findings can be downloaded here: https://www.york.ac.uk/spru/projects/admiral-nursing/	Thank you for your comment. The committee agreed that development of appropriate relationships with case managers is an important issue, and it is hoped that current, ongoing research in this area will help to further refine these recommendations in future updates of the guideline.
Social Policy Research Unit, University of York	Full	147	21 - 23	Yes – this point came out strongly in our study (https://www.york.ac.uk/spru/projects/admiral-nursing/) 'Having a named person to contact in times of crisis, and the security that they would not left to manage alone'. We found that it is important to carers that this person has the time to get to know the family/their situation and also has expertise in dementia	Thank you for your comment. The committee agreed having a named point of contact is an important issue, and it is hoped that current, ongoing research in this area will help to further refine these recommendations in future updates of the guideline.
Social Policy Research Unit, University of York	Full	147	33 - 34	Again, we have also found that carers highly value this continuity (https://www.york.ac.uk/spru/projects/admiral-nursing/)	Thank you for your comment. The committee agreed continuity of care is an important issue, and it is hoped that current, ongoing research in this area will help to further refine these recommendations in future updates of the guideline.

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Social Policy Research Unit, University of York	Full	147	10	Yes – our study (https://www.york.ac.uk/spru/projects/admiral-nursing/) also found that carers felt let down and 'abandoned' by memory services that did not offer regular follow-up	Thank you for your comment. The committee agreed ensuring people feel appropriately supported post diagnosis is an important issue, and it is hoped that current, ongoing research in this area will help to further refine these recommendations in future updates of the guideline.
Social Policy Research Unit, University of York	Full	154	5	Not just the person with dementia's needs – the named coordinator should assess and find ways to meet the carer's needs too (https://www.york.ac.uk/spru/projects/admiral-nursing/)	Thank you for your comment. This whole section refers to care coordination for the person living with dementia themselves. The committee did also look at evidence on case management for carers of people living with dementia, but agreed the evidence was not sufficiently well developed to be able to make recommendations.
South London and Maudsley NHS Foundation Trust	Short	3	2,3	The definition of dementia used says "a collection of symptoms including memory loss…". Dementia need not include memory loss as a symptom so we would suggest changing to ""impairment in multiple cognitive domains which may include memory loss"	Thank you for your comment. The committee noted the guideline contains links to diagnostics criteria for specific subtypes of dementia, and that the included was a suitable 'lay' definition for the introduction to the guideline.
South London and Maudsley NHS Foundation Trust	Short	4	13-22	We accept that mild cognitive impairment was out of scope for the guideline but the follow up and management of mci varies considerably from service to service and clinicians and CCGs would welcome some evidence based guidance on the assessment management and follow up of people with this condition. Would it be possible for NICE to consider this topic for a future guideline?	Thank you for your comment. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.

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South London and Maudsley NHS Foundation Trust	Short	7	5-19	There is evidence that alcohol misuse is often missed in older people. Heavy alcohol use can contribute to cognitive decline as well as lead to risk of falls, interaction with medication etc It is important that people with dementia and their carers have a history obtained about their alcohol use, are given information about the health risks (including those of cognitive impairment) associated with heavy alcohol use if appropriate and are offered evidence based brief interventions for alcohol misuse if appropriate. (see Royal College guidance on substance misuse in older people).	Thank you for your comment. The committee noted this point, and agreed it should be covered under the recommendation in the guideline to take a history from the person living with dementia (and a suitable informant if one is available).
South London and Maudsley NHS Foundation Trust	Short	9	14	Advance Care planning- our view is that it is vital that care plans are reviewed at transitions of care – eg when moving into a care home. We recommend incorporating this into the recommendation	Thank you for your comment. The committee agreed with this point, and recommendation 1.12.2 states that advance care and support plans should be reviewed afters every transition between care settings.
South London and Maudsley NHS Foundation Trust	Short	9	21	Initial assessment 'If possible, from someone who knows the person well' – the importance of collateral history in diagnosis cannot be over-emphasised and we would suggest wording this even more strongly eg "every effort should be made to obtain history from relatives friends or professional carers to get as accurate a picture as possible about the	Thank for your comment. The committee agreed this was an important part of the assessment process, and felt the current wording to do this "if possible" was the most appropriate way to word the recommendation.

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				person's symptoms and how they affect activities of daily living."	
South London and Maudsley NHS Foundation Trust	Short	10	11	Previous NICE guidance indicated that it was good practice to request basic blood investigations as part of the assessment of cognitive impairment. We are uncertain why this is not in the current guidance.	Thank you for your comment. The committee agreed with the suggestion that it was appropriate to retain this recommendation from the previous guideline, and therefore "undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline" has been added to the recommendation for initial assessment in non-specialist settings.
South London and Maudsley NHS Foundation Trust	Short	10	25, 26	Structural imaging to "rule out" reversible causes needs more clarity. This could be seen to imply that everyone needs a scan to "rule out" reversible causes. We would wish to avoid scanning a large number of older people with clear history of AD who do not need further test to make the correct diagnosis. It might be better to phrase the guidance " If history suggests that the presentation is not typical for Alzheimer's disease, or if dementia is present in a younger person where rarer causes are more likely , then investigations should be carried out to clarify the diagnosis. The purpose of the scan should be to help make a definitive diagnosis, not to "rule out" extremely rare reversible conditions".	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."

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South London and Maudsley NHS Foundation Trust	Short	11	15	Access to lumbar puncture for CSF and PET scanning is not widespread. Both procedures are expensive, potentially distressing, and not always accurate or helpful (clinical experience indicates that these tests often do not give an answer, particularly in older people with multiple medical co-morbidities. The recommendation needs more clarity or it could be interpreted in the wrong way. It might be useful to start by saying for whom such investigations are not helpful ie older people with a clear history of gradual cognitive decline and cognitive deficits compatible with AD. The investigations are primarily indicated for younger people where neuropsychological testing and MRI/CT have not clarified the diagnosis.	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these test could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
South London and Maudsley NHS Foundation Trust	Short	15	23	Could transcranial magnetic stimulation be specifically mentioned under the section on non-invasive brain stimulation here please? We are getting referrals asking this to be considered, and carers and relatives are asking about it - whereas	Thank you for your comment. Transcranial magnetic stimulation was included as part of the evidence base considered by the committee, and therefore they agreed it was appropriate to clarify the recommendation to "do not offer non-invasive brain stimulation (including transcranial magnetic

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				as far as we are aware there is no evidence that this intervention improves outcomes for people with dementia	stimulation) to treat mild to moderate Alzheimer's disease, except as part of a randomised controlled trial."
South London and Maudsley NHS Foundation Trust	Short	20	14	The example given in the text of a suggested scale to assess anticholinergic side effects is the ACB (anticholinergic burden scale). This scale is now slightly out of date. Please consider also mentioning the AEC scale which was designed as an update to other scales, builds on the work of the ACB scale and is more comprehensive – covering all drugs in the BNF. Its scoring method is based on the most up to date in vitro and clinical data. It is freely available in a simple useable form on line (medichec.com) (reference- Bishara D et al Anticholinergic effect on cognition (AEC) of drugs commonly used in older people (Int J Ger Psych 2016)	Thank you for your comment. The committee noted the existence of this new and potentially improved tool, but were not aware that it had yet been validated in the same way as the other tools included in the review. As a result, the committee agreed it was best to retain the reference to the ABS, but that this was presented solely as an example, and that the use of more modern validated scales would be appropriate when they are available.
South London and Maudsley NHS Foundation Trust	Short	20	19	The guidance should state that antipsychotic medication can be appropriately prescribed for the treatment of psychosis in dementia. This includes both the treatment of long standing psychotic disorders and the treatment of psychotic symptoms in the context of dementia.	Thank you for your comment. The committee agreed with this point and noted the guideline allowed the use of antipsychotics for people with "hallucinations or delusions that are causing them severe distress."

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South London and Maudsley NHS Foundation Trust	Short	20	24	Section 1.7.2 needs expansion and linking to other sections. 5. For care homes interventions for BPSD should be aligned to an appropriate support programme for staff (section 1.13 lines 20-24). Good practice is for interventions to support staff to improve communication skills and their delivery of person-centred care (see systematic review by Prof Gill Livingston (BJPsych 2014). These were the two key components of effective training/support interventions. 6. The concept of "challenging behaviour" representing an unmet need is a very important and useful one to use when supporting staff to develop care plans to manage people with BPSD. It has been widely used in clinical practice (Newcastle Model) and in the TREA model for which there is some evidence (Cohen Mansfield- see reference below) and is supported in the British Psychological Society Guidance on non-pharmacological interventions in BPSD (2013)- see below for reference 7. The WHELD model of care (Ballard et al 2016 and 2017- see below) is emerging	Thank you for your comment. Please find below a response for each of the papers you cited. Livingston (2014) was excluded because data was not pooled in the systematic review, but the individual included studies were checked for eligibility in the guideline. Ballard (2016) was excluded during the screening on title and abstract level because this paper was not relevant to the review question. Ballard (2017) is referred as Ballard (2016) in Appendix F because this paper was first published online in 2016. Ballard (2016) was excluded because the study was a multimodal intervention consisting of exercise, antipsychotic review, social interaction and person centred care. In relation to antipsychotic review, it was unclear whether medications were withdrawn or changed. Cohen-Mansfield (2000) would have been excluded because this paper is not an RCT or a systematic review of RCTs.

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				as an effective model which supports specialist staff mentoring and supporting "dementia champions" in care homes to deliver person-centred care, antipsychotic reductions and social and exercise interventions. We were unsure whether the committee looked at this model. 8. Work with carers living with a person with dementia at home who has BPSD must include the psychoeducational approaches recommended in Section 1.11 lines 17-29. 9. Drugs for BPSD have limited effectiveness, so the bulk of the care of the person with dementia with non-cognitive symptoms rests with untrained family members or junior care staff. So the importance of support and information for these carers (in line with sections 1.13 and 1.11) must be emphasised more clearly at the start of section 1.71. References 1) Ballard et al. (2016). Impact of Antipsychotic Review and Non-pharmacological Intervention on	

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				Antipsychotic Use, Neuropsychiatric Symptoms, and Mortality in People With Dementia Living in Nursing Homes: A Factorial Cluster-Randomized Controlled Trial by the Well-Being and Health for People With Dementia (WHELD) Program. American Journal of Psychiatry 173 (3), 252-262 2) Ballard et al. (2017). Impact of antipsychotic review and non-pharmacological intervention on health-related quality of life in people with dementia living in care homes: WHELD—a factorial cluster randomised controlled trial. International Journal of Geriatric Psychiatry. International Journal of Geriatric Psychiatry 32(10), 1094-1103 3) Briefing paper: Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia. British Psychological Society (2013)	

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				4) Cohen-Mansfield (2000) Nonpharmacological management of behavioral problems in persons with dementia: The TREA Model. Alzheimer's Care Quarterly 1(4), 22-34	
South London and Maudsley NHS Foundation Trust	Short	22	11	We were concerned that just stating not to use melatonin to manage sleep problems may lead to inappropriate use of even more dangerous and similarly ineffective drugs- such as anticholinergic antihistamines (promethazine) and benzodiazepines (which increase fall risk). We propose either a change in the wording to a more blanket 'Do not offer pharmacological treatments to manage sleep problems in people living with dementia' , or else offer cautious support of the use of melatonin for people with dementia with severe insomnia in a time limited fashion for people who have not responded to sleep hygiene measures	Thank you for your comment. The committee noted this concern, but agreed there was not sufficient evidence on other pharmacological treatments to be able to make recommendations (either positive or negative), and agreed that an absence of alternatives was not a reason to promote the use of a drug (melatonin) where there is evidence of a lack of efficacy.
South West London and St George's Mental Health NHS Trust	Short	9	17	Please consider defining a 'non-specialist setting'	Thank you for your comment. This has been addressed by adding some examples of what would be considered a specialist setting, and therefore a non-specialist setting would be anything not covered by that term.

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South West London and St George's Mental Health NHS Trust	Short	10	18	This may be a good opportunity to raise awareness off anti-NMDA receptor encephalitis which can present with impaired cognition and memory deficits.	Thank you for your comment. The committee noted there were a number of rarer presentations which might be of relevance in clinical practice at this point, but agreed it would not be appropriate to make an exhaustive list of possible diagnoses.
South West London and St George's Mental Health NHS Trust	Short	17	19	Please consider changing term from 'drug' to 'medicine' (drugs are not always medicines)	Thank you for your comment. Unfortunately, this recommendation comes from a section of NICE technology appraisal 217 that has not been updated as part of this guideline, and therefore it is not possible to make changes to this wording as part of the guideline update.
South West London and St George's Mental Health NHS Trust	Short	17	21	There is a reference here to shared care – what is not clear from the guideline is the expectation of where this group of patients are cared for – with the growing number of dementia sufferers it is not feasible that they can all be managed by specialist services and I would expect non-complex patients following diagnosis to be managed in primary care and being re-referred to specialist as the need arises – in this case there would not be 'shared care' –consider removal of this reference to shared care.	Thank you for your comment. Unfortunately, this recommendation comes from a section of NICE technology appraisal 217 that has not been updated as part of this guideline, and therefore it is not possible to make changes to this wording as part of the guideline update.
South West London and St George's Mental Health NHS Trust	Short	19	Footnotes	All footnotes specify 'informed consent should be obtained and documented' patients may not have capacity to consent - consider adding reference to use of mental capacity act	Thank you for your comment. The committee noted that throughout this guideline, issues around consent always interacted with those on capacity, and there was nothing unique in this respect about the situation of using medicines off-license. The guideline already contains a reference to the

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					Mental Capacity Act (and the accompanying Code of Practice) to cover these issues.
South West London and St George's Mental Health NHS Trust	Short	19	5	We welcome the recommendations regarding the pharmacological management on non-alzheimers dementia - off-label prescribing can often present barriers to primary care management and we would appreciate consideration to potential impact on secondary care services this may have.	Thank you for your comment. The committee noted that, as always when NICE makes recommendations for the use of off-license medicines, this is only done when there is clear evidence of benefit from their use.
South West London and St George's Mental Health NHS Trust	Short	21	Footnote 6	Footnote specifies 'informed consent should be obtained and documented' patients may not have capacity to consent - consider adding reference to use of mental capacity act	Thank you for your comment. The committee noted that throughout this guideline, issues around consent always interacted with those on capacity, and there was nothing unique in this respect about the situation of using medicines off-license. The guideline already contains a reference to the Mental Capacity Act (and the accompanying Code of Practice) to cover these issues.
South West London and St George's Mental Health NHS Trust	Short	26	4-5	'providing information on carer's employment rights for carers who work or want to work' – may wish to change to: 'providing information on employment rights for carers who work or want to work'	Thank you for your comment. The committee agreed it was appropriate to retain the current wording in the guideline, to make clear this information was around the carer's own legal rights, not rights for the person living with dementia.
South West London and St George's Mental Health NHS Trust	Short	26	6	Consider adding 'and offer convenient times'	Thank you for your comment. The committee agreed with this point, and that this was covered by the recommendations in the guideline around ensuring the support provided to carers is accessible.

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St Helens and Knowsley Teaching Hospitals NHS Trust	Short Long	12 124	24	This comment applies to both the recommendation on case finding in the short version of the draft guidance and the comment on the acute hospital CQUIN within the long version. The recommendation regarding case finding in the short version is clear. Removal of the requirement for case finding would allow the resources currently used for this to be used elsewhere to improve patient care. The comment about the CQUIN within the long version says that "acute hospitals were required to report on the number of positive diagnoses as a proportion of the number of patients who had been formally tested for dementia". This was the second step of the CQUIN. The first step of the CQUIN was case finding so the draft NICE guidance does interact with the requirements of the CQUIN. The reference to the second step in the CQUIN and not the first within the long guidance is misleading. We feel that the committee should consider either issuing a clear statement that their guidance does affect the CQUIN or remove the reference to the CQUIN altogether.	Thank you for your comment, and for pointing out this error. This section of the guideline has been rewritten to make clear that this guideline does not affect the interpretation of the CQUIN: "The committee noted that case finding for dementia was introduced in acute hospitals as part of the Commissioning for Quality and Innovation (CQUIN) 2013/14 guidance, and that the committee's recommendations should be interpreted as applying to situations outside this existing guidance."

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St Helens and Knowsley Teaching Hospitals NHS Trust	Short Appendix C	13 24	1	This comment applies to the recommendation on page 13 in the short guidance and review question 17 in Appendix C. We are concerned that the title of the recommendation in the short guidance is misleading and that the recommendation itself is not suitable for acute hospital practice. The recommendation in the short guidance is entitled "telling the difference between delirium and dementia". Research question 17 in Appendix C is "what are the most effective methods of differentiating dementia or dementia and delirium from delirium alone?" The recommendation in the short guidance implies that the aim is to identify delirium but the research question suggests that the aim is to identify dementia. In acute hospital practice, the focus is on identifying patients with delirium (with or without dementia) and differentiating them from patients with dementia alone. The difference between the approach in acute hospitals and research	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is covered by the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.

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				question 17 has resulted in the exclusion of validation studies of the 4AT from the review. The 4AT is a screening test for delirium which is increasingly used in acute hospital practice (https://www.the4at.com). Completion of the 4AT is a mandatory requirement for attainment of the Best Practice Tariff for hip fracture. In our Trust, the 4AT is embedded within the Emergency Department documentation for patients who are 65 years and over. Neither the long Confusion Assessment Method (CAM) nor the Observational Scale of Level of Arousal (OSLA) is in routine use in acute hospitals in the United Kingdom. A considerable amount of resource for training and education would be required to implement them. The time taken to complete the long CAM makes it unsuitable for acute hospital practice. We request that the committee consider changing the wording of the recommendation regarding differentiating dementia from delirium to make it clear that the recommendation does not apply to delirium screening and therefore may not be suitable for acute hospital practice.	

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Sunrise Senior Living	Full	300	74	This statement should be expanded to include activities that are tailored to specify the individual's preferences, routines, abilities and limitations	Thank you for your comment. The committee agreed there were a range of factors that would go into appropriately tailoring activities for individuals, but that it was not possible to give an exhaustive list of all factors that should be considered.
Sunrise Senior Living	Full	300	76	This recommendation will provide a therapeutic model for supporting people to live well with dementia and to potentially reduce or slow the rate of progression of the functional disability associated with the symptoms	Thank you for your comment and your support for this recommendation.
Sunrise Senior Living	Full	332	82	The recommendation should guide to check for physical and social environmental causes of distress (noise, glare, relationships with others)	Thank you for your comment. The committee agreed with this point but felt this was covered by the phrase "clinical or environmental causes."
Sunrise Senior Living	Full	332	83	The recommendation should include clinical interventions (pain management for example)	Thank you for your comment. The committee agreed with this point but felt this was covered by the phrase "check for and address clinical or environmental causes" in the previous recommendation, with pain being a highly relevant clinical cause.
Sunrise Senior Living	Full	333	88	The recommendation should include clinical interventions (pain management for example)	Thank you for your comment. The committee agreed with this point but felt this was covered by the phrase "check for and address clinical or environmental causes" in a previous recommendation, with pain being a highly relevant clinical cause.
Sunrise Senior Living	Full	333	90	In my opinion this recommendation has the potential consequence of invalidating the emotional experience of the individual. I think it	Thank you for your comment. The committee discussed your comments however they agreed that the current wording of

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				should read: "For people living with dementia who experience agitation or aggression, validate their emotional experience and offer reassurance and the opportunity for meaningful activity and interaction to address any unmet emotional need"	the recommendation was the clearest reflection of the available evidence.
Sunrise Senior Living	Full	369	100	The recommendation for staff training should include an understanding of the progressive nature of the condition and how to support an individual at different stages of dementia, with different levels of ability and disability	Thank you for your comment. The recommendation on staff training has been modified to mention training on "understanding the signs and symptoms of dementia, and the changes to expect as the condition progresses," The committee agreed that, with the currently available evidence, it was not possible to be more specific than this in the recommendations.
Sussex Partnership NHS Foundation Trust	Short	8	1.1.6	The guidance covers the whole dementia journey and not all of it is applicable to secondary care but it isn't stated who should provide what care 1.16 Offer written information: we are concerned that there is not a standard of information and we will end up with multiple different sources. Organisations such as Alzheimer's Society, for example have great literature	Thank you for your comment. The committee noted that the organisation of services differed around the country, and in the absence of robust evidence it was not possible to recommend one of these models above the others. The committee agreed there were a number of potential sources of good written information, and the important thing was that areas had information available to cover different dementia subtypes, rather than the particular source they used for the information.
Sussex Partnership NHS Foundation Trust	Short	9	1.2	1.2 Diagnosis we need to check that one of the tools they suggest is part of our assessment	Thank you for your comment. The committee noted these tools are all validated for use as part of an assessment for someone with suspected dementia.

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				process- again are there validated recommended tools to ensure consistency	
Sussex Partnership NHS Foundation Trust	Short	9	1.1.11	1.1.11 Advance care planning; where should discussion sit? We are concerned that different agencies may be involved at different stages along the care pathway e.g. in primary care.. How will information be shared? We need to avoid duplication and take a whole systems approach to advanced care planning.	Thank you for your comment. The committee agreed that information on advance care planning should be recorded and shared (with permissions) with different agencies involved in the person's care, to avoid unnecessary duplication (see recommendation 1.3.5).
Sussex Partnership NHS Foundation Trust	Short	10	22	**1.Section 22 Dementia diagnosis in specialist dementia diagnostic services** We are concerned that this recommendation may imply that there is no need for occupational therapy and other allied health professional involvement as part of the diagnostic pathway: Specific referral criteria could include: To consider a referral to an occupational therapist for specialist assessment in the following instances • In complex cases where the medic/team is querying a dementia diagnosis. • The person lives alone and there is no informant and the basic screening measures	Thank you for your comment. The committee noted that no evidence was identified on occupational therapist or other allied health profession assessment as part of the diagnostic process, and therefore it was not possible to make recommendations on this topic. The committee did agree it was appropriate to include a recommendation around neuropsychological testing as part of

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				of ADL in level 1 assessment (i.e. FAQ) needs further support and exploration. • There is a question over deterioration/decline in the person's functional ability and further information is needed to inform the diagnosis (i.e. to establish baseline performance and if there is a deficit and/or decline in occupational functioning which is essential for a dementia diagnosis*). If needed the assessment can be repeated at a later date by the OT to determine whether there has been a decline in functioning.* • Adds considerably in the context of complex diagnostic formulations alongside other specialist assessments such as neuropsychiatry, in some cases the OT assessments avoids the need for a neuropsychiatric referral (in cases where there has been no deterioration in functional ability). -There is also no mention of neuropsychology anywhere in the diagnostic pathway in section 22.	the diagnostic process in specialist settings. Therefore, the following recommendation was added to the guideline: "Consider neuropsychological testing if it is unclear: • whether or not the person has cognitive impairment • whether or not their cognitive impairment is caused by dementia or • what the correct subtype diagnosis is." The committee also noted that there was no evidence that would enable it to make recommendations on which specific tests should be used as part of this process, and that this would often be different between different neuropsychologists.

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Sussex Partnership NHS Foundation Trust	short	11	1.2.1 2	Question 1: We are concerned that this recommendation may imply that all people diagnosed with a dementia need to be in secondary care to have care coordination. May need to call it something else, and people may remain in primary care as we are looking to support them to do some diagnosis and treatment Would implementation of any of the draft recommendations have significant cost implications? Potentially if they are recommending CSF analysis/ and more complex scanning to determine type of dementia then this may be taken up by services more than it is now and would be a cost implication (currently commissioned to CT or MRI scan everyone. Would need to ensure it made it clear that this was only if diagnosis not clear	Thank you for your comment. The committee agreed that many people living with dementia would be manged in primary care, but that care coordination was equally relevant for people in this setting. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
Sussex Partnership NHS Foundation Trust	Short	13	23	**1.3.1 Care coordination** This recommendation will be a challenging change in practice because we feel it's unrealistic in services as things currently stand to have a	Thank you for your comment. The committee noted there would be challenges and costs associated with care coordination, but that there was clear evidence this was an

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				single named care coordinator throughout their entire dementia journey. The content of this section is broad and it is not clear when the care coordination starts and ends in the description. There are examples in the Trust where care coordination is provided in Primary Care as part of a whole system dementia pathway – the Golden Ticket	effective intervention to improve care for people living with dementia. The committee did note that the most appropriate person to be the care coordinator may change over time, so would not necessarily remain the same person. However, they agreed that at any given moment in time, it was important for there to be a single individual tasked with coordinating care.
Sussex Partnership NHS Foundation Trust	Short	15	1.4	**Section 1.4 Interventions to promote cognition, independence and wellbeing** 1.4 Interventions to promote cognition etc. most people with mild to moderate dementia will be in primary care-different CCGs have different funding arrangements. This is not currently funded by commissioners in some areas of our organisation, who currently have insufficient resources to provide carer support and education We are concerned that this recommendation has no mention of occupational therapy assessment as the core skills of occupational therapists meet the needs identified in this section:	Thank you for your comment. This section has been revised as a result of the feedback received during consultation, and now contains references to 4 specific and distinct interventions; namely: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia. Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia."

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Sussex Partnership NHS Foundation Trust	Short	15	1.4.1	We recommend these words are added to the existing wording (see bold for our additions) 1.4.1 add to end of existing sentence… 'person's preferences and functional ability **following an Occupational Therapy assessment**'.	Thank you for your comment. The committee noted that no specific evidence was found around occupational therapy (assessments) except as part of larger occupational therapy interventions, and therefore it was not possible to make recommendations on this topic.
Sussex Partnership NHS Foundation Trust	Short	15	1.4.3	1.4.3 add to start of existing sentence… **'Following comprehensive Occupational Therapy assessment** consider providing a needs-based re-ablement programme (including elements of cognitive rehabilitation) to people living with mild to moderate dementia **AND THEIR CARERS** who are not already accessing them.	Thank you for your comment. The committee noted that no specific evidence was found around occupational therapy (assessments) except as part of larger occupational therapy interventions, and therefore it was not possible to make recommendations on this topic.
Sussex Partnership NHS Foundation Trust	Short	20	1.6	1.6 Medicines that may cause cognitive impairment and use of tools for assessing anticholinergic burden - are there recommended validated tools?	Thank you for your comment. There are a number of validated tools available, but there is currently no evidence as to which is the most appropriate to use. The recommendation does contain reference to the anticholinergic burden scale, which is a validated UK tool that can be used.
Sussex Partnership NHS Foundation Trust	Short	25	1.11	1.11 Supporting Carers: 1.11.1 offering carers a psychoeducation and training intervention – we are currently not funded by CCGs to provide a service to carers. The guidance should state who should provide support and training to carers. There are examples in the trust where we have provided evidenced based courses for carers (not	Thank you for your comment. NICE guidelines do not give recommendations on how particular services should be funded, but the committee noted there was clear evidence that training for carers was both effective and a cost-effectiveness use of resources, and therefore were confident it was an intervention that should be offered to all carers of people living with dementia.

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				specifically dementia) using a psychoeducational and skills training approach. Psychoeducational training for carers of people with dementia could be provided through our Recovery College. Funding& resources will need to be considered as most parts of the trust are not commissioned by CCG's to provide this.	
Sussex Partnership NHS Foundation Trust	Short	25	14	**Section 1.11 Supporting Carers** We are concerned that this recommendation does not clearly specify the important role carers can have in supporting the person living with dementia: We recommend considering rewording "training in how to provide care" to "**training carers to be able to support person living with dementia to maintain skills and independence for as long as possible".** We are also concerned about funding of caring and where	Thank you for your comment. The committee noted the concerns raised about the cost of these recommendations, and therefore agreed it was important to focus the recommendations directly on those areas where there was good evidence of both effectiveness and cost-effectiveness. As such, they agreed it was appropriate to retain the original wording, which stayed as close as possible to the interventions in the included evidence base.
Sussex Partnership NHS Foundation Trust	Short	27	1.13	1.13 Staff Training: 1.13.1 Provide all staff with training. We are concerned that this recommendation will have significant cost implications. The guidance provides a really comprehensive list as to what should be included in such training and we should be providing it to	Thank you for your comment. The committee noted that the guideline did contain two separate recommendations, a briefer recommendation for all staff and a more exhaustive list for "staff who deliver care and support to people living with dementia." The committee noted that all the things included in

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				all staff as a mandatory training, & involve service users and carers in the provision. Training should include having difficult conversations etc . Training could be tailored such as: all staff receive dementia awareness and dementia friendly communities training and staff working in specialist older adults and /or dementia services receive more in depth training and mentoring.	this list were ones where there was robust evidence they were effective in improving care for people living with dementia.
Sweettree Homecare Services	Short	9	17-27	As below	Thank you for your comment. The committee noted this concern, but agreed that appropriate initial assessments in non-specialist settings were key to ensure there were not a considerable number of unnecessary referrals to specialist dementia diagnostic services.
Sweettree Homecare Services	Short	10	1-10	This recommendation implies that the initial assessment be carried out in a non-specialist environments. This will be a challenge, as within primary care factors such as time, knowledge and skills will affect the effectiveness. There would need to be a clinic specifically for this assessment as 10 minutes will not be enough. The primary care environment would need to be skilled to carry out such initial testing, which would include an understanding of the tools. Generic first stage diagnostic assessment has not been successful in the past	Thank you for your comment. The committee noted this concern, but agreed that appropriate initial assessments in non-specialist settings were key to ensure there were not a considerable number of unnecessary referrals to specialist dementia diagnostic services.

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Sweettree Homecare Services	Short	11	15-25	The challenge is that the value of taking CSF and using PET is well researched but there needs to be a network of specialist testing centres as this is not automatically offered due to resources.	Thank you for your comment. The committee noted there are issues around access to imaging and CSF examination in certain areas, but agreed the evidence showed these test could be of diagnostic value in some cases, and therefore were appropriate to include in the recommendations. The committee noted that the 'consider' recommendation for CSF examination came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management."
Sweettree Homecare Services	Short	12	1	The reliance of CT and MRI has been contested yet these are the only resources available, so can it be that if the CT or MRI is ruling out Alzheimer's we should be looking at an alternative diagnostic measure.	Thank you for your comment. The committee noted the recommendations made for diagnostic tests were based on the best evidence available from a systematic literature review of the diagnostic accuracy of tests for dementia and dementia subtypes.

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Sweettree Homecare Services	Short	15	9-11	The wording "Consider providing…elements of Cognitive Stimulation" is highly problematic. Whilst there is strong research and clinical evidence for CST when used as a manualised intervention, *there is NO evidence for any benefits if just elements of the programme are used and no evidence, in general, for structured group activities.* Further, having a clear manual, which can be followed by a range of health and social workers at all levels of expertise; eases implementation and minimises preparation time, providing a highly cost-effective intervention. This change in wording is open to different interpretations and could be concluded that any type of structured group is sufficient, and there will be a lack of governance and adherence to any sort of standardisation. We would suggest reverting to the wording from the 2006 NICE guidelines, which state that *"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia"*.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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Sweettree Homecare Services	Short	15	1	The challenge here is the recognition of how dementia goes beyond the person and its effect on the family as a whole. This is difficult for a person who has been diagnosed under the age of 65 and their needs are significantly different. This has been highlighted within the short version but how are services going to develop for the younger population. Look to www.ypwd.org as an example	Thank you for your comment. The committee agreed there were specific challenges in delivering care and support for younger people living with dementia, and noted that specific recommendations have been made on this topic throughout the guideline, wherever there is evidence to do so.
Sweettree Homecare Services	short	22	11	The challenge here is that Melatonin is being prescribed for those with dementia. The reason, context and guidance needs to be clear.	Thank you for your comment. The committee agreed it was appropriate to make this recommendation more specific, to focus directly on the population for which there was evidence. Accordingly, this has been amended to "do not offer melatonin to manage insomnia in people living with Alzheimer's disease."
Sweettree Homecare Services	Short	25	15-29	This is a strong recommendation; the challenge here is to make this mandatory, but also to cost out how much this resource would affect services and to map out the number of organisations who provide this across all sectors.	Thank you for your comment. The committee agreed there would be costs associated with providing carers with the specified training and support, but agreed the evidence showed this was an effective and cost effective intervention, and would be an appropriate use of resources.
Sweettree Homecare Services	Short	26	1-9	This needs to be mapped out as to who provides this initial support and the quality of the support provided. Should it be Dementia Advisors or the Memory Clinic team? This needs to be mandatory; allowing individual services to determine their level of support will be led by cost and time.	Thank you for your comment. The committee agreed that due to the number of carers this recommendation is relevant to, this training is likely to need to be a specifically commissioned service. The committee noted that the full guideline contains examples of UK specific training packages (such as START) that can be used to deliver this training in a structured way.

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Sweettree Homecare Services	Short	26	10	This is a sweeping statement, carers report back that they struggle with groups as it is almost matching up each person's experiences which can be distressing.	Thank you for your comment. The committee agreed the evidence available, from both subgroup analyses of the RCT data and the meta-regression model, showed that on average, group sessions were more effective than individual, telephone or online sessions. However, the committee also agreed both that the group sessions would need to be well run/moderated, and that this format would not be the most suitable for all individuals, due to differences in their circumstances and preferences. They therefore agreed it was appropriate for the recommendation for group sessions to be kept at the weaker "be aware" level, and that the guideline should also recommend support for carers is "provided in a format suitable for them (for example individual or group sessions, or online training and support)", to ensure this is not taken as a blanket statement that group sessions are the most appropriate format for all carers.
Sweettree Homecare Services	Short	27	13-29	We have worked on this within the dementia service at www.sweettree.co.uk. Recruitment criteria is that dementia carers will have up to 6 months experience of working with dementia and this will be determined at interview and within a 4 day induction. The 4-day induction includes a three-hour dementia awareness session, this will be followed up with a day course on interventions using ABC methodology and the use of iCST. The	Thank you for your comment and your support for the deliverability of this recommendation.

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				service is using the VIPS tool to audit its care provision and is embarking on a second audit to include the support workers.	
Sweettree Homecare Services	Full	41	11	The use of a solution-focused approach has reduced the need for regular Admiral Nurse visits as a robust summary/self-management plan, contact by email and phone and a 3 monthly face-to-face has led to some actions being taken forward and implemented. admiralnurse@sweettree.co.uk	Thank you for your comment. The committee agreed that Admiral Nurses were a group that could be involved in effectively delivering a number of the recommendations included in the guideline.
Sweettree Homecare Services	Full	296	43-51	Regarding Cognitive Stimulation, we have several comments: 1) "Unclear whether it was specific content of the interventions or simply being part of a group". We would argue that this is an incorrect conclusion. Whilst the literature on non-pharmacological interventions spans several decades and hundreds of studies, the evidence base for manualised, Cognitive Stimulation is considerably stronger than for other interventions, including Reminiscence. For example, a systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions.	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				Several trials within the Cochrane review concluded that the results were consistently in favour of structured group such as Cognitive (Woods et al, 2012). 2) "The two interventions are not mutually exclusive" It is correct that Cognitive Stimulation incorporates some aspects of Reminiscence. However, the key focus of Cognitive Stimulation (more specifically the manualised 'CST' programme which is widely followed) is on generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). We run regular CST groups at Sweettree and believe that this provides a different message and thus reduces stigma associated with dementia and old age. The experience of CST groups has been overwhelmingly positive.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				3) "There would be no difference in cost of delivery between providing an intervention with a more varied range of components". We would argue that this assumption cannot be made without a cost effectiveness analysis. There is strong evidence for the cost effectiveness of manualised CST, with two key papers published since the 2006 guidelines (Knapp et al, 2006; D'Amico et al, 2015). However, an alaysis of a different model of provision has not been conducted, to our knowledge. 4) "This was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" . This appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according to important key principles which fit with the underlying theoretical models. We would encourage NICE to argue for more adherence to protocol and evidence base, rather than less.	

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Sweettree Homecare Services	Full	352	2-5	Admiral Nursing www.dementiauk.org are already implementing the recommendations. The challenge is the inconsistency across areas due to (1) not having Admiral Nurses who could co-ordinate these recommendation (2) inconsistent provision of Dementia Advisors and (3) fragmented carer pathways across services	Thank you for your comment. The committee agreed that Admiral Nurses were an important group who could be involved in implementing the recommendations made, but the evidence did not enable the committee to make specific recommendations around how this should be organised at a local level.
Sweettree Homecare Services	Full	353	1-21	As above	Thank you for your comment. The committee agreed that Admiral Nurses were an important group who could be involved in implementing the recommendations made, but the evidence did not enable the committee to make specific recommendations around how this should be organised at a local level.
Sweettree Homecare Services	Full	375	1-5	The challenge here is that the guidance decided to merge recommendations on younger people with dementia into the other sections. Though the evidence base was robust should we consider a "younger people with dementia" guidance to include the increasing number of experts working in this field	Thank you for your comment. The committee agreed that at this time it was appropriate to include recommendations for younger people living with dementia as subsets within the broader recommendations, as the amount of evidence specifically on younger people living with dementia is still small. However, this is currently an area where a considerable amount of research is ongoing, and the committee hope it will be possible to make more specific recommendations on this in future updates of the guideline.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	14/15	28-2	Recommendation 1.3.6: There is a cost implication in providing staffing to support people who do not have a carer and in providing	Thank you for your comment. NICE does not provide guidance on how specific services should be funded, but the committee did agree it was important for dementia services to be

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				affordable transport / transport for people who find it difficult to use. Which service will be responsible for providing this?	accessible to as wide a range of people living with dementia as possible.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	7	12-13	Recommendation 1.1.3 is to consider using a structured tool. Could the guidance detail which specific tools are recommended?	Thank you for your comment. The committee agreed that the evidence was not sufficiently robust to enable them to recommend one specific tool as being the most appropriate to use for this purpose.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	15	9-11	Recommendation 1.4.2: Has NICE moved away from Cognitive Stimulation Therapy (CST) in accordance with the CST manual which is clear on frequency, content and duration? Is there scope for services to be more flexible on this now? Is it expected that this is provided by specialist MH services?	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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					recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
Tees Esk and Wear Valleys NHS Foundation Trust	Short	29	8/9	Could Occupational Therapists be listed as specialist clinicians?	Thank you for your comment. The committee were keen to point out that this definition solely referred to the question of who should give advice before pharmacological treatment for Alzheimer's disease is started. It was not intended as a more general statement around who would count as a specialist clinician. The final version of the guidance should make this point clearer.
Tees Esk and Wear Valleys NHS Foundation Trust	Full and Short	general	general	It would be helpful if the guidance could clarify, particularly for the treatment sections, which service is to lead for the standards (i.e., Local Authority/ Primary Care/ Specialist Mental Health Service). Without this detail, there is potential for all services to assume another service is responsible and for gaps in service provision to appear.	Thank you for your comment. The committee would have liked to specify which service should be responsible for each part of the guideline, and noted the concerns you raise, but agreed that in the absence of any evidence on who should be responsible for these standards on which to make recommendations within the guideline, these decisions would have to be made at a local level

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Tees Esk and Wear Valleys NHS Foundation Trust	Full	general	general	Guidance on the use of specialist services is limited, particularly specialist mental health physiotherapists and the specialist skill set they have in providing specialist rehabilitation for those with dementia.	Thank you for your comment. No evidence was identified on specialist mental health physiotherapists, and therefore the committee agreed they were not able to make recommendations on this topic.
Tees Esk and Wear Valleys NHS Foundation Trust	Full	297	general	It is noted in the draft full guideline that no recommendation on prescribed exercise will be made until the Dementia and Physical Activity (DAPA) study is published. The website for the DAPA study says it is not due for completion until June 2018 (the same time that this guidance will be published). It is likely that the research will not be published in time to be included in the dementia guidance. Early indications suggest exercise needs to be 'prescriptive' to be most effective; will NICE specify which professionals should be delivering this?	Thank you for your comment. The DAPA study was not published in time for inclusion within the guideline, and therefore the committee agreed it was not possible to make recommendations around exercise at this time. The study has been passed to the NICE surveillance team, who will make a decision about whether the guideline needs to be updated when the study publishes.
The Lewy Body Society	Short	General	General	Our charity has experience of families of people living with Lewy body dementia either not being able to find a care home that will accommodate them due to lack of understanding of the disease by staff or being asked by care home providers to remove family members due to complex needs.	Thank you for your comment. The committee noted this concern, and agreed it was important for services to be available that are accessible to people with all dementia subtypes, including those with complex presentations. However, they agreed the provision and organisation of these services was outside the scope of this guideline.

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The Lewy Body Society	Short	General	General	Our charity recommends that the New International Guidelines issued in June 2017 Diagnosis and management of dementia with Lewy bodies - Ian McKeith et al *Neurology*: doi 10.1212/WNL.0000000000004058 is referenced.	Thank you for your comment. The committee noted these guidelines were referenced in recommendation 1.2.12 of the guideline, on validated clinical criteria to assist subtype diagnosis.
The Royal College of Physicians and Surgeons of Glasgow	Short	General	General	The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow represents Fellows and Members throughout the United Kingdom. While NICE has a remit for England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments. The College welcomes this Quality Standard in an important area for both the public and the caring professions. It is a wide ranging document which has the potential to drive up standards of assessment and management in dementia, improving both diagnosis and of care (medical and non-medical). It welcomes the principle of working with patients, their families and carers.	Thank you for your comment and your support for the guideline.

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The Royal College of Physicians and Surgeons of Glasgow	Short	11 12	15-29 5-11	Our expert reviewer felt the assessment / diagnosis strategy recommended lacks of good supportive data to show that the routine use of biomarkers and sophisticated imaging would be cost-effective and give worthwhile clinical gain. In dementia research, positive biomarkers have become a requirement for participant recruitment in Alzheimer disease-specific trials, and to establish drug-target engagement and as surrogate markers of treatment efficacy. However at present there is no good evidence that their widespread use in clinical practice would significantly improve outcomes. Routine use of biomarkers will only really become justified if disease-modifying treatments become available – and there are no such interventions at present. Therefore the recommendation to use biomarkers in diagnosis is premature and risks diversion of scarce resources. The same is true for diagnosis of dementia with Lewy bodies, front-temporal dementia and vascular dementia.	Thank you for your comment. The committee noted that the 'consider' recommendations for CSF examination and imaging came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF and imaging earlier in the diagnostic pathway, and to counter that conception agreed it was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed this should address any concerns about the guideline advocating a sudden expansion in the use of complex diagnostic tests, or their use in determining if someone has dementia at all, rather than to support subtyping.

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The Royal College of Physicians and Surgeons of Glasgow	Short	13	2 - 5	Another of our reviewers notes that delirium will be the presenting complaint of most older people with cognitive impairment/dementia at the hospital front door i.e. Emergency Departments, Medical Admissions Units & acute receiving units. The use of the Long Confusion Assessment Method (CAM) requires specialist training and is not routinely used in many British (including Scotland) hospitals for delirium screening. The Observational Scale of Level of Arousal (OSLA) is also not a tool in routine clinical use. The 4AT is the screening tool of choice in this instance. No special training is required The National Hip Fracture database in England also using 4AT There was no mention of other delirium screening tools were used e.g. SQID (single question in delirium).	Thank you for your comment. The committee noted that the work undertaken on the 4AT so far all focused on its use as a screening test. The committee noted there had been some confusion at consultation as to the meaning of the included recommendation on dementia/delirium, and stressed this recommendation did not cover either: 1) Screening for delirium, which is covered by the NICE delirium guideline. 2) Diagnosing delirium in someone who already has a diagnosis of dementia. This recommendation focused on the situation of a person with a current diagnosis of neither delirium nor dementia, but with cognitive impairment that made both a possible diagnosis, and how they should be differentiated. The committee agreed that in this complex situation it was unsurprising that a longer instrument was needed than in the case of screening. The wording of the recommendation has now been amended to try and clarify the meaning.
The Royal College of Physicians and Surgeons of Glasgow	Short	14	3 - 5	The Scottish equivalent to the Mental Capacity Act 2005 is the Adults with Incapacity (Scotland) Act (AWI) 2000	Thank you for your comment and this information.

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The Royal College of Physicians and Surgeons of Glasgow	short	23		There is a lack of information on swallowing assessment / modifying diet in those with dementia who develop dysphagia. Dysphagia is a major problem, particularly in those with more advanced dementia, often exacerbated by inter-current illness and therefore contributing to acute hospital admission. A structured approach to assessment, including use of water swallow test, can detect those at high risk of aspiration. Speech and Language therapists have an important role in advising on dietary modification such as thickening of fluids or optimal food texture, and on positioning when eating / drinking.	Thank you for your comment. On the specific issue of dysphagia, the committee agreed it was appropriate to add an extra recommendation to the section on palliative care, to "consider involving a speech and language therapist if there are concerns about the safety of eating and drinking."
The Royal College of Physicians and Surgeons of Glasgow	Short	23	1	With Reference to the phrase *'Consider using a structured observational pain…'* the wording should be more directive. Pain is under reported in people with dementia. Also we know dementia can be associated with falls. Pain can drive behavioural issues e.g. aggression. Consider is too weak an option. This recommendation should be stronger.	Thank you for your comment. The committee discussed this and agreed that, because of the limited nature of the evidence base available on pain assessment, a 'consider' recommendation remained the most appropriate.

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The Royal College of Physicians and Surgeons of Glasgow	Short	23	25	Mirabegron is recommended as a safer alternative to anti-muscarinics for treatment of urinary incontinence in dementia. However this is on the basis of its pharmacological profile only; there are no good data showing benefit from this drug in those with dementia.	Thank you for your comment. The committee noted the indication in the technology appraisal was "for treating the symptoms of overactive bladder only for people in whom antimuscarinic drugs are contraindicated or clinically ineffective, or have unacceptable side effects," and agreed people living with dementia were covered by this population.
The Royal College of Physicians and Surgeons of Glasgow	Short	25	General	Our reviewer considered there was no mention of delirium education in this section. There is evidence around delirium and cognitive decline/acceleration Reference Association of Delirium With Cognitive Decline in Late Life: A Neuropathologic Study of 3 Population-Based Cohort; JAMA Psychiatry. 2017;74(3):244-251 D Davis et al There is an increased mortality associated with delirium Reference *Impact of delirium on short-term mortality in elderly inpatients: a prospective cohort study, Gonzalez et al , Psychosomatics 2009;50(3):234-8*	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in delirium. The references you cite are not randomised controlled trials, and therefore would not meet the criteria for inclusion within this section of the guideline.

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				There is increased institutionalisation with delirium	
The Royal College of Physicians and Surgeons of Glasgow	Short	27	General	There is no consideration of delirium education - comments as above	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in delirium.
The Royal College of Physicians and Surgeons of Glasgow	Short	28	1 -2	Our reviewer recommends that carers and/or family members should have the opportunity to attend and take part in staff dementia training sessions. Given the research around negative attitudes and behaviour around dementia and delirium. carers and/or family members should be central to staff training sessions. They should be delivering some of it not just participating in it. Reference Towards an understanding of why undergraduate teaching about delirium does not guarantee gold-standard practice—results from a UK national survey, *Age and Ageing*, Volume 44, Issue 1, 1 January 2015, Pages 166–170 J Fisher et al	Thank you for your comment. The committee noted these points but agreed that in the absence of robust evidence, they were not able to be more specific about the roles carers or people living with dementia should play in staff training.

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The Society and College of Radiographers	Short	7	12	The Society and College of Radiographers advocate the use of a decision tool and urge that information must be shared with healthcare practitioners ideally prior to any planned visits to imaging/radiotherapy departments. Practitioners will then be enabled to book longer appointment times or make appropriate adjustments for examinations and treatments. The Society and College of Radiographers support the use of a communication passport with people living with dementia. Sharing information is challenging in clinical imaging and radiotherapy; patients attend for relatively short periods of time. There is often no detailed communication from referrers rather simply requests for examination/treatment on short request cards; the provision of information prior to outpatient attendances will alert staff to any additional needs of people living with dementia.	Thank you for your comment. The committee would support any interventions that successfully ensure that information is appropriately shared and available to services when it is needed.
The Society and College of Radiographers	Short	9	10	The Society and College of Radiographers support the notion of advance planning and advance decision to refuse treatment. It will be challenging for practitioners involved in the care of patients to be aware of notifications; specifically attendances for clinical imaging examinations and radiotherapy treatment. How will practitioners	Thank you for your comment. The committee noted this concern, and agreed it as important for local areas to have policies in place to ensure information on advance decisions and planning was appropriately shared.

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				know of advance planning and decision in relation to consent?	
The Society and College of Radiographers	Short	14	18	It is essential that the support plans are also shared with providers of outpatient care. The paragraph states that information should be easily shared. Currently it is rare that practitioners in diagnostic imaging and radiotherapy settings are provided with pertinent information – The Society and College of Radiographers champion the provision of pertinent information and also the use of communication passports to improve the care of people living with dementia.	Thank you for your comment. The committee would support any interventions that successfully ensure that information is appropriately shared and available to services when it is needed.
University College London	Short and Full	General	general	It seems an omission not to include physical examination and in particular a measurement of pulse and blood pressure to manage vascular risk factors, and to help with diagnosis.	Thank you for your comment. The committee agreed with this suggestion, and therefore a reference to a "physical examination" has been added to the recommendation around initial assessment in non-specialist settings.
University College London	Short	8	3	Offer people the opportunity to take part in research e.g. via JDR (join dementia research)	Thank you for your comment. The committee agreed with the value of making people living with dementia aware of chances to be involved in research, and therefore added a recommendation to "tell people living with dementia (at all stages of the condition) about research studies they could participate in."
University College London	Short	10	23	There needs to be a recommendation to consider atypical presentations of Alzheimer's disease (see NIA-AA criteria and Dubois criteria) which specifically mention that a clinician should	Thank you for your comment. The committee noted that this point was covered in recommendation 1.2.11, which gives advice on specific clinical criteria to use to assist diagnosis, including the NIA criteria mentioned.

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				consider an atypical presentation such as posterior cortical atrophy (PCA), or logogenic aphasia (LPA). If these atypical forms are not considered, and only verbal episodic memory included in the guidance, then there is a risk that misdiagnoses are made, and individuals who may benefit from treatment will not receive that.	
University College London	Short	10	25	There has been change from previous guidance so that now structural imaging is only with the guidance of "to consider". We think that there are some important consequences of this change, the first is that the use of structural imaging to help in the subtyping of the diagnosis should be included as was reported in the earlier guidance. It is notable that most of the diagnostic criteria and recommendations from consensus groups have recommended imaging and usually MRI as part of diagnosis. For example, for Alzheimer's disease, the NIA – AA recommendations include MRI, the Dubois (IWG) criteria include MRI showing hippocampal or medial temporal lobe atrophy as part of the diagnostic criteria. The international FTD criteria mentioned on page 11 of the draft guidance as also the NINDS-AIREN criteria all recommend the use of MRI in	Thank you for your comment. The committee made 2 changes to address this issue. First, the recommendation on structural imaging has been changed from a 'consider' to an 'offer'. Secondly and additional caveat, based on that from the last guideline, has been added that "structural imaging is not always be needed, if dementia is well established and the subtype diagnosis is clear."

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				diagnosis, and in some of the criteria, MRI is essential to making a diagnosis. We felt that there may have been omissions in the literature considered about the use of MRI in diagnosis - in particular in subtyping – AD; Vascular, FTD etc. . Studies that could have been considered include Burton et al 2009, Korf et al, 2004 in Neurology, Scheltens et al, 1992, Muri et al 2011, Vemuri, 2009, Decarli 2007, Likeman, 2005, Duara, 2008 Neurology, Whitwell, 2008 Neurology, and Verhagen, 2016 European Radiology. These papers show for that MRI can help in subtyping and making a diagnosisAlzheimer's disease that medial temporal lobe atrophy has 80% sensitivity and specificity for prediction of Alzheimer's disease versus normal controls, and a similar sensitivity and specificity for progression to Alzheimer's disease in people with a clinical diagnosis of MCI. Furthermore, studies such as the Verhagen study show that the use of MRI changes clinician's diagnosis, and studies where there is post mortem confirmation shows that MRI have very good concordance with pathological diagnosis.	

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University College London	Short	11	14 and on	These sections which refer to advanced imaging such as FDG PET should include the guidance that an MRI should be performed first before moving onto these other tests which are either more invasive or involve radiation exposure.	Thank you for your comment. The committee made 2 changes to address this issue. First, an additional recommendation was included that after initial assessment in specialist care, to "only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." If those criteria were satisfied, the committee agreed it would then be appropriate to "offer" structural imaging, and this recommendation has consequently been made stronger. This therefore means that structural imaging is now a standard part of the pathway before any more complex imaging, or biomarker tests, are considered.
University College London	Short	11	28	The guidance suggest that the older a person, the less accurate cerebrospinal fluid examination will be. This is only correct for its positive predictive value. The negative predictive value (i.e. suggesting that it is less likely that somebody has Alzheimer's disease is maintained even in older individuals). In other words if somebody has CSF when they are aged seventy-five, and the CSF suggests that there is no support for Alzheimer pathology that makes Alzheimer's disease as the aetiology much less likely, a large number of studies have shown this.	Thank you for your comment. The committee agreed with this point, and for clarity the recommendation has been amended to "be aware that the older a person is, the more false positives will be found with cerebrospinal fluid examination."

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University College London	Short	12	3	It is reasonable not to use EEG "to diagnose" Alzheimer's disease, but the wording should be changed so that words "in the" should be changed to "to". The reason for this is that as part of the diagnostic process of somebody suspected of Alzheimer's disease, it may well be very important to acquire an EEG because subclinical seizures can be a very treatable cause of memory impairment and otherwise people get a mis-diagnosis of Alzheimer's disease. I think there should be a recommendation to consider the use of EEG in those who may be having seizure activity which may mimic Alzheimer's disease or another dementia.	Thank you for your comment. The committee agreed that, for clarity, this recommendation should be modified to "do not use electroencephalography to diagnose Alzheimer's disease." In the absence of evidence, the committee agreed it was not possible to make a more positive recommendation about when it might be used.
University College London	Short	15	9, 10, 11	"Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them". This is a significant shift from the previous NICE guidelines, which stated that "People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia". All the research evidence is for a structured, manualised, 14 CST programme, which was developed using elements of a range of existing therapies. T*here is NO evidence for any benefits if just elements of the programme are used and no evidence, in general, for structured group activities.* Further, having a clear manual, which can be followed by a range of health and social workers at all levels of expertise; eases implementation and minimises preparation time, providing a highly cost-effective intervention. This change in wording will create ambiguity and is likely to be interpreted that any type of structured group is sufficient, and there will be a lack of governance and adherence to any sort of standardisation. CST is now a required standard for the Memory Services National Accreditation Programme (MSNAP) and an audit in 2017 suggested that around 85% of MSNAP accredited memory services routinely offer group CST to people	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				following a diagnosis of dementia. Approximately 50% of all UK memory services are accredited and anecdotal evidence suggests that a similar pattern of CST provision is occurring in non-accredited memory services. This widespread provision is offering hope for people post diagnosis, social support and a structured, evidence-based therapy which maintains cognitive functioning and normalises the experience of dementia. Several other reports have endorsed CST since the 2006 guidelines. For example, the World Alzheimer Report (Alzheimer's Disease International), in 2012 and subsequently; have stated that CST should routinely be given to people with early stage dementia. Such a change in wording could have a devastating clinical impact and we recommend reverting to the previous wording, as above.	
University College London	Short	16	19	The recommendations should consider including the situation where somebody is on Memantine (but only Memantine), This may have been started as an alternative to a cholinesterase inhibitor and the guidance should say "consider cholinesterase inhibitor, in addition to Memantine". In other words, the guidance 1.5.3 should be symmetrical in that there are some	Thank you for your comment. The committee noted this concern, but agreed that since the majority of the evidence was specifically on the addition of memantine to a cholinesterase inhibitor, and cholinesterase inhibitors are the recommended first line treatment for people with mild dementia, the current wording of the recommendation was the most correct one. They did, however, note that in practice people were likely to also consider the addition of

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				people who would benefit from a cholinesterase inhibitor, who are already on Memantine but because both could not be prescribed together, had only been started on one.	cholinesterase inhibitors for people who had already started on memantine.
University College London	Short	25	14-29	The full document contains specific mention of the START intervention for carers and includes the recommendation: "a specific psychoeducation and skills training intervention was more appropriate than making a more generic recommendation around multicomponent interventions, both because of the economic evidence described in the "trade-off between net health benefits and resource use" section below, and because it was a clearly defined intervention type that should be practical to implement in practice." However, in the short document, the section on 'Supporting carers' (Section 1.11) currently recommends everything that is included in START without mentioning a specific intervention. START, which was developed and evaluated with carers in the UK, should be specifically recommended in the Summary Guidance.	Thank you for your comment. The committee agreed that START was one highly relevant example of an intervention that could be used to meet the requirements of the recommendations for carer training. However, they agreed that many other trials also showed similar benefits to those from the START intervention, and therefore it was not appropriate to specifically mention START ahead of other interventions that could be offered.
University College London	Full d	305-309	Table 79	Table 79 should include the Cochrane review by Ballard et al (2006) (Ballard CG, Waite J, Birks J.	Thank you for your comment. Ballard (2006) was excluded because there was a more recent systematic review available

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				Atypical antipsychotics for aggression and psychosis in Alzheimer's disease. Cochrane Database of Systematic Reviews 2006, DOI: 10.1002/14651858.CD003476.pub2) as it provides clear and detailed evidence relating to benefits and harms associated with risperidone and olanzapine use in people with dementia and, importantly, presents evidence for efficacy in relation to specific target symptoms - aggression and psychosis. Based on data from 5 RCTs of risperidone (0.5-2mg/day versus placebo) and 4 RCTs of olanzapine (1-10mg/day versus placebo), there is clear evidence of modest efficacy following risperidone use. Findings in relation to psychosis symptoms include: • Significant reduction in psychosis symptoms amongst risperidone treated patients (not found for olanzapine). • Risperidone 2mg/day was associated with significantly higher dropout rates due to adverse events than 1mg/day, *with no additional benefits in terms of reduction in psychosis symptoms* • Risperidone and olanzapine treated patients had a significantly higher	on the same topic (Ma 2014). The committee discussed the benefits and harms of antipsychotics when developing recommendations. This can be seen in the section of 'Trade-off between benefits and harms' for antipsychotics.

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				incidence of serious adverse cerebrovascular events (including stroke), extrapyramidal side effects and other important adverse outcomes. These findings are highly relevant for clinicians, as they provide evidence of efficacy and the trade of between benefits and harms (detailed in forest plots)	
University College London	Full	General	general	We note that the wording for non-pharmacological and psychological interventions is primarily "consider", whereas the wording for pharmacological interventions is "recommend" or "offer". (e.g. short guidelines 1.5.1 **recommend** AChE, but section 1.4.2 states "**consider** elements of cognitive stimulation", despite both CST and AChE having similar benefits). This is likely to lead to over-medicalisation of dementia treatment and is not rooted in the evidence-base.	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST and the recommendation has therefore been amended to an 'offer'. Specifically, "offer group cognitive stimulation therapy to people living with mild to moderate dementia".
University College London	Full	302-333	General	This section aims to provide guidance on the most effective pharmacological and non-pharmacological interventions for managing non-cognitive symptoms, such as psychosis, depression, behavioural changes in people living with dementia. However, guidance on the management of psychosis symptoms is largely absent from the draft document, and the	Thank you for your comment. The committee agreed the limited evidence base on managing psychosis in people living with dementia was an issue, and some additional information on this has been added to the committee's discussion of the evidence for that section. Your individual suggestions for changes in this section have been responded to where they appear.

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				evidence base for antipsychotic drug use is discussed almost entirely in the context of aggression and agitation. Suggested amendments include the following:	
University College London	Full	327-328	Section on antipsychotics	'Evidence to recommendations section (14.1.5.1) 'Pharmacological treatments' describes the 'Trade-off between benefits and harms' and the 'Quality of evidence' for antipsychotic drug use. These sections should make reference to the fact that, in the majority of placebo controlled RCTs, psychosis was not the main treatment indication or primary outcome.	Thank you for your comment. Some commentary addressing this has been added to the evidence to recommendations section as suggested.
University College London	Full	277	37	This section considers the economic analysis of CST, but uses a base case model, rather than published health economic studies. There have been two key papers published considering the cost effectiveness of manualised CST (Knapp et al, 2006; D'Amico et al, 2015). Both are listed in the references in Appendix J, but only D'Amico et al (2015) has been considered in the evidence. These papers look at the cost of the delivery, as well as the changes in use of health and social care services for those in receipt of the intervention.	Thank you for your comment. The Knapp (2006) paper was not a cost-utility study and therefore did was not consistent with the reference case. The D'Amico (2015) paper however, was a cost-utility study and was eligible for inclusion as part of the economic review. Please note that the effectiveness evidence used in Knapp (2006) was based on Spector (2003), and has been considered by this guideline by the way of inclusion in our quantitative synthesis of parameters for the model developed by NICE.

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				Furthermore, the NHS Institute of Innovations and Improvements invested in an 'economic analysis of the alternatives of anti-psychotics for individuals living with dementia', conducted by Matrix Evidence in 2011: https://www.acss.org.uk/wp-content/uploads/2016/03/NHS-Institute-for-Innovation-and-Improvement-antipyschotic-drug-evaluation-2011.pdf. This analysis chose CST as the gold-standard non-pharmacological intervention and concluded that, by combining health care cost savings and quality of life improvements, use of CST could save the NHS around £54.9 million annually.	
University College London	Full Appendix E	296 342 onwards	5	The full report (p.296), states that 'no evidence of benefits were found in any outcomes other than cognition'. The research evidence for Cognitive Stimulation has grown enormously since the 2006 guidelines. However, the tables of evidence (Appendix E, p.342 onwards) exclude several essential studies noted below. Table 1 below includes several randomised controlled trials on Cognitive Stimulation, noting a) outcomes (other than cognition) that significantly improved and	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger

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				b)whether or not they were included in the evidence review. Table 1: Cognitive Stimulation outcome data Authors of RCT paper, Outcomes which significantly improved in addition to cognition, Included in evidence, appendix E? Spector et al, 2003 Quality of life Yes Yamanaka et al, 2013 Mood Yes Capotosto et al, 2017 Quality of life No Paddick et al, 2017 Anxiety, behavioural symptoms, quality of life No Orrell et al, 2014 Quality of life, Activities of daily living Yes Niu et al, 2010 Depression, apathy No Stewart et al, 2017 Depression No A synthesis of 22 systematic reviews on psychosocial interventions for dementia, including 197 unique studies, has been published since the consultation went out (McDermott et al, 2018). Only two interventions were specifically recommended in the conclusions: group Cognitive Stimulation and Multi-component exercise. Of the	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life, but the pooled result of all the studies included in the meta-analysis could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not

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				former, they concluded that 'group Cognitive Stimulation improves cognitive function, social interaction and quality of life'. This synthesis is unique in its methodology and offers the most up-to-date information on ALL psychosocial interventions for dementia. Further, a Cochrane systematic review (Woods et al, 2012) of 15 RCTs on Cognitive Stimulation found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects AND that there is evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. Within this review, many trials had positive trends (approaching significance) in these outcomes and this data contributed to the meta-analysis. In summary: • There is consistent evidence that Cognitive Stimulation improves other domains in addition to cognition. Much of this data was available within the reviewed studies, suggesting some misunderstanding or misinterpretation of the results. • The evidence reviewed (listed in Appendix E) omitted several key trials. In addition to those noted above, we spotted other key	make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the meta-analysis could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Stewart (2017) would have been excluded because they used a before-after study design. This type of study design was excluded because there was enough evidence on randomised controlled trials (RCTs). All included reviews by McDermott (2018) had been already considered in Appendix O and the updated search for RCTs

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				missing trials including that of Matsuda et al (2007) and Wong et al (2017). References: Capotosto E, Belacchi C, Gardini S, Faggian S, Piras F, Mantoan V, Salvalaio E, Pradelli S, Borella E (2017). Cognitive Stimulation Therapy in the Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. International Journal of Geriatric Psychiatry,32:331-340 Matsuda, O. (2007). Cognitive stimulation therapy for Alzheimer's disease: the effect of cognitive stimulation therapy on the progression of mild Alzheimer's disease in patients treated with donepezil. International Psychogeriatrics, 19(2), 241-252. McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., ... & Orrell, M. (2018). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. Aging and Mental Health, DOI 10.1080/13607863.2017.1423031	would have been found individual studies included in these reviews. Matsuda (2007) was a non-randomised study excluded by Woods (2012) which was used as the source of RCTs for cognitive stimulation therapy. Wong (2017) would have been excluded because the aim was to investigate the feasibility and cultural appropriateness of CST in Hong Kong. Olazaran (2010) was included as a systematic review in Appendix O but data was not extracted because Olazaran (2010) did not report details of the individual studies in included in their systematic review.

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				Niu, Y. X., Tan, J. P., Guan, J. Q., Zhang, Z. Q., & Wang, L. N. (2010). Cognitive stimulation therapy in the treatment of neuropsychiatric symptoms in Alzheimer's disease: a randomized controlled trial. Clinical rehabilitation, 24(12), 1102-1111. Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. International psychogeriatrics, 29(6), 979-989. Stewart, D. B., Berg-Weger, M., Tebb, S., Sakamoto, M., Roselle, K., Downing, L., ... & Hayden, D. (2017). Making a Difference: A Study of Cognitive Stimulation Therapy for Persons with Dementia. Journal of Gerontological Social Work, 1-13. Yamanaka K, Kawano Y, Noguchi D, Nakaaki S, Watanabe N, Amano T, Spector A (2013). Effects of cognitive stimulation therapy Japanese Version (CST-J) for people with dementia: A single-bling, controlled trial. Aging & Mental Health, 17:579-586.	

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				Wong, G. H., Yek, O. P., Zhang, A. Y., Lum, T., & Spector, A. (2017). Cultural adaptation of cognitive stimulation therapy (CST) for Chinese people with dementia: multicentre pilot study. International Journal of Geriatric Psychiatry.	
University College London	Full	296	5	"The committee… noted it was unclear whether it was the specific content of the interventions that was valuable, or simply the result of being part of a group and undertaking any mentally stimulating activity". We would argue that this is an erroneous conclusion. Whilst the literature on non-pharmacological interventions spans several decades and hundreds of studies, the evidence base for manualised, Cognitive Stimulation is considerably stronger than for other interventions, including Reminiscence. For example, a systematic review by Olazaran et al (2010) concluded that Cognitive Stimulation demonstrates the best evidence for improving cognitive functioning amongst all non-pharmacological interventions. Several trials	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				within a Cochrane review compared Cognitive Stimulation with an active, social control group, yet the results were consistently in favour of structured group Cognitive Stimulation over a social control (Woods et al, 2012). **References** Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, Woods B, Beck C, Auer S, Lai C, Spector A, Fazio S, Bond J, Kivipelto M, Brodaty H, Rojo JM, Collins H, Teri L, Mittelman M, Orrell M, Feldman HH, Muñiz R (2010). Non-pharmacological therapies in Alzheimer's disease: A systematic review of efficacy. Dementia and Geriatric Cognitive Disorders;32:161-178 Woods B, Aguirre E, Spector A, Orrell M (2012). Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews,;15:CD005562.	
University College London	Full	296	5	"They noted that in practice the two interventions are not mutually exclusive, with cognitive stimulation and reminiscence both forming part of the activities included within those groups".	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a

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				It is correct that Cognitive Stimulation incorporates some aspects of Reminiscence. However, the key focus of Cognitive Stimulation (more specifically the manualised 'CST' programme which is widely followed) is on generation of *new* thoughts, ideas and associations within the sessions. This is believed to engage executive functioning skills and enable new semantic connections to be made. CST is based on theories of mental stimulation, and uses principles of person centred care. It includes clear key principles which need to be adhered to for effectiveness. It also shifts the focus, emphasising the importance of the person's views and options in the current day, rather than focusing on the past (which is the aim of Reminiscence). We believe that this provides a different message and thus reduces stigma associated with dementia and old age. **Reference** Spector A, Thorgrimsen L, Woods B, Orrell M (2006) Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy	manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				(CST) to people with dementia. Hawker Publications, UK.	
University College London	Full	296	5	"The most appropriate recommendation was for people to be provided with access to structured group activities, with cognitive stimulation and reminiscence both forming part of the activities included within those groups…. This was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" The evidence base for Cognitive Stimulation is consistently stronger than for Reminiscence (see Woods et al, 2005, for example). The conclusion in the report that "this was likely to lead to better outcomes for a range of people than one narrowly focused on a very specific intervention model" appears to be based on no evidence and also a misunderstanding of CST, which is not "narrowly focused on a specific intervention model". Instead, CST has a variety of interventions depending on the interests and abilities of the group, and is delivered according	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				to important key principles which fit with the underlying theoretical models. **Reference:** Woods, B., Spector, A. E., Jones, C. A., Orrell, M., & Davies, S. P. (2005). Reminiscence therapy for dementia. *The Cochrane Library*.	
University College London	Full	302	3	Delusions and hallucinations should be included in the first paragraph as only aggression, anxiety, apathy, agitation, depression and sleep disturbances are currently listed.	Thank you for your comment. This has been changed as suggested.
University College London	Full	302	11	The impact of delusions on people with dementia and their families and on formal caregivers is considerable and can increase the risk of verbal and physical aggression towards caregivers, particularly when there are beliefs that a carer is stealing, trying to harm, having an affair or is an imposter.	Thank you for your comment. The committee agreed that both hallucinations and delusions could have serious effects on people living with dementia and their carers.
University College London	Full	302	37	Psychosis should also be considered as a separate entity, as NICE guidance in relation to schizophrenia is not sufficient or appropriate.	Thank you for your comment. The guideline did look for evidence on managing psychosis in people living with dementia, which was included in the review on managing non-cognitive symptoms in people living with dementia.
University College London	Full	321	35	Evidence statement section (14.1.4.3.1) 'Atypical antipsychotics versus placebo' makes reference to global ratings of behavior or agitation and should include BEHAVE-AD (see Ballard et al 2006).	Thank you for your comment. Ballard (2006) was excluded because there was a more recent systematic review available on the same topic (Ma 2014). Although Ma (2014) reported BEHAVE-AD as one of the outcomes, the committee agreed

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					that their preferred measure was the Neuropsychiatric Inventory (NPI).
University College London	Full	332	2	Recommendations (14.1.6). The section entitled 'Agitation, aggression and distress' should include the term psychosis in the title.	Thank you for your comment. This has been changed as suggested.
University of Bradford	Short	general	general	A range of psychosocial interventions are suggested but more detail is required about the targeting of such interventions to the stage of dementia	Thank you for your comment. The committee agreed it would have been able to provide more detailed targeting of the recommendations for psychosocial interventions, but agreed the evidence was not sufficient for them to be able to do so. They noted a number of recommendations for future research in this area were made, which they hoped would mean these issues can be resolved in future updates of the guideline.
University of Bradford	Short	3	15-17	The reference is dated	Thank you for your comment. Some additional information has been added to this section around the increase in diagnosis rates in recent years.
University of Bradford	Short	6	18	Is reference to human rights more appropriate than the term 'human value"	Thank you for your comment. Both words would be appropriate, but "human value" was chosen to avoid the conception that this point referred solely to protections under the Human Rights Act, but something broader.
University of Bradford	Short	7	11	Examples of recommended structured tools would be helpful	Thank you for your comment. The committee agreed that the evidence was not sufficiently robust to enable them to recommend one specific tool as being the most appropriate to use for this purpose.
University of Bradford	Short	8	116	Presume that what is meant by legal rights and responsibilities is addressed in the full document	Thank you for your comment. Further information on this is provided in the full version of the guideline. In particular, in the committees discussion of the evidence in section 6.

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University of Bradford	Short	13	23	This recommendation should be expanded – community resources, services and support	Thank you for your comment. The committee agreed that all these relevant points should be coved within the general term of "care."
University of Bradford	Short	21	17-19	Consider rewording this statement	Thank you for your comment. The committee considered this but agreed the current wording accurately reflected the intent of the recommendation.
University of Bradford	Short	28	3	Is there sufficient evidence to specify multi sensory stimulation as opposed to other therapeutic modalitiies	Thank you for your comment. The committee noted that the evidence identified within the guideline was for multi-sensory stimulation, and therefore agreed this was the appropriate intervention to mention within the guideline.
University of Bradford	Full	General		We are concerned that the overall document only refers to treatment in the context of pharmacological therapy. The implication is that this is the only form of treatment available and all else is social care	Thank you for your comment. Having reconsidered the evidence around CST, the committee agreed it was appropriate to make a stronger recommendation for CST and the recommendation has therefore been amended to an 'offer'. Specifically, "offer group cognitive stimulation therapy to people living with mild to moderate dementia". The committee further agreed that the evidence showed this intervention was as effective in the short-term as pharmacological treatment.
University of Bradford	Full	General	general	The document covers people at all stages of the dementia trajectory from the point of diagnosis to end of life care and in the community as well as hospital and care settings. In so doing what might be key recommendations at different stages and in different environments are lost	Thank you for your comment. The committee noted that in many areas the evidence base only covered people in a particular setting (e.g. the majority of the evidence on staff training came from people living in care homes). The committee agreed that wherever possible it was appropriate to try and extrapolate this evidence to the more general population of people living with dementia, as otherwise there was a risk of particular groups not being covered, solely

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					because studies happened not to have been done in those populations.
University of Bradford	Full	General	general	There doesn't seem to be much discussion of diversity in the informal carer population. (Apart from a brief reference on page 348) Might needs differ?	Thank you for your comment. The committee agreed there would be differences in the needs of informal carers depending on their particular background and circumstances. Whilst the committee agreed the RCT evidence identified did not enable them to make different recommendations for interventions for specific groups, they did recommend that the support provided to carers should be "tailored to their needs and preferences and to what they want it to achieve"
Vision UK	Short v	8	3	Section 1.1.6. At the time of diagnosis many patients and carers are in a state of shock and need more time to digest things. Patients and carers can be more receptive to information and help at a time soon after the diagnosis where things are discussed in their own home	Thank you for your comment. The committee agreed that it was important to offer additional opportunities for people to receive information, as people will often not be able to take everything in at the time of diagnosis, but agreed that in the absence of evidence it was not possible to specify how and when these should be done. They noted the guideline did also contain recommendations to "direct people and their family members or carers (as appropriate) to relevant services for information and support", and to ensure "they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service."
Vision UK	Short	6	18-24	This recommendation should include "the importance of determining the effect of dementia on physical co-morbidities (LT conditions, sensory	Thank you for your comment. The guideline contains a specific review question on the management of comorbidities in people living with dementia, and recommendations on this topic are included in that section of the guideline.

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				impairments) and their management and vice versa	
Vision UK	Short	8	23	Need a clearer definition of "a person's record". This should include primary care record, care plan and social care record. Reference the NHS England Guidance on Care Planning	Thank you for your comment. The committee agreed some confusion has been introduced in this recommendation by the statement to "tell all relevant services what the person has decided", which has now been deleted. The committee noted the importance of having information contained in a single record so it was accessible to multiple services, but agreed that in the absence of evidence, they could not give specific guidance on how this system should be organised. A reference to the NHS England document mentioned has now been added to the start of the guideline.
Vision UK	Short	9	18	Need to identify, treat and / or exclude potential physical causes of cognitive impairment and assess anticholinergic burden of medications	Thank you for your comment. The committee agreed with this suggestion and added a recommendation to "conduct a physical examination, undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline, and use cognitive testing."
Vision UK	Short	10	17	Recommend that there is greater clarification that cerebrospinal fluid (CSF) examination will NOT be routine (see lines 28 and 29) but more for younger, atypical and / or early onset dementia. The main issue with is not undertaking this but the standardisation of lab analysis. The specialists likely to be undertaking such examinations will most likely be neurologists who are used to doing such tests for people with neurological and	Thank you for your comment. The committee noted that the 'consider' recommendations for CSF examination and imaging came at the end of the diagnostic pathway, and would consequently only be of relevance for the small number of people who still did not have a diagnosis after all the prior possible diagnostic steps had been considered. However, they noted that a number of stakeholders had interpreted this recommendation as bringing CSF and imaging earlier in the diagnostic pathway, and to counter that conception agreed it

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				neurodegenerative disorders. What is not currently available is the analytical methodology. Also there is great concern through Europe and North America about the lack of consistency between labs in their methodology and results. This is the subject of a European wide initiative led by Prof Kai Blennow	was appropriate to add an additional recommendation before all of those on imaging and biomarkers. Specifically: "Only consider further diagnostic tests if: • it would help to diagnose a dementia subtype and • knowing more about the dementia subtype would change management." The committee agreed this should address any concerns about the guideline advocating a sudden expansion in the use of complex diagnostic tests, or their use in determining if someone has dementia at all, rather than to support subtyping.
Vision UK	Short	10	19	Need to emphasise that potential for dementia occurs from three decades earlier in people with Downs' syndrome and a decade earlier in people with other causes of LD compared with sporadic dementia. Please refer &&	Thank you for your comment. The committee agreed with this point, and made the following comments in their discussion of the diagnostic evidence in the full guideline: "The committee agreed that physicians should be aware of the additional challenges of diagnosing dementia in certain vulnerable groups, such as people with learning difficulties and Down's syndrome, and those people with language and sensory impairment, lower educational levels and a low standard of literacy. Whilst the evidence base did not allow them to make specific recommendations for how the diagnostic pathway should be different for these groups of individuals, they agreed that it was important that people from these more difficult to diagnose groups should be assessed by a clinician with specialist skills in those areas, who would be

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					familiar with the difficulties and able to make appropriate adaptations to the process used."
Vision UK	Short	10	22	Dementia diagnosis in specialist diagnostic services: up to 1/3 of people referred to such services are given a diagnosis of Mild Cognitive Impairment. There should be a recommendation about how such people are managed – bear in mind that some are on the cusp of a diagnosis whilst others maybe much earlier in the disease process to indeed may never develop dementia	Thank you for your comment. The diagnosis and management of mild cognitive impairment was not within the scope of this guideline, and therefore it was not possible to make recommendations on this topic. A number of stakeholders have raised this as an important issue needing guidance, and this feedback has been based to the commissioning team within NICE for consideration when the topics of future guidelines are discussed.
Vision UK	Short	14	9	Recommend include consideration of impact of dementia on physical co-morbidities and sensory impairments and vice versa. See reference for Diabetes and Dementia in the NICE Guideline Type 2 diabetes and adults Dec 2015	Thank you for your comment. The committee agreed with this suggestion and an additional point as been added to this recommendation to "ensure it contains information on the management of any comorbidities the person has."
Vision UK	Short	14	25	Making services accessible: include a statement for those with learning and /or physical and sensory disabilities and people with Young Onset Dementia (YoD).	Thank you for your comment. The committee noted that they did not want to try and create an exhaustive list of groups here, because of the risk of this leading to the assumption that any not mentioned were therefore unimportant. However, they agreed that learning disabilities, sensory impairment and physical disabilities were sufficiently important that they should be added to the recommendation. The committee noted that younger people living with dementia were at least partially covered under the heading of

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					"people who have other responsibilities (such as work, children or being a carer themselves)."
Vision UK	Short	15	5	Section 1.4: add a bullet about the importance of healthy lifestyle- exercise, low alcohol and no smoking; what is good for your heart is good for your head && add statement about prevention	Thank you for your comment. No specific evidence as identified to make recommendations on these topics, but the committee agreed a number of these issues are covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
Vision UK	Short	16	1	Pharmacological interventions: recommend the addition of a section on when to review interventions, what to review and how to assess benefit. The latter should take into account information from patients and carers and include consideration of: not just improvement in cognition, BPSD and / or function but also slowing of decline, stabilisation. In a neurodegenerative condition improvement (especially sustained improvement) is NOT the usual outcome.	Thank you for your comment. The committee considered this suggestion but agreed that, in the absence of any evidence being identified, it was not possible to include a section such as that suggested in the recommendations.
Vision UK	Short	20	20	Recommend strengthening text with recommendations about how to assess to pain. Ref: Rasmussen Foskett, Mason et al Guidance on the recognition, assessment and management of pain in people who have dementia Dec 2014	Thank you for your comment. The committee agreed that, in the absence of any evidence meeting the criteria for inclusion in the guideline, it was not possible to give more detail in these recommendations. They noted the guideline did have a separate section containing recommendations on pain assessments for people living with dementia.

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Vision UK	Short	22	23	Recommend inclusion of a sentence about holistic care plans that include an evaluation of the effect of dementia on the management of long-term conditions and vica versa. Most guidelines consider long-term conditions in isolation. Also consider an "Anticipatory Care Plan" in people with LT conditions to avoid inappropriate secondary care presentations / admissions.	Thank you for your comment. The committee agreed with this suggestion, and a point has been added in the section on care and support plans to "ensure it contains information on the management of any comorbidities the person has."
Vision UK	Short	22	24	Pain: Recommend more specific advice about the recognition, assessment and management of Pain in people with dementia. Ref: Rasmussen Foskett, Mason et al Guidance on the recognition, assessment and management of pain in people who have dementia Dec 2014 Recommend greater emphasis on fact that people with dementia usually don't volunteer they have pain or discomfort; carers need to ask specifically and should remember FEET (Feet, eyes, ears and teeth) and the importance of regular review of these areas especially in Care Home residents. References: North West Dementia Centre. Pain in Dementia – factsheet 2005; www.guidelines.co.uk/central_nervous_system_wp_dementia_jun14	Thank you for your comment. The committee agreed that in the absence of evidence meeting the inclusion criteria for the guideline, it was not possible to make more specific recommendations than those currently included for using a structured observational pain assessment tool, and a stepwise treatment protocol for people who are in pain.
Vision UK	Short	24	10	Anticipatory care plans are valuable at other times e.g. for people the long-term conditions to	Thank you for your comment. The committee agreed with this point, and a cross-reference has been added from this

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				avoid inappropriate secondary care presentations / admissions.	recommendation to the section on advance care planning to improve the clarity of this recommendation.
Vision UK	Short	25	16	Add a bullet about prevention, recognition and management of delirium to the training	Thank you for your comment. The committee discussed this, but agreed that due to the potential high cost impact of widely delivered carer training, it was important to focus the recommendations on areas with robust evidence of effectiveness and cost effectiveness, and few of the studies included specifically included carer training in delirium
Vision UK	General			This Vision UK response is a result of a collaboration of the Vision UK Dementia and Sight Loss Committee involving representatives from: Blind Veterans UK, GOC, Alzheimer's Society, ABDO, RCGP, RNIB Scotland, Royal College of Psychiatrists, Old Age Faculty, College of Optometrists, UCL, RCN, TPT, Royal College of Ophthalmologists. We are happy to support the submission from these and other members of Vision UK.	Thank you for taking the time to comment on the guideline.
Vision UK	Full	General	General	We are concerned that the use of the phrase 'sensory impairment' may prove confusing and non-specific and would be better replaced with 'vision and hearing impairment'. This is particularly relevant to this document as sensory interventions are quoted which are not the same but easy to confuse.	Thank you for your comment. For clarity, this has now been changed to "sensory impairment (such as sight or hearing loss)".

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Vision UK	Full	389	31	The ProVide study (https://www.college-optometrists.org/the-college/research/research-projects/provide-dementia.html) demonstrated that 1/3 of patients have visual impairment which is related to falls. This is already part of the falls NICE guidance but due to the increased prevalence of visual morbidity in this group special provision should be made. We recommend that special attention is made for visual assessment and rehabilitation is made for patients with dementia suffering falls and that they have a vision check as part of their post-fall assessment.	Thank you for your comment. The committee noted this evidence and concern, but agreed that in the absence of specific evidence on how this should be managed differently in people living with dementia, this should be covered by a cross-reference to the NICE falls guideline, and by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia." They also agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years"
Vision UK	Full	394	21	We are concerned that no reference has been made to visual impairment. The ProVide study recently demonstrated that there is an increased level of visual impairment compared to the non-dementia population with 1/3 of people with dementia suffering from visual impairment. The RCOphth, College of Optoms and VISION UK recommend yearly optometry checks in people with dementia. https://www.visionuk.org.uk/vision-uk-dementia-	Thank you for your comment. The committee noted this evidence and agreed that, because of the specific concerns about under-diagnosis of visual impairment in people living with dementia, it was appropriate to add an additional recommendation to the guideline to "consider referring adults with diagnosed dementia for an eye examination every 2 years", in line with the recommendations for hearing tests for people living with dementia in the NICE guideline on hearing loss.

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				sight-loss-committee-statement-dementia-eye-examinations/	The committee agreed that once someone was identified as having visual impairment, they should then be covered by the recommendation to "ensure that people living with dementia have equivalent access to diagnostics, treatments and care services for comorbidities to people who do not have dementia."
VoiceAbility	Short	14	6	We are concerned that this recommendation fails to recognise an important statutory right. Practitioners (named professionals) should ensure that people are aware of their rights to independent advocacy under the Care Act 2014 as well as the Mental Capacity Act 2005. There is a very close working relationship between these two Acts. Under the Care Act where a person would experience substantial difficulty in doing one or more of the functions outlined in the Care Act s67(4), which encompasses people who may lack capacity to make decisions about their care (including people with fluctuating capacity), they will receive the support of either an appropriate individual if they have one OR an independent advocate OR both (under certain circumstances defined in the Care & Support Independent Advocacy Regulations), to support them to be involved in assessments, care & support planning, care reviews, safeguarding enquiries or review.	Thank you for your comment. The committee noted that there were important issues around capacity (and access to advocacy services) at all stages of the diagnosis and treatment pathway for people living with dementia. They agreed it would be impractical to list every situation in which this was important, and that mentioning what health and social care professional should do in specific circumstances left the risk of people interpreting this as meaning these issues were less important in situations where they are not explicitly mentioned. The committee therefore agreed the most appropriate way to deal with these overarching issues was for the guideline to link to the Mental Capacity Act, the Care Act, and the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018), where these issues can be discussed in more detail.

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VoiceAbility	Short	14	6	We are concerned that the wording 'availability of local advocates (advocacy) services' under this recommendation may not be accurately interpreted as a statutory entitlement. If advice is simply given on the basis of what people may in practice have access to this may mask both need and the failure to commission adequately.	Thank you for your comment. The committee agreed that no recommendation in a NICE guideline can override a person's legal rights, and these issues are covered in detail in the Mental Capacity Act, the Care Act, and the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018). They noted, however, that many areas provide advocacy services over and above just those that are a legal right, and it was important to make people aware of any such services available in their local area.
VoiceAbility	Short	26	12-15	We are concerned that this recommendation does not go far enough. Carers should be informed of their right to an independent advocate under the Care Act 2014 (s67 (3)) to support them with their carers assessment, support plan or review of their plan or safeguarding enquiry or review (s68 (2) if they would experience substantial difficulty in carrying out one or more of the functions in s67 (4) / s68 (3).	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to the Care Act within the guideline.
VoiceAbility	Short	27	12	We believe staff should also receive training in the statutory principle of the Care Act 2014 as well as the principles of the Mental Capacity Act 2005	Thank you for your comment. The committee agreed with this suggestion, and reference to the Care Act has been added to this recommendation.

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VoiceAbility	Short	28	1	We believe consideration should also be given to giving independent advocates the opportunity to attend, take part in and help to co-deliver staff dementia training sessions	Thank you for your comment. The committee discussed this issue but agreed that, in the absence of any evidence, it was not possible to include this within the recommendations.
VoiceAbility	Short	28	8	This recommendation should make explicit that independent advocates (under the Mental Capacity Act and Care Act) have a right to see records about the person's care.	Thank you for your comment. The committee agreed that rather than these issues being considered individually within a condition-specific guideline (which would only be able to consider evidence in people living with dementia, and not the broader evidence on this topic) the most appropriate way to address these issues was by cross-referring to both the Mental Capacity Act and the Care Act within the guideline, as well as the NICE guideline on decision-making and mental capacity (which is due to be published in July 2018).
West London Mental Health NHS Trust	Short	15	9, 10, 11	It is unclear why the recommendation for offering Cognitive Stimulation Therapy (CST) to all individuals with mild to moderate dementia has been removed. Since the last guidance was published in 2006, there has been increasing numbers of studies exploring the evidence for the effectiveness of CST and findings have repeatedly demonstrated significant benefits of delivering this type of therapy. Two notable systematic reviews include: McDermott et al., (2018) and Woods et al., (2012).	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger

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				Therefore, it appears that now more so than previously, the evidence base points strongly in the direction of offering structured CST to patients with mild to moderate dementia. **References:** McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., ... & Orrell, M. (2018). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging & mental health*, 1-11. Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *The Cochrane Library*, 15.	recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
West London Mental Health NHS Trust	Short	15	9, 10, 11	Whilst considering the evidence base, all the research demonstrating the effectiveness of CST has been based upon the delivery of the manualised and structured CST group programme (Spector, Thorgrimsen,Woods & Orrell, 2006). There is currently no convincing evidence to suggest that the benefits detected would also	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a

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				apply if only "elements" of CST were delivered. As such it is unclear what evidence the current guidelines are based upon to be suggesting that structured group activities should include "elements of cognitive stimulation and reminiscence therapy". Whilst there are elements of reminiscence therapy in the manualised CST groups, there is no evidence to suggest that reminiscence therapy on its own is as effective or comparable to a structured CST group. Research demonstrates that CST is the most effective at improving cognitive functioning compared to all other non-pharmacological interventions (including reminiscence therapy; Olazaràn et al, 2010). There are many different "elements" to the CST groups and it would seem far less "evidence based" and clinically effective for individual clinicians to be making decisions regarding which elements are the effective components. Despite many suggestions that the social contact element of CST groups is one of the main predeterminants of the observed improvements, a study by Woods et al. (2012) demonstrated that results consistently favoured a structured CST group over and beyond a social control group. Therefore, if	manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."

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				we are to begin separating out the elements of CST, we are likely to lose the overall effectiveness of the group as a whole. **References:** Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., ... & Spector, A. (2010). Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and geriatric cognitive disorders*, *30*(2), 161-178. Spector A, Thorgrimsen L, Woods B, Orrell M. (2006). *Making a difference: an evidence based group program to offer Cognitive Stimulation Therapy (CST) to people with dementia.* London, UK: Hawker Publications. Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *The Cochrane Library*, 15.	
West London Mental Health NHS Trust	Short	15	9, 10, 11	The ambiguous use of language in the current guidelines is a big shift from the 2006 guidance, which appeared to confidently advocate for the importance of offering non-pharmacological	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in

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		22	5,6	interventions in addition to pharmacological treatments. It is documented on page 5 that the term 'consider' is used to reflect a recommendation for which the evidence of benefit is less certain". As highlighted in comment 1, we would argue that the evidence for the effectiveness of CST is much more certain and reliable than it was in 2006, and therefore it is not clear why the current guidelines are looking to move away from adherence to a protocol and the evidence base. The use of the tentative term "consider" demonstrates a lack in confidence in the existing evidence base for the effectiveness and importance of offering CST to people living with mild to moderate dementia. It further devalues the importance of psychological and/or non-medical approaches, in an already heavily medical dominated field. We would argue that there is a clear disparity between the language used for non-pharmacological interventions in comparison to the pharmacological interventions. The 2006 guidance clearly "recommended" the use of CST,	equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this into two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." For the recommendation on treating anxiety and depression, the committee agreed this should remain a 'consider' recommendation for two reasons. First, because the evidence covered a range of different interventions and it was not possible to identify which ones were effective, and secondly because there are cases of more mild depression in which alternatives such as "active monitoring" (recommended in the NICE depression guideline) would be appropriate instead of a psychological intervention.

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				whereas despite the growing body of evidence for its effectiveness, the current guidance has opted to move away from the evidence based recommendation of CST and replace this with the option to "consider" the use of CST and Reminiscence, which agreeably has limited supporting evidence for the benefit of this. This is notably distinct from the current guidance on pharmacological treatments which continue to be "recommended". This tentative use of language also applies to the guidance given for dementia and depression/anxiety, whereby the evidence for psychological treatment is much more robust and indisputable " For people living with mild to moderate dementia who have mild to moderate depression and /anxiety, **consider** psychological treatments"	
West London Mental Health NHS Trust	Full	296	5	It is reported on page 296 that "No evidence of benefit [for CST] was found on outcomes other than cognition". As referred to in comment 1, this is not accurate as there have been a number of studies that have been able to demonstrate significant improvements across a variety of	Thank you for your comment. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a

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				domains in addition to cognition. These studies are listed below: 1. Capotosto, E., Belacchi, C., Gardini, S., Faggian, S., Piras, F., Mantoan, V., ... & Borella, E. (2017). Cognitive stimulation therapy in the Italian context: its efficacy in cognitive and non-cognitive measures in older adults with dementia. *International journal of geriatric psychiatry*, *32*(3), 331-340. 2. Niu, Y. X., Tan, J. P., Guan, J. Q., Zhang, Z. Q., & Wang, L. N. (2010). Cognitive stimulation therapy in the treatment of neuropsychiatric symptoms in Alzheimer's disease: a randomized controlled trial. *Clinical rehabilitation*, *24*(12), 1102-1111. 3. Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., ... & Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *The British Journal of Psychiatry*, *204*(6), 454-461.	manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia." Please find below a response for each of the papers you cited. Spector (2003) reported an improvement in quality of life, but the pooled result of all the studies included in the meta-analysis could not differentiate an effect between cognitive stimulation therapy (CST) and the control group. Regarding Yamanaka (2013), the committee agreed that the mood measure used in the study was not appropriate to pool with the other quality of life measures found in other studies, so this data point was not included. Capotosto (2017) and Paddick (2017) have now been included as evidence for CST. The inclusion of these studies did not

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				4. Paddick, S. M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., ... & Mushi, D. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: feasibility and clinical efficacy using a stepped-wedge design. *International psychogeriatrics*, *29*(6), 979-989. 5. Spector, A., Thorgrimsen, L., Woods, B. O. B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *The British Journal of Psychiatry*, *183*(3), 248-254. 6. Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *The Cochrane Library*, 15. 7. Yamanaka, K., Kawano, Y., Noguchi, D., Nakaaki, S., Watanabe, N., Amano, T., & Spector, A. (2013). Effects of cognitive	make a meaningful difference to any of the results of the analysis. Orrell (2014) reported an improvement in QoL-AD but the pooled result of the meta-analysis including other relevant trials could not detect clinically meaningful differences in quality of life between people living with mild/moderate dementia offered cognitive stimulation therapy versus usual care. Niu (2010) was excluded from this review question due to it recruiting participants with >5 points in the Neuropsychiatric Inventory, which the committee agreed was a fundamentally different population to the general population of people living with dementia. Woods (2012) was included in Appendix O. This systematic review was used as a source for individual RCTs on CST.

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				stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial. *Aging & mental health*, *17*(5), 579-586. In addition, a systematic review (Woods et al, 2012) found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, in addition to any medication effects as well as showing evidence that Cognitive Stimulation is associated with improvements in quality of life and communication. This is in keeping with our own experience of CST groups. The carers of people who attend our groups comment that they notice significant improvements in alertness and engagement with family members as a result of attending the group.	
West London Mental Health NHS Trust	Appendix J	10	11/12	Similar to the majority of organisations, all CST groups take place in the team base and therefore the cost of staff travel/costs is not applicable.	Thank you for your comment. We are aware that some organisations have facilities available to them for which they do not have to pay, and accordingly a sensitivity analysis was conducted where these costs were excluded. The results of this sensitivity analysis in the base case produced an ICER of

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					£17,111/QALY, making CST cost-effective if QALYs are valued at £20,000 each. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
West London Mental Health NHS Trust	Appendix J	10	11/12	As mentioned, all our groups take place in the team base and therefore there are no additional venue costs for running the group.	Thank you for your comment. We are aware that some organisations have facilities available to them for which they do not have to pay, and accordingly a sensitivity analysis was conducted where these costs were excluded. The results of this sensitivity analysis in the base case produced an ICER of

Stakeholder	Document	Page No	Line No	Comments	Developer's response
					£17,111/QALY, making CST cost-effective if QALYs are valued at £20,000 each. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations, a stronger recommendation for CST and a weaker recommendation for reminiscence. Specifically: "Offer group cognitive stimulation therapy to people living with mild to moderate dementia. Consider group reminiscence therapy for people living with mild to moderate dementia."
West London Mental Health NHS Trust	Appendix J	10	14	The preparation time for each session appears to be an over estimation and the group materials are more likely to be prepared by the Band 4 Assistant, who may spend 0.5 hours, a week preparing. Therefore, considering this and the	Thank you for your comment. Economic models produced by NICE are based on the best available evidence along with the committee's judgement about the quality and applicability of that evidence to current practice across the whole of the NHS. The parameter in question has been tested in a one-way

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				comments above, it is thought that the total cost per session is likely to be less than the £233.19 per patient calculated, and perhaps more akin to the cost of £90 per session as documented by Knapp et al. (2006). **References:** Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *The British Journal of Psychiatry*, *188*(6), 574-580.	sensitivity analysis in the model and was found not to alter the committee's conclusion about the cost-effectiveness of the intervention. Our analysis uses up to date costing for staff, and unlike the Knapp (2006) analysis, assumed that the researchers were not skilled in delivering CST and therefore incurred training costs. Furthermore, our analysis assumed that there were external venue costs, and costs associated with the transportation of patients to receive CST. These assumptions were ratified by the guideline committee for use in our economic analysis. The committee has reconsidered the evidence base around CST and reminiscence therapy, and come to the conclusion that there were errors in the recommendations made in the draft guideline, both in equating CST and reminiscence therapy, and badging both under the heading of structured group activities. The committee agreed the evidence base was stronger for CST (as a manualised intervention) than for reminiscence therapy, both in terms of effectiveness and cost-effectiveness. The committee therefore agreed it was appropriate to split this in to two separate recommendations,

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**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

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[i] Alzheimer's Research UK, NHS Health Check 40-64 Dementia Pilot (http://www.alzheimersresearchuk.org/about-us/our-influence/reports/nhs-health-check-40-64-dementia-pilot/ accessed 12/10/17)

[ii] Alzheimer's Research UK, *Blood test indicates Alzheimer's brain changes* (https://www.alzheimersresearchuk.org/blood-test-indicates-alzheimers-brain-changes/ accessed 06/02/18)

[iii] Alzheimer's Research UK, *Treatments of Tomorrow* (http://www.alzheimersresearchuk.org/wp-content/uploads/2016/09/Treatments-of-tomorrow-web.pdf accessed 06/02/18)

[iv] *Prime Minister's challenge on dementia 2020: Implementation plan* (https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020 accessed 06/02/18)

[v] The Lancet Neurology Commission, *Defeating Alzheimer's disease and other dementias: a priority for European science and society* (http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(16)00062-4/abstract accessed 06/02/18)

[vi] Alzheimer's Society, *Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society* (https://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk accessed 06/02/18)

[vii] Alzheimer's Research UK, *Diagnoses in the UK* (https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk// accessed 06/02/18)

[viii] Alzheimer's Research UK, *NHS Health Check 40-64 Dementia Pilot* (http://www.alzheimersresearchuk.org/about-us/our-influence/reports/nhs-health-check-40-64-dementia-pilot/ accessed 12/10/17)

[ix] Public Health England, *Recommendation against national dementia screening* (https://www.gov.uk/government/news/recommendation-against-national-dementia-screening accessed 06/02/18)