NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Dementia (update)

Date of quality standards advisory committee post-consultation meeting:
20 March 2019

2 Introduction

The draft quality standard for dementia was made available on the NICE website for a 4-week public consultation period between 29 January and 26 February 2019. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 39 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1, 2 and 3.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Most stakeholders supported the quality standard and the areas identified for quality improvement.
- The process for prioritising the areas in the draft quality standard was queried. Concerns were raised about whether these are the key improvement areas, and about removal of statements from the 2010 and 2013 quality standards.
- More emphasis is needed on:
  - the role of families and carers
  - the sub-types of dementia and the different experiences of people with different types of dementia.
- It needs to be clearer that memory services do not have responsibility for all the statements.
- Include the multimorbidity quality standard in the list of related quality standards.
- There is a lack of content on ongoing management of dementia and monitoring of health.
- The statements only make sense for people with an early diagnosis of dementia.
- People with dementia should be treated with dignity and respect.
- Refer to NHS England's Accessible Information Standard in the equality and diversity section for each statement.

Consultation comments on data collection

- Stakeholders suggested data sources that could be used and ways to collect the data.
- A stakeholder raised issues around collecting data on people with Parkinson's.
- Dementia-specific quality of life data collection methods should be used.

Consultation comments on resource impact

- A stakeholder raised concerns that the choice of statements is based on resource rather than need.
- Stakeholders stated that resources should be available to achieve the statements, and specified which statements could require additional funding.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. **[new 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Statement
  - Make it clearer that not all types of dementia can be prevented and not all risk factors are modifiable.
  - Groups that the statement should focus on:
    - ◊ adults who have not developed signs of dementia
    - ◊ people with mild cognitive impairment
    - ◊ people with long-term conditions that increase the risk of dementia, such as diabetes, stroke and hypertension.
  - Change the statement to say that the risk of dementia can be delayed or reduced.
  - Have a statement on a national public health campaign to raise awareness instead, and deliver health promotion messages in settings outside of primary care, like schools and workplaces.
  - Advice around diet needs to be consistent.
- Measures
  - Some stakeholders raised concerns about the demands of data collection, others thought this was straightforward.
  - How is access to the interventions or programmes recorded?
  - Data sources for the outcome measures were suggested, such as the Alzheimer's Research UK Dementia Attitudes Monitor and NHS Health Checks.
  - Measure uptake of interventions and continuation to next review.
- Audience descriptors

  - Practitioners will need training in knowing the signs of dementia, how to advise people on reducing the risks and giving information on eye health.
  - Practitioners should measure that people have attended training.
  - Stakeholders suggested other roles to add to the list of health and public health practitioners, such as allied health professionals.
- Definitions
  - The definition of lifestyle changes should include hearing health interventions, sight tests and dancing.
  - Define ‘behaviour change interventions and programmes’. Stakeholders gave examples of these, such as weight loss programmes, smoking cessation and NHS Health Checks.
- Equality and diversity considerations
  - Needs to be appropriate for auditory, visual and learning disability.
  - Add health literacy considerations to all health messaging.

5.2 Draft statement 2

Adults with suspected dementia are referred to a specialist dementia diagnostic service. **[2010, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- General
  - There is no evidence presented that this is not already happening in practice.
  - There will be resource implications to allow for implementation of this.
- Statement
  - Examples were given of settings that are appropriate for diagnosis to take place in, in addition to memory clinics, such as community settings (home or care home), cognitive neurology and disorder clinics, primary care or other non-specialist settings.
  - Advice can be provided to a referrer by a specialist service without a formal appointment being made.
  - More emphasis is needed on the importance of support and information following diagnosis, including peer support and support for carers.
  - Family and carers need to be involved.
  - Emphasise the importance of thorough neuropsychological assessments for some people experiencing, or reporting, cognitive changes.
  - People diagnosed with dementia should regularly have eye tests to manage any visual impairment.
  - Diagnosing the correct sub-type of dementia is important to ensure people receive the right treatment and support.
- Measures
  - Add a timeframe from referral to assessment and from referral to diagnosis.
  - Add a target on diagnosis rates.
  - Additional outcome measures were suggested, such as numbers of cases of depression identified and treated.
  - The statement measures would not pick up cases where advice was given to a referrer without a formal appointment being made.

  - Some stakeholders felt that the data to measure the statement could be hard to collect, others thought data is readily available.
  - Some stakeholders queried how the statement would contribute to the outcome measure.
- Audience descriptors
  - Add speech and language therapists to the list of healthcare professionals.
  - Subtype of dementia and access to treatment, support and advance care planning should be documented.
- Equality and diversity considerations
  - People's understanding and communication needs should be added.

5.3 Draft statement 3

Adults with dementia have a named care coordinator. **[2010, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- General
  - Support for the statement.
  - Stakeholders raised concerns about the funding available to resource additional care coordinators.
  - The skills required for the care coordinator have not been specified. It needs to be clearer whether this is a registered professional.
- Statement
  - Stakeholders suggested using the term ‘care navigator’ or ‘dementia navigator’ instead of care coordinator.
  - Add to the statement that people with dementia have a care plan.
- Rationale
  - Vision impairment should be listed as a long-term condition that people with dementia have.
- Measures
  - Some stakeholders thought it could be difficult to measure, as the coordinator could sit within different services, or it might not be a single person. Others thought data collection would be straightforward.
  - If the piloted NICE indicator NM64 is used, the definition would need to be amended.
  - Quality of life needs to be more clearly defined so that it can be measured.
  - Carer-reported quality of life was suggested as an outcome measure.
- Audience descriptors
  - Stakeholders gave examples of who could deliver this, such as Alzheimer‘s Society‘s Dementia Connect service and dementia care advisers.
  - Allied health professionals should be listed in the examples of health or social care practitioners.

  - This should be a healthcare professional, not a social care worker.
  - The frequency of reviews should be specified.
  - The care coordinator should identify unpaid carers and work with families and carers as equal partners, involve them in care planning, arrange respite care for them and give information and support.
  - Care coordinators need training in offering advice on having sight tests and raising awareness of the importance of having good vision.
  - The role of the care coordinator should be holistic and support long-term co-morbidities. This should not just be the responsibility of the care coordinator.
- Equality and diversity considerations
  - Change the reference to speech and language difficulties instead of speech difficulties.

5.4 Draft statement 4

Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences. **[2013, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Statement
  - Families and carers should be involved in the choice of activities and have their preferences noted.
  - The statement does not support the opportunity for rehabilitation to improve well-being and function.
- Rationale
  - Add that the person should find the activities enjoyable.
- Measures
  - Stakeholders suggested additional outcome measures, such as lack of depression.
  - Quality of life needs to be more clearly defined so that it can be measured.
  - Stakeholders felt that data collection to check whether the statement is being achieved could be difficult, as activities are provided by different services.
  - Data collection could be through surveys, unless it is recorded at care reviews.
- Audience descriptors
  - Needs to be clearer who commissions and provides these services.
  - Many voluntary agencies only see themselves as referring agents.
  - Allied health professionals should be listed in the examples of health or social care practitioners.
  - Include more examples of activities in this section.
- Definitions
  - Stakeholders suggested activities to include in the definition, such as dance or dance movement therapy, therapeutic food-related activities and everyday activities like dementia-friendly cinema screenings and walking groups.
  - The key point is that the person with dementia enjoys the activities, and the activities listed as examples might not be ones they would enjoy.

- Equality and diversity considerations
  - Add people with communication needs and considering cultural and religious preferences.

5.5 Draft statement 5

Adults with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. **[2010, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- General
  - There is no evidence presented that this is not already happening in practice.
  - Liberty protection safeguards should be considered at this stage.
  - This could put high demand on the health and social care professionals doing the assessment if service providers refer to them, and they might not know the person very well.
- Statement
  - The statement should be extended to say that people with dementia who are distressed have an intervention following assessment, if needed.
  - Include managing pain in the statement.
  - Comments on the structured assessment:
    - a clearer definition is needed
    - how would this be recorded
    - include a full visual assessment
    - families and carers should be involved
    - it needs to be timely
    - hearing loss and communication issues should be considered as a cause of distress
    - use of assessment tools for distress and pain should be included
    - exclude physical causes of distress (earache, toothache, long toenails, eye conditions) before looking at a structured assessment for behavioural and psychological symptoms of dementia, such as anxiety, apathy, agitation and depression.
- Measures
  - Data collection should be straightforward.
  - Quality of life measures should be supplemented with measures of distress.

  - Stakeholders suggested additional outcome measures, such as use of benzodiazepines, fewer urinary tract infections, episodes of delirium, and ear, eye and dental checks.
  - Antipsychotic prescribing will not capture the outcome of the statement.
- Audience descriptors
  - Service providers must have arrangements in place to refer to health and care professionals to do the assessment.
  - Health and care professionals need to be trained in understanding distress in people with dementia and how to treat it.
  - Social care workers will not be qualified to do this.
  - Sensory loss should be included as a cause of distress in the professionals' descriptor.
  - Allied health professionals and music therapists should be listed in the examples of health or social care practitioners.
  - A supporting patient decision aid for antipsychotic medication should be included in the information for healthcare professionals and people with dementia.
  - Families should receive training and support.
- Definitions
  - Non-pharmacological and pharmacological treatments for distress should be listed to make the statement measurable.
  - Non-pharmacological options should include dance movement therapy, music therapy and other arts therapies.
  - Define distress.
- Equality and diversity considerations
  - Refer to early onset dementia.

5.6 Draft statement 6

Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each health and social care review. **[2010, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- Statement
    - Enough time for an in-depth conversation is needed, and the time available at every care review might not be enough.
    - People might not be ready to have this conversation at diagnosis and there might not be enough time. It should be discussed at an early stage, but when the person is ready.
    - Advice on advance care planning may be better promoted through information and advice services rather than the assessment/review process.
    - Families and carers should be involved in this and seen as equal partners.
- Rationale
    - Make it clearer that it means before people lack the mental capacity to make decisions, not lack the capacity to communicate.
    - Include information about Advance Decision to Refuse Treatment or a registered Lasting Power of Attorney.
- Measures
    - Change process measure to ‘proportion of adults who feel supported…’.
    - Additional outcome measures were suggested, including number of people with Lasting Power of Attorney for Health and Lasting Power of Attorney for Welfare Advance Statements
- Audience descriptors
    - Service providers should have systems in place to share advance care plans between professionals, such as electronic plans.
    - Staff need training to be confident and competent in having these discussions.
    - Greater clarity is needed around which professionals have responsibility for this.
    - Care coordinators can discuss this with the person when they are ready.

  - Decisions and wishes about future care should be documented and health and care professionals need to know how to document them in a legally binding way.
  - Allied health professionals should be listed in the examples of health or social care practitioners.
  - People should have the contact details for the person they can contact to discuss this when they want to.
- Definitions
  - Include in the definition of advance care planning:
    - ◊ Do Not Attempt Resuscitation (DNAR) orders
    - ◊ Discussing aspects of care the person considers a priority
    - ◊ Making decisions about surgery for cataracts early and when people have capacity to decide.

5.7 Draft statement 7

Carers of adults with dementia are offered education and skills training. **[2010, updated 2019]**

Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

- General
  - Additional resources will be needed to provide this.
  - Carers will need support to be able to leave the person they care for to attend training.
- Statement
  - Include support for carers in the statement. Support should include social and emotional support, such as access to therapy and peer-support, and practical support, such as respite care, information about financial assistance, befriending and volunteer services.
  - The statement should say ‘information and advice’ instead of ‘education and training’.
  - Make it clearer that this means informal carers.
- Rationale
  - Highlight a carer’s ability to have control over day-to-day life and the risk of loneliness.
- Measures
  - Additional measures were suggested, such as the availability of support, information and advice, offer of respite care and inclusion on the carers’ register.
  - The process measure should not only measure carers who have had a carers’ assessment, as not all carers have them.
  - Some stakeholders thought the statement could be hard to measure, whereas others thought data would be available.
- Audience descriptors
  - Charities should be listed in the examples of service providers.

  - Allied health professionals should be listed in the examples of health or social care professionals.
- Definitions
  - Training should include:
    - ◊ non-verbal and emotional communication
    - ◊ recognising potential malnutrition or dysphagia and how to access specialist advice when needed
    - ◊ safe swallowing, reducing risk of aspiration and enabling nutrition and hydration needs to be met
    - ◊ resilience building
    - ◊ dementia sub-types
    - ◊ information and resources like e-learning and library books
    - ◊ access to helplines
    - ◊ support for advance care planning
    - ◊ information and advice services
    - ◊ education about available treatments
  - The content and quality of the training is not defined.
  - Examples of training courses and psychoeducation interventions were given, such as STrAtegies for RelaTives (START).
- Equality and diversity considerations
  - Include cultural or religious factors that make access more difficult.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Stakeholders suggested that some of the statements from the 2010 and 2013 quality standards on dementia should still be included. These were:
  - People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area
  - People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health
  - People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs
  - Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.
  - People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support
  - People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
  - People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
  - People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
  - People with dementia live in housing that meets their specific needs.
  - People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
  - People with dementia are enabled with the help of their carers to maintain and develop their involvement in and contribution to their community.
- Other additional areas suggested by stakeholders were:

- Addressing deafness and hearing loss in adults living with dementia.
- Staff training in dementia care, including person-centred care.
- Promoting opportunities to engage in research at all stages of the condition.
- Use of person-centred, holistic care plans, developed in partnership with the person with dementia.
- Dementia sub-types.
- Prescribing memantine for people with moderate and severe Alzheimer's Disease.
- Rehabilitation and re-enablement.
- Access to help with home care.
- Education for communities.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Section	Comments
1	Action on Hearing Loss	General	About us Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. 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 give people support and care; develop technology and treatments and campaign for equality. Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss or deafness, which could be caused by various factors including age, genetic predisposition, exposure to loud sounds, complications at birth or other health problems. We use the term 'people who are deaf' to refer to people who are severely or profound deaf who use British Sign Language (BSL) as their first or preferred language and may consider themselves part of the Deaf community, with a shared history, language and culture. Introduction Action on Hearing Loss welcomes the opportunity to comment on NICE's Dementia Quality Standard. We welcome the aims of the Quality Standard to improve the prevention, assessment and management of dementia in adults. **At present, we are concerned that the Quality Standard does not fully consider the importance of addressing deafness and hearing loss in adults living with dementia. We think the Quality Standard needs to be changed to better reflect how properly diagnosing and managing hearing loss and good communication can support the delivery of high-quality dementia care. The changes set out below will bring the Quality Standard in line with NICE's recently published *Hearing Loss in Adults: Assessment and Management Guideline*,[1] which recommends that adults with diagnosed or suspected dementia should receive a hearing assessment.** In our response, we have provided feedback on the wording of the Quality Statements and answered the consultation questions. For ease of reference, the key points from our response are summarised below: • **A Quality Standard should be added on the importance of addressing deafness and hearing loss in adults living with dementia (see Comment 2).**

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[1] NICE, 2018. *Hearing loss in adults: assessment and management*. NG98. Available at: https://www.nice.org.uk/guidance/NG98

ID	Stakeholder	Section	Comments
			- **The definition of 'Lifestyle changes' in Quality Statement 1 should be changed to include examples of hearing health interventions that reduce the risk and impact of dementia (see Comment 4).** - **The 'Health and social professionals' paragraph in Quality Statement 5 should be changed to include sensory loss as an example of a clinical cause of distress in adults with dementia (see Comment 11).** - **A reference to NHS England's *Accessible Information Standard*[2] should be added to the 'Equality and diversity considerations' sections in all the Quality Statements (see Comments 5,7,8,9,12,13 and 14)**
2	ADMP UK	General	On the whole we do welcome this updated guideline, albeit we acknowledge limitations on the types of activities and therapy input that are mentioned as examples. As an Association for Dance Movement Psycho/therapy, we do notice the marked absence of references to either dance as a preventive and wellbeing enhancing activity as well as dance movement therapy as an intervention that can offer psychological support at times of distress and/or psychological (and physical) need. Evidence stemming from reviews such as the dementia Cochrane review (Karkou and Meekums 2017; Lyons, Karkou, Richards et al 2018; Kiepe, Stockigt and Keil 2012) and other systematic reviews in arts therapies (Beard 2012; Schmitt and Frolich 2007; Cowl and Gaugler 2014) is missing. So are references to dancing as a form of prevention and a wellbeing enhancing activity (Guzman-Garcia Hughes, James and Rochester 2013; Karkou, Oliver and Lycouris 2017). Furthermore, systematic reviews and meta-analysis of studies in the field by Koch Kunz, Lykou and Cruz (2014) and Strassel Cherkin, Steuten et al (2011) discuss the positive outcomes of dance movement therapy for a number of these different populations including older people with or without dementia. Key references missing: Karkou V, Meekums B. Dance movement therapy for dementia. Cochrane Database of Systematic Reviews 2017, Issue 2. Art. No.: CD011022. DOI: 10.1002/14651858.CD011022.pub2. Lyons, S., Karkou, V., Roe, B., Meekums, B., & Richards, M. (2018). What research evidence is there that dance movement therapy improves the health and wellbeing of older adults with dementia? A systematic review and descriptive narrative summary. The arts in psychotherapy, 60, 32-40. Kiepe, M. S., Stöckigt, B., & Keil, T. (2012). Effects of dance therapy and ballroom dances on physical and mental illnesses: A systematic review. The Arts in Psychotherapy, 39(5), 404-411. Beard, R. L. (2012). Art therapies and dementia care: A systematic review. Dementia, 11(5), 633-656.

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[2] NHS England, 2017. *Accessible Information Standard.* DCB 1605. Available at: www.england.nhs.uk/accessibleinfo

ID	Stakeholder	Section	Comments
			Schmitt, B., & Frölich, L. (2007). Creative therapy options for patients with dementia--a systematic review. Cowl, A. L., & Gaugler, J. E. (2014). Efficacy of creative arts therapy in treatment of Alzheimer's disease and dementia: A systematic literature review. Activities, Adaptation & Aging, 38(4), 281-330. Guzmán-García, A. H. J. C., Hughes, J. C., James, I. A., & Rochester, L. (2013). Dancing as a psychosocial intervention in care homes: a systematic review of the literature. International journal of geriatric psychiatry, 28(9), 914-924. Karkou, V., Oliver, S., & Lycouris, S. (Eds.). (2017). The Oxford handbook of dance and wellbeing. New York: Oxford University Press. Strassel, J. K., Cherkin, D. C., Steuten, L., Sherman, K. J., & Vrijhoef, H. J. (2011). A systematic review of the evidence for the effectiveness of dance therapy. Alternative Therapies in Health & Medicine, 17(3). Koch, S., Kunz, T., Lykou, S., & Cruz, R. (2014). Effects of dance movement therapy and dance on health-related psychological outcomes: A meta-analysis. The Arts in Psychotherapy, 41(1), 46-64.
3	Alive	General	Alarmed that elements of 2010 and 2013 standards are 'no longer considered national priorities for improvement'. The consultation document does not offer supporting evidence that national standards on these 14 points have been met to a uniformly high level across the country and hence do not need to be included.
4	Alive	General	The criteria for inclusion and the quality measures in the new draft seems to be based more around the capacity to collect data at a local level than around the needs of people living with dementia, and of their carers. The statement that these 14 points 'may be useful at a local level' suggests complacency and a lack of understanding of the realities at local level for many people. It keeps us in the land of 'postcode lotteries'.
5	Alzheimer's Research UK	General	Alzheimer's Research UK is the world's leading dementia research charity dedicated to causes, diagnosis, prevention, treatment and 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. • Treat dementia effectively. Through these important strands of work, we're bringing about breakthroughs that will change lives. Alzheimer's Research UK welcomes the opportunity to comment on the Dementia quality standards consultation.
6	Alzheimer's Society	General	**The consultation documents lack detail outlining the rationale for the selection and development of the quality standards, particularly in providing evidence for why they are priorities for quality improvement. It is also unclear how stakeholder responses to the topic consultation have fed into their development.**

ID	Stakeholder	Section	Comments
			The grouping of stakeholder responses into broad topics rather than specific focus areas means that they do not necessarily relate to the focus of the QS that has been developed as a result. We would ask NICE to provide further information on this development process.
7	Berkshire Healthcare NHS Foundation Trust	General	It would be helpful for the QS to emphasise that much of the support can be provided by Primary Care/Social Care/Public Health to ensure Commissioners do not assume responsibility for all standards sits with Memory Services
8	The British Dietetic Association	General	On page 4 the following nutrition related documents are missing and we feel need to be included as documents to be considered alongside the quality standards: SACN (2018) Statement on Diet, Cognitive Impairment and Dementias www.gov.uk/government/publications/sacn-statement-on-diet-cognitive-impairment-and-dementia Dementia Training Standards Framework (2018) www.hee.nhs.uk/our-work/dementia-awareness/core-skills • NICE CG32 (2006) Nutrition support for adults: oral nutrition support enteral tube https://www.nice.org.uk/guidance/cg32 NICE Quality Standard 24 (2014) Nutrition support in adults www.nice.org.uk/guidance/qs24 BMA (2018) Clinical Assisted Nutrition and Hydration (CANH) www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration
9	British Geriatrics Society	General	The British Geriatrics Society feel that there is nothing else to add to these standards and are happy to endorse.
10	The British Psychological Society	General	**References:** British Psychological Society (2014). *A Guide to Psychosocial Interventions in Early Stages of Dementia*. Leicester: BPS. British Psychological Society (n.d.). Evidence briefing: ‘Behaviour that challenges’ in dementia. Leicester: BPS Burns, A & Buckman, L (2013). *Timely diagnosis of dementia: Integrating Perspectives, Achieving Consensus*. NHS England. Collerton, D. & Damone, R. (2014). Cognitive assessment of people who may be developing dementia. In R.Guss (Ed). *Clinical Psychology in the Early Stage Dementia Care Pathway*. Leicester: BPS. Cummings, J. L. (1997). The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology*, 48, S10-S16.

ID	Stakeholder	Section	Comments
			End of Life Care and Post Bereavement Support Shifting the Conversation from Difficult to Important (2018) - http://hubble-live-assets.s3.amazonaws.com/lifestorynetwork/redactor2_assets/files/52/End_of_Life_Care___Post_Bereavement_Support_Shifting_the_Conversation_from_Difficult_to_Important.pdf Holle, D., Halek, M., Holle, B. & Pinkert, C. (2016) Individualized formulation-led interventions for analysing and managing challenging behaviour of people with dementia –an integrative review. *Aging & Mental Health*, 13, 73–83; 6. Lee, R. P., Bamford, C., Poole, M., McLellan, E., Exley, C., & Robinson, L. (2017). End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PloS one*, 12(6), e0179355. doi:10.1371/journal.pone.0179355 Manthorpe, J., Hart, C., Watts, S., Goudie, F., Charlesworth, G., Fossey, J.& Moniz-Cook, E. (2018) 'Practitioners' understanding of barriers to accessing specialist support by family carers of people with dementia in distress', *International Journal of Care and Caring*, 2(1): 109–23 Memory Services National Accreditation Programme (2018). Standards for Memory Services (6th Ed). London: Royal College of Psychiatry. Moniz-Cook E, Hart C, Woods B, Whitaker C, James I, et al. (2017) Challenge Demcare: management of challenging behaviour in dementia at home and in care homes: development, evaluation and implementation of an online individualised intervention for care homes; and a cohort study of specialist community mental health care for families. *Programme Grants Appl Res* ; 5, 15 Moniz Cook, E.D., Swift, K., James, I.A. et al. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Dementia and Cognitive Improvement Group*. DOI:10.1002/14651858.CD006929.pub2 Moniz-Cook, E., Woods, R., Gardiner, E., Silver, M., & Agar, S. (2001). The Challenging Behaviour Scale (CBS): development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology, 40(3),* 309-22. Novella, J.L., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F., & Blanchard, F. (2001). Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. *Quality of Life Research*, 10:443–52.

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			Rand, S. & Caiels, J. (2015). *Using Proxies to Assess Quality of Life: A Review of the Issues and Challenges.* Canterbury: Quality and Outcome of Person-centred Care Policy Research Unit Rochon, P. A., Vozoris, N., & Gill, S. S. (2017). The harms of benzodiazepines for patients with dementia. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, *189*(14), E517-E518. Surr, C. and Gates, C. (2017) What works in delivering dementia education or training to hospital staff? A synthesis of the evidence. *International Journal of Nursing Studies.* 75: pp172-188 DOI: 10.1016/j.ijnurstu.2017.08.002 Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., Drury, M., … Dennison, A. (2017). Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature. *Review of educational research*, *87*(5), 966-1002. Teri, L., Truax P., Logsdon R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist (RMBPC). *Psychology and Aging*, 7,4, 622-31. Vasse, E., Moniz-Cook, E., Rikkert, M., Cantegreil, I., Charras, K., Dorenlot, P., . . . Vernooij-Dassen, M. (2012). The development of quality indicators to improve psychosocial care in dementia. *International Psychogeriatrics, 24*(6), 921-930. doi:10.1017/S1041610211002523
11	Compassion in Dying	General	We thoroughly welcome this quality standard as a way to achieve personalised care for adults with a diagnosis of Dementia. We are particularly pleased with the clear focus on advance care planning and involving people in decisions about their treatment and care. These things are crucial if people with dementia are to be given the best possible care and it is right that the quality standard reflects this.
12	Dementia UK	General	It is disappointing that there appears to be less focus on the role of the family carer/supporter in these Quality Statements. The evidence indicates that the health and social care services have still not seriously considered how dementia affects the whole family or the impact of supporting someone with dementia. Statements 2-6 in particular should have the family carer/supporter incorporated into the statements as they are a vital part of the assessment, diagnostic and intervention stages.
13	The Lewy Body Society	General	Background The Lewy Body Society, established in June 2006 in the UK, was the first charity in Europe exclusively concerned with Lewy body dementia. Our mission is to fund clinical research to improve the diagnosis and treatment of the disease. We also raise awareness of Lewy body dementia among the general public and those in the medical profession and decision making positions, and we provide information resources for patients and carers.

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			Our overall response to the draft quality standard In general, we support the draft quality standard and believe that it does focus on the key areas for quality improvement. However, we feel that there is too little focus on the sub-types of dementia, with a risk that there may be a lack of recognition of the diversity of experience of people living with different types of dementia. We note the comments made by Parkinson's UK in the initial stakeholder exercise that informed the draft standard about the need to improve diagnosis of dementia with Lewy bodies and Parkinson's dementia, and welcome the evidence that they provided. Others also referred to sub-types. For example the Royal College of Psychiatrists said: "People with non-Alzheimer's form of dementia should also have access to improved assessment and treatments (e.g. vascular disease, lewy body disease…) with some access to subtype specific treatment pathways." We welcome this statement in the narrative of the briefing paper: "Stakeholders felt that identifying a dementia subtype in a specialist diagnostic service is a quality improvement area, as knowing the subtype will determine how dementia is managed. Getting a diagnosis in the right setting also allows for planning services and coordinating care." However, it isn't clear in the draft standard how this view from stakeholders has been responded to. The issue of dementia sub-types may be implicit throughout the entire standard – for example personalised care plans would of course be dependent on the type of dementia – but we believe more explicit acknowledgements of the types of dementia would be helpful.
14	Public Health England	General	Public Health England supports the proposed updated changes
15	Royal College of General Practitioners	General	The Quality Standard on Multimorbidity should be listed here. Most people with dementia have at least three other long term conditions and care of people with dementia can be improved by looking at care holistically, taking into consideration physical and mental comorbidities.
16	Royal College of Nursing	General	In general, this is an excellent document.
17	Royal College of Occupational Therapists	General	The RCOT Specialist Section Older People's Dementia Forum welcomes this updated quality standard for the management of health and social care support for adults with dementia.
18	Royal College of Physicians	General	The RCP is grateful for the opportunity to respond to the above consultation. We would like to endorse the response submitted by the Association of British Neurologists (ABN).
19	Skills for Care	General	Seems to cover the key areas well.
20	Tide	General	Tide is the UK wide involvement network for carers of people living with dementia, hosted by the Life Story Network CIC. We do not provide direct support to carers in their caring role as many other organisations do this. Rather, we enable carers to get involved to influence policy, practice and research. We offer a bespoke carers development programme to help them to recognise themselves as experts by experience and to give them the

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			confidence and skills to be able to speak up and tell their stories with impact. More information about tide is available here: www.tide.uk.net Tide carers welcome the opportunity to submit evidence to this inquiry on quality standards. We have conducted an online survey which was open between 08/02/2019 and 20/02/2019. The output from the survey has been collated and is presented below. **In total 23 carers submitted their responses.** A common theme from the carers’ responses to the original consultation questions published by NICE was their inaccessibility. Many carers stated that the use of specialist (medical) terminology excessive usage of professional jargon presented a barrier to their participation in the consultation. Taking this feedback into account, and following a conversation with a NICE team member, tide has amended and simplified the questions for the survey. The questions we asked our carers were: 1. What is your understanding of these statements? Do they make sense? 2. Is anything missing or could it be improved? 3. Based on your lived experience, is this the quality of service/support you currently receive? 4. Any other comments? Carers’ answers to these questions are presented below: **1. What is your understanding of these statements? Do they make sense?** • The statements make sense to me but the use of technical and medical 'words' will need explanation to most of the people we work with. • I understand them and like the revised statements • No they don't make sense yet but with real services in place and working, not just tick boxes we wouldn't be asking these questions • Yes they make sense • They are aspirational rather than necessarily realistic. Who will call a care home to account if they are not met? They make sense but are unattainable unless the system changes. • It has some good structured points for the person with dementia. • The standards make sense as far as they go but they are limited in scope. They cover diagnosis and end of life but ongoing management is very lightly touched on. There are not any effective treatments for dementia but there are treatments for many of its co-morbidities. Sometimes however these treatments

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			have to be modified to take account of the inability of the person with dementia to co-operate or comply with the treatment. Some consideration might be given to maximising the usefulness of treatment for co morbidities by modifying its delivery or timing. • For the beginning and the end of the dementia pathway but they do not address health care monitoring particularly in sensory auditory and mobility decline in the middle to late stages of dementia. They talk about skills training for carers in what! They are already the experts by necessity. • Yes they make sense • They are "statements" but bear little or no resemblance to what actually happens or is in place • Yes all statements are a very sensible approach to the subject, but No. 5 would have to be at the earliest onset of the diagnosis. • Yes • I understand the statements completely. They make good points • Yes • The NICE website defines what Quality Standards are "Quality standards set out the priority areas for quality improvement in health and social care." Do they make sense? Broadly, yes. • Yes they make sense • What care reviews? My mum has Vascular Dementia and her ability to understand complex questions is not there anymore, Dementia is a progressive disease and understanding becomes even more difficult even with simple questions, as I said 'What reviews?' They make sense to people with an early diagnosis of certain types of Dementia but not all. • There is no mention of people who have a Learning Disability and do get Dementia as well, and much earlier in their life especially people with Downs' syndrome. • Yes • I understand the statements, though find some a little ambiguous, do they really understand the impact dementia has • They certainly do. 2. Is anything missing or could it be improved? • Transparency. Speed of services needs to be improved so care can be provided and lessen the suffering. • Treat everyone with the respect that they deserve, they may have forgotten somethings but have a wealth of knowledge that they can share • Statements cover is OK • As statements they are good but having statements is not the same as it working in practice into

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			- I think it covers most issues - No but I don't think some points are realistic - Let's first focus on getting these statement achieved in practice - Yes by thinking of those people - Dignity and Respect **3. Based on your lived experience, is this the quality of service/support you currently receive?** - No I would say that the quality of service and support is not of a high standard across the country. There are some examples of excellent practice and a significant amount of good practice; but there are also significant areas where poor or uninformed practice occurs. - No, I get no support or help to look after my grandmother. - There are so many that have not been as lucky as me but this should change so that excellent support is available for all - No - My mum needs bite size training to cope with dad, one to one as she is coping with deafness herself. I have to plan out there week on a white board so its clearer for her. Mum gets letters of events to go to but she cannot go as dad wants to go with her. Support is offered but doesn't fit her needs. - No - Not at all. My relative was managed best at home. Hospitalisation was a disaster. Care plans were only personalized when we arranged help privately and wrote them ourselves. Requests for therapeutic interventions were ignored until a psychiatrist requested them. - NO - Very good - caring support - access to support services - No - Most definitely NOT. - No - Statements 1 & 2 were met, statements 3, 4 and 6 were not. Statements 5 was met but later than it could/should have been. Statement 6 was perhaps not very relevant in our circumstances. Based on My late wife's dementia, myself as main carer. - No

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			• No it definitely was not anything like that • No **4. Any other comments?** • I would be happy to discuss further but as a local area coordinator in an area of York I am working hard to get community engagement for people living with dementia and their carers. We come across prejudice and ignorance amongst sections of the community. Would be happy to share how we are tackling this and get some advice • CCGs should be commissioning services based on absolute best practice. Come and visit the nursing home where my husband has lived for two years, and you will see that these well-meaning statements bear little resemblance to the situation he is in. When will psychiatrists start running clinics in nursing homes, instead of expecting me to take my husband to a clinic appointment - miles away with no transport available? The private sector, from whom most services are provided, is driven by profit not compassion. Meaningful activities? Forget it. • Dad only likes me to sit with him but I then can't take mum to events that are offered. • It's not an inspiring document. There is no indication that a specialised dementia service is envisaged, and some of the earlier standards have been removed without explanation. • Difficult one - but need to ask relatives / friends who are not in daily contact with person for opinion in any noticeable changes in spouse/parent/partners/behaviour if you are becoming concerned. • Everyone involved in policy and procedure setting should volunteer at dementia clinics and meet with people in real life settings not just during consultation. You can glean far more from observation than from questionnaires alone • Boxes are being ticked again, the sad thing is usually nothing changes and if it does, it's never quick enough. Great statements that sound good, never achievable for the people who matter. • No • No • Good practice • Thank you for putting this together...it is certainly needed in my experience
21	Alive	Question 1	No

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22	Alzheimer's Society	Question 1	**In answer to question 1, we agree that most of the statements do reflect key areas for quality improvement, however some of the standards, whilst reflecting important areas for care or support, do not reflect areas where there is evidence that *improvement* is needed (e.g. they are not already happening to a high standard), and some key priorities for quality improvement have been missed. This results in quality standards that are not as ambitious as they could be, missing the opportunity to have a greater impact in driving improvements in care and support that people with dementia and carers desperately need.** The consultation document states that NICE quality standards (QS) describe high-priority areas for quality improvement in a defined care or service area, and are intended to drive up the quality of care. NICE also state that areas prioritised for quality statements should be areas of care where there is evidence of variation in delivery of care, where there would be expected contribution to improving the experience of care or services as well as their safety and effectiveness, and that they be measurable (NICE quality standards process guide). As explained below for individual quality standards, we believe that not all of the quality standards selected are those that best meet the objectives of the QS, and some areas that better meet these objectives have been omitted.
23	Department of Health and Social Care	Question 1	On the whole, yes. We particularly welcome the addition of the new prevention quality standards measure. We would particularly emphasise the need to engage with groups not yet reached e.g. BAME. However, we believe that it would be appropriate to maintain the quality standard relating to training in the 2010 standards People with dementia receive care from staff appropriately trained in dementia care, as the Dementia 2020 Challenge highlights the importance of dementia training for health and social care staff, particularly at tier 2 and tier 3 levels.
24	MHA	Question 1	**Does this draft quality standard accurately reflect the key areas for quality improvement?** Partly - we are pleased to see recognition for the skills and education needs of carers of people living with dementia. However we are disappointed that the 2010 statement *'People with dementia receive care from staff appropriately trained in dementia care'* will no longer be considered a national priority. In our experience, while great achievements have been made in the training of health professionals, training of social care staff – by suitably qualified and experienced trainers - needs continued focus, particularly those in domiciliary care and supporting organisations. We believe there should be continued national commitment to ensure a range of staff are trained in dementia care and this should continue to be reflected in the standard.
25	Alive	Question 2	Don't know
26	Alzheimer's Society	Question 2	**In answer to question 2, we believe that most of the proposed data collection measures would be feasible to put in place.**

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			However, we note that some QSs include outcomes of ‘self-reported or carer-reported quality of life for adults with dementia’ (QS2, QS3, QS5, QS8). It should be recognised that dementia specific quality of life data collection methods should be used, as standard measures of quality of life can be inaccessible to people with dementia. It should also be considered that this data collection in itself requires resource.
27	Department of Health and Social Care	Question 2	We would advise the local health and social care systems would be better placed to respond to this question, as they will have a more detailed understanding of the current local data collection mechanisms. Existing published NHS Health Check data could be utilised to monitor the risk reduction messages quality standards.
28	Neurology Academy Limited	Question 2	Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place? This statement is unrealistic. Most local structures will be unable to gather data as people with Parkinson’s who attend memory services are not seen on a regular basis. Often, they are diagnosed, started on treatment, signposted to services and then discharged. The opportunity to discuss advanced care planning does not make sense unless this is done by a GP or nurse specialist, who will more than likely not have sufficient time to do this at each care review. The NHS is currently discouraging regular appointments in a bid to reduce service demand and this goes against achieving this target.
29	Nottinghamshire County Council	Question 2	Healthcare provider response: We have a well-established commissioned diagnosis service across Nottingham / Nottinghamshire – Memory assessment Service (MAS) which collects and collates data from a quantitative and qualitative perspective. Social Care Response: Mosaic contains some questions at Contact around dementia and diagnosis. Introduced by ASCH to support the need to understand this health condition which was not being captured adequately. Also, under commissioned support, the PSR ‘Memory and Cognition’ should indicate the support needs are related to dementia-related symptoms (however this may or may not be diagnosed). Both of these are sources can be used to potentially identify service users with dementia. There is a report within the BI Hub (‘Adults Reports’ section and then ‘Assessments and Reviews’ section) which is named ‘ARHC_001 - Health Conditions’. This reports on any ‘Reported Health Conditions’ as recorded at a service user’s review or assessment (subject to accurate recording of course). There is a column in this report under the ‘Mental Health’ category for ‘Dementia’.

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			This report will only help to identify SUs with dementia once diagnosed so wouldn't assist with statements 1 and 2 in the draft quality standard. Whether the information already captured in the reviews/assessments could be used in conjunction with other information to provide evidence for statements 3-7 would be reliant on the other bits of information being available within Mosaic in a reportable format at present i.e. tick box options/radio buttons/dropdown menu responses. If it's just free-text within Mosaic where the information would be it becomes pretty much impossible to report on. There may be something within the reviews/assessments such as the part within the 'Introduction and being involved in your review' section of the Care and Support Assessment form that lists 'People contributing to this review' that could be reported on to evidence statement 6 regarding 'Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each care review'. However, it's not something that is currently reported on so would require a new report to be requested/built. As for the other statements no reporting is currently available on any of the specifics required and the specifics required are not captured within Mosaic at present. Therefore to obtain such information would in all likelihood require Mosaic form changes and the new report builds. To be sure on the number of carers of people with dementia, the quality of these data would need improvement. The Performance team reports on Carers assessments and reviews (numbers only) quarterly but we do not link to the person cared for (they may not be in the system). This could be re-introduced but data quality would need to improve. The linkages between carers assessments (carer) and the service user(s) (cared for) in Mosaic are not always clearly captured. Any evidence of providing training or a plan for a carer would need to be captured at assessment or some such point in more detail if required. The annual (stat) survey on service users does not target service users with dementia. The survey of carers (carried out every other year) doesn't target this cohort either. So, some bespoke survey would need to be introduced for this.
30	Alive	Question 3	No. This question suggests the rationale for the new National Standards appears to be resource-led, rather than driven by the real needs of people living with dementia. The language around 'potential cost savings or opportunities for disinvestment' gives great cause for concern: it supports cost cutting at a time when indicators are that needs and demand for services for people living with dementia, and for their carers, will only increase.

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31	Alzheimer's Society	Question 3	**In answer to question 3, we believe most of the QSs may be achievable considering the resources required to deliver them, however some do require funding.** In particular, QS4 requires funding to commission services that provide activities to promote wellbeing, and QS7 requires commissioning of education and skills training for carers. QS3 may also require funding for commissioning named care coordinators such as dementia advisers, as with health and social care practitioners already stretched in the current system, it would be difficult for them to take on this role without additional resource. QS6 may also require additional resource to allow sufficient time for advance care planning discussions at each care review. Additionally, for some of the QSs to be successful, training is needed for staff, which also requires funding. In particular, training on risk reduction (QS1), training in understanding and assessing distress (QS5), and training in advance care planning discussions (QS6). The need for funding may be a barrier to achieving or working towards the QS.
32	Department of Health and Social Care	Question 3	NHS England allocates funding to Clinical Commissioning Groups (CCGs) which commission services on behalf of their local populations. It is for CCGs to decide how best to use the funding allocated to them in line with local healthcare needs and priorities, working with other local commissioners and organisations
33	Neurology Academy Limited	Question 3	Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. Current commissioning arrangements for memory services and simple diagnostic services are outdated and not fit for purpose to deliver these standards. There is no comprehensive map for current services and no overall equity of provision. They are delivered by a range of providers. Additionally, many people are not referred to a local memory service until the meet the criteria for dementia. The first standard on prevention will thus not apply. Primary care is already stretched and will not engage in this type of activity in a focussed way beyond general lifestyle well being advice in a catch all manner. To meet statement 1 adequately Brain Health Clinics or centres need to be established.
34	Nottinghamshire County Council	Question 3	Healthcare provider response: Diagnosis – a well-established service MAS is currently commissioned and currently provides a diagnostic service in a community setting. Given the expected rises in numbers this may need review to ensure demand and capacity can be met moving forward. Named Coordinator – this would need considerable interagency agreement and pathway development to ensure a coordinated approach to this role. Different IT systems may prove to be a challenge in taking this forward. Promoting wellbeing for patients with dementia – would require training support across agencies and coordination of messages

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			The structured assessment – would need interagency agreement and pathway development – shared assessment?? Development of the advanced care pathway for this cohort of patients would be welcomed – again this would require IT systems to work together to ensure key information is shared appropriately Carers education / skills / training – this area of support (from a secondary care perspective) has unfortunately borne the brunt of cost efficiencies over the last 18 months with the loss of Day services – Mid Notts, access to COMPAS workers – that will require some rethinking.
35	Nottinghamshire County Council	Question 4	Healthcare provider response: MAS service would be able provide an excellent case study for diagnosis. Social Care Response: The most achievable way to do this would be to have care navigators however this has not been possible due to staffing implications. Currently all identified carers are offered information, advice, guidance or a carers assessment. All homecare providers are required to provide dementia awareness training to their staff teams. The Dementia Quality Mark for care homes is available to assess provision. Falls awareness training Information is provided about Lasting Power of Attorney. We have some care homes that have achieved the Gold Standards Framework for end of life care.
36	Action on Hearing Loss	Statement 1 (general)	**The Quality Statement that adults should be informed of interventions and programmes that reduce the risk of dementia is welcomed.** As highlighted in Comment 2, an increasing body of evidence suggests that early intervention and support for hearing loss may reduce the risk and impact of dementia. Hearing aids may have an important role to play in reducing the risk of cognitive decline and the onset of dementia, but despite this, we know that less than two-fifths of people who need hearing aids have them. Hearing aids are most effective when fitted early, but evidence suggests that people wait up to ten years on average before seeking help for their hearing loss and the

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			average age for referral is in the mid-70s.[3] Good health and social care practitioners awareness of hearing loss, hearing aids and role of the GP in referring adults for a hearing assessment is therefore crucial for ensuring early diagnosis and prompt access to treatment. **Consultation questions**: Commissioners and health and social care professionals implementing this Quality Statement should refer to NICE's recently published *Hearing Loss in Adults: Assessment and Management Guideline*,[1] which provides clear guidance on the best approaches for diagnosing and managing loss. The Guideline highlights that delays in referral for hearing difficulties will reduce people's ability to "function at work and home" and make it harder for them to look after their own health. Commissioners should also refer to NHS England's forthcoming JSNA guide.[4] This guide has been co-produced by NHS England, the Local Government Association, the Association of Directors of Public Health and other stakeholders, and will be published later this year. The guide provides data, evidence and insight to help local authorities and NHS commissioners develop robust hearing needs assessments that properly reflect local needs.
37	Action on Hearing Loss	Statement 1 (Definitions)	**The definition of 'Lifestyle changes' should be changed to include examples of hearing health interventions that reduce the risk and impact of dementia.** As highlighted in Comment 2, early intervention and support for hearing loss may have an important role to play in helping adults with dementia stay healthy and may even reduce the risk of them developing dementia in the first place. Referencing these issues in the definition of 'Lifestyle changes' will therefore support the aim of this Quality Statement to improve awareness of how the risks of developing dementia can be reduced. **We recommend that the following sentence should be added to the end of the paragraph:** ***"Health and social care practitioners should also be mindful of how hearing aids can improve hearing function and quality of life, and how this could delay the progress of dementia or improve its management [see NICE's Hearing Loss in Adults: Assessment and Management Guideline]"***
38	Action on Hearing Loss	Statement 1 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** NHS England's *Accessible Information Standard*[2] provides clear guidance for NHS and adult social care services on meeting the communication and information needs of people with disabilities and sensory loss. It is therefore highly relevant for the successful implementation of Quality Statement 1.

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[3] 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.

[4] NHS England et al. Forthcoming 2019. *Guidance for Local Authorities and NHS commissioners on assessing the hearing needs of local populations*.

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			We recommend that the following sentence should be added to the end of the paragraph: ***"When providing information to people with disabilities and sensory loss, practitioners should refer to the recommendations set out in NHS England's Accessible Information Standard"***
39	ADMP UK	Statement 1	Quality statement One: Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. We welcome prevention strategies in informing adults of the risk of developing dementia and the need for lifestyle changes. Amongst the options available to improve the wellbeing of adults and prevent the onset of dementia, engagement in physical and creative activities such as dancing need to be clearly outlined. Examples of evidence missing: Guzmán-García, A. H. J. C., Hughes, J. C., James, I. A., & Rochester, L. (2013). Dancing as a psychosocial intervention in care homes: a systematic review of the literature. International journal of geriatric psychiatry, 28(9), 914-924. Kiepe, M. S., Stöckigt, B., & Keil, T. (2012). Effects of dance therapy and ballroom dances on physical and mental illnesses: A systematic review. The Arts in Psychotherapy, 39(5), 404-411. Karkou, V., Oliver, S., & Lycouris, S. (Eds.). (2017). The Oxford handbook of dance and wellbeing. New York: Oxford University Press. Hui, E., Chui, B. T. K., & Woo, J. (2009). Effects of dance on physical and psychological well-being in older persons. Archives of gerontology and geriatrics, 49(1), e45-e50. Merom, D., Cumming, R., Mathieu, E., Anstey, K. J., Rissel, C., Simpson, J. M., ... & Lord, S. R. (2013). Can social dancing prevent falls in older adults? a protocol of the Dance, Aging, Cognition, Economics (DAnCE) fall prevention randomised controlled trial. BMC public health, 13(1), 477. Merom, D., Grunseit, A., Eramudugolla, R., Jefferis, B., Mcneill, J., & Anstey, K. J. (2016). Cognitive benefits of social dancing and walking in old age: the dancing mind randomized controlled trial. Frontiers in aging neuroscience, 8, 26.
40	Alzheimer's Research UK	Statement 1	We welcome the addition of the prevention and health promotion interventions statement, as we recognise the importance of increasing public awareness of the potential to reduce the risk of developing dementia. It is good that there is recognition of the need to get the tone of prevention messaging right so it is does not blame or promote stigma. In terms of data sources to inform outcomes, the Alzheimer's Research UK Dementia Attitudes Monitor (2019) will be updated on a regular basis and includes specific questions on public awareness and understanding of the link between dementia and lifestyle. The monitor could be utilised to assess impact of interventions at a national level.

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			In terms of data sources to inform uptake of healthy lifestyle behaviour, it may be possible to capture any messaging or interventions offered as part of an NHS Health Checks. Whether the data can be captured will depend on the service specification and IT system utilised, which will be locally variable. We would recommend that the Quality Standards specify that NHS Health Checks should routinely capture relevant data.
41	Alzheimer's Society	Statement 1	**We support QS1**, Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. We believe this is a priority for improvement. This is important because more than one third of cases of dementia are potentially avoidable through modifiable lifestyle factors, with current evidence suggesting mid-life changes can have most impact on reducing risk (Lancet Commission, 2017), yet only 34% of British adults are aware that is possible to reduce their risk of developing dementia (Ipsos Mori poll for ARUK, 2018).
42	Association for Family Therapy and Systemic Practice	Statement 1	"Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes". For clarity, it might be worth specifying adults who have not developed signs of dementia. Lifestyle interventions, such as taking up of extending physical activity could be engaged with by people with dementia at different stages and an overemphasis on this could be detrimental to engagement. In addition, the phrasing of the statement might suggest to some people that dementia is preventable by these measures; phrasing such as "lifestyle interventions can delay or reduce risk of developing dementia" is more in keeping with the NG16 guideline.
43	The British Dietetic Association	Statement 1	Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. It is important to note that some dementia risk factors are non-modifiable for examples age and genetics. Scientific Advisory Committee on Nutrition (2018) SACN Statement on Diet, Cognitive Impairment and Dementias www.gov.uk/government/publications/sacn-statement-on-diet-cognitive-impairment-and-dementia suggests the most convincing evidence is based on the Mediterranean style diet. To support quality improvement in this section it is important to understand the need for a balance between healthy living (a nutritionally balanced diet and providing the opportunity for those living with dementia to enjoy the food and drink of their choice (preference or cultural etc.) but also recognising that this groups nutritional needs may be different from general population/healthy eating/prevention messages particularly as the condition progresses. Are health trainers competent in this area of dementia prevention?
44	The College of Optometrists	Statement 1	The training and support provided to service providers, health and public health practitioners, commissioners, and adults having NHS Health Checks would be critical to the success of this statement. This training and support should include information regarding eye health and care.

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			Recent studies suggest that there are genetic links between the risk of developing dementia and the risk of developing cataract. Evidence also suggests that cataract surgery can improve quality of life, and may even slow cognitive decline in people with dementia. We recommend including the need to have regular sight tests to the information provided to adults about the risk factors for dementia.
45	Dementia Clinical Network NHSE; London	Statement 1	Prevention was out of scope of the NICE Guidance June 2018, so why is prevention included within the quality standards?
46	Dementia Clinical Network NHSE; London	Statement 1	If this statement is to be included: Need to define what is meant by ‘behaviour change interventions & programmes’.
47	Dementia Clinical Network NHSE; London	Statement 1	If this statement is to be included: Dementia risk reduction messaging is being rolled out as part of the NHS heath check. This could be monitored by the number of people attending a Health Check. The learning from this could be rolled out with other behaviour change interventions pilot project
48	Dementia Clinical Network NHSE; London	Statement 1	If this statement is to be included: We would recommend highlighting people with with Mild Cognitive Impairment to ensure that they receive appropriate risk reducing information; Non Dementia Pathways
49	Dementia UK	Statement 1	Q1 & Q3-Prevention or delay in development of dementia can be managed by working on modifiable risk factors (lifestyle issues) for some forms of dementia. This should be a part of NHS Health Checks as detailed but it should be noted that the rates of diabetes, obesity and heart disease still remain stubbornly high despite a prevention focus over the past few years. The messages may need to be altered to encourage the population to listen, to understand it means them and have more information about possible consequences that people can relate to. They should also be delivered in a more structured way within the schools, workplace, local community as well as primary care. More resources needs to be put into prevention and delay which could release resources in the future. As a lot of the advice on diet can be contradictory there needs to be funds spent on research so one consistent message can be given as too many mixed messages leads to confusion and people deciding not to change their lifestyle. Q2- Quality measures appear to be appropriate.
50	Neurology Academy Limited	Statement 1	Does this draft quality standard accurately reflect the key areas for quality improvement? No only partially as some of the wording within the statements is too all encompassing e.g. statement 1: I would suggest the word MAY be reduced here. While evidence for risk is growing, the evidence for risk factor MODIFICATION is still not quite there; also, can we generalise this to ALL dementia? Where is the evidence that this has any impact on PDD/DLB…, so it should be, ‘risk of developing some types of dementia’.
51	NHS England	Statement 1	We acknowledge the importance of raising awareness that lifestyle related risk factors such as diet, smoking, alcohol, activity etc which are as important for preventing dementia as they are for preventing cancer and heart disease. However, AHPs do not systematically collect information about this in relation to dementia or any other conditions. Collation of data would potentially cause significant additional demand for the system (SC)

ID	Stakeholder	Section	Comments
52	NHS England	Statement 1	For the quality measures set out in each of the statements of this Quality Standard: the emphasis throughout the Standard is on local implementation and data collection. Consequently, consultation with local clinical and commissioning leads at network / CCG level is imperative. (CF)
53	NHS England	Statement 1	To measure this statement accurately would require a defined list of the specific change interventions (e.g. smoking cessation, weight loss management) and what the behaviour change programmes are (e.g. NHS Health Check). How 'access to the interventions or programmes' is recorded would also need to be confirmed. (CF)
54	NHS England	Statement 1	Dementia prevention does not seem to have been a priority so far but now this is to be addressed and this standard reflects the key areas for quality improvement. Data collection for the interventions that are documented should be relatively straightforward to collect for example in the NHS health checks since they are already in place and data available. The other interventions may be more difficult unless data collection is considered at the outset. The suggested increasing public awareness will be helpful to increase the profile and can be run alongside or part of similar previous campaigns that identify similar risks. Currently this is not widely adopted but relatively easily remedied with minimal additional cost or increased workforce provision. I would presume PHE would lead any campaign. There have been previous initiatives and some have continued their practice of alerts to screen patients with chronic disease, Parkinson's and learning disability but there are currently no specific incentives. The health check can include discussion of risks as part of other health advice. (PS)
55	Parkinson's UK	Statement 1	While the evidence for risk is growing, the evidence for risk factor modification is less conclusive. There is also less evidence to support the impact on risk for people with Parkinson's dementia and dementia with Lewy bodies. We recommend changing the wording of the statement to reflect this to – 'Adults accessing behaviour change interventions and programmes are informed that the risk of developing some types of dementia may be reduced by making lifestyle changes.'
56	PJ Care	Statement 1	Whilst those who seek help may benefit from advice, it will not aid those who are not actively seeking help for any known health problem. Perhaps a national 'Dementia Risk' campaign and screening that is triggered in the same way as breast, cervical, prostate etc., screening would assist. This would solidify the need to reduce risk factors in the public psyche as currently I'm not sure that members of the public associate lifestyle factors with dementia. It would need media coverage to gain a hold in my view.
57	Public Health England	Statement 1	There is an opportunity to strengthen the standard around risk reduction, as the evidence has built up since the 2015 National Institute for Health and Care Excellence (NICE) Guidelines on risk reduction were produced. The most significant evidence since 2015 has been the Lancet Commission on Dementia, which came out in 2017. It highlights a life course model that could reduce risk by 35%. This is a different approach to previous evidence and highlights the role of hearing loss in midlife as a new area for consideration. This can be viewed at: https://www.thelancet.com/commissions/dementia2017.

ID	Stakeholder	Section	Comments
58	Roche Products Ltd & Roche Diagnostics Ltd	Statement 1 Rationale	The early signs of dementia are not well known by the majority of the public and often go undetected. More consideration needs to be given to the whole pathway as early detection in those who do not have access to behaviour change interventions and programmes should be considered. To best support early diagnosis, the broader public should be targeted, for example, a public health campaign may be necessary to raise awareness of brain health and dementia in a similar way to the FAST stroke campaign. Earlier diagnosis will require an increase in public and health care professional understanding that Alzheimer's starts long before symptoms are present. 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. Additionally, 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.
59	Roche Products Ltd & Roche Diagnostics Ltd	Statement 1 Quality measures b)	As specified in these standards, training for practitioners is important when advising and supporting people to reduce the risk of developing dementia. It also is necessary to include a broad representation of practitioners within this category as it is important for GPs, primary care nurses and other critical stakeholders to have skills in detecting early signs of dementia. This is important as there are many touch points in the system where patients with early symptoms of dementia may present. Practitioners play a crucial role in supporting patients early and providing adequate education about the benefit of earlier detection.
60	Royal College of General Practitioners	Statement 1	The standard should specifically refer health promotion for people with long term conditions that increase risk of dementia (e.g. Diabetes, stroke, hypertension, Cardiovascular disease). The following could be documented in their annual QoF. Advice being given about importance of good management of their long term condition and lifestyle measures Engagement with lifestyle / prevention measures The denominator could be the people with long term conditions who are at risk of dementia. Measurement should not just be uptake but also how many people continue e.g. to next annual review and achieve outcomes e.g. weight loss, better control of blood pressure or diabetes, lower alcohol intake, smoking cessation. Would also be helpful to link with outcomes associated with Social Prescribing initiatives
61	Royal College of General Practitioners	Statement 1	Health and Public Health Practitioners: need to measure that people have attended appropriate training
62	Royal College of General Practitioners	Statement 1	NHS Health Check: ensure that check includes an item of Dementia risk, supplies information about how to reduce this risk and who to contact it about addressing this
63	Royal College of General Practitioners	Statement 1	Equality and Diversity: needs to be appropriate for auditory, visual and learning disability (see National Guidance on Communication Standards).
64	Royal College of Nursing	Statement 1	Statement 1. Removal of quality standard from 2010 - People with dementia receive care from staff appropriately trained in dementia

ID	Stakeholder	Section	Comments
			This is an area of concern, the current vacancy rate in many areas means training and education are subject to much longer time periods between refreshers (level 2 dementia training are now offered every five years in some trusts). We would ask that NICE consider the evidence around training before removing this quality standard.
65	Royal College of Nursing	Statement 1 (measure)	There are several behaviour change interventions that could incorporate the aims of this statement. For example, stop smoking programmes, weight loss programmes, etc. As these interventions already exist, we do not feel that it would be difficult to collect data and measure outcomes for this quality standard.
66	Royal College of Psychiatrists	Statement 1	This is a challenging and vague indicator to assess and measure. It will also be hard to implement as it's so vague "he risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes". This needs to be more specific and evidenced. It's not clear that this standard accurately reflects the Key priorities for quality improvement in Dementia and it will be very hard to measure any impact, effectiveness or input.
67	Royal College of Speech and Language Therapists	Statement 1	RCSLT recommends adding health literacy considerations to all health messaging
68	The Society & College of Radiographers	Statement 1 P7	As per PHE initiative, Making Every Contact Count, the Society and College of Radiographers believes this quality statement should include the wide variety of professionals and people that offer advice to patients and service users. Notably Allied Health Professionals (AHPs) are the third largest group of staff in the NHS with a huge number of interactions with staff and service users each day. It must also be recognised that local authority, care, housing, emergency services staff etc. all have a role and currently offer lifestyle advice. There should be recognition of the need for cross-sector collaboration involving everyone with patient / service user/client contact.
69	Action on Hearing Loss	Statement 2	**The references to sensory health in this section are welcomed.** As highlighted in Comment 2, research shows that hearing loss can be misdiagnosed as dementia or make symptoms of dementia appear worse. An increasing body of evidence also shows that hearing loss can increase the risk of dementia or accelerate cognitive decline. Ensuring these issues are properly considered will therefore support the aims of this Quality Statement to ensure adults with suspected dementia receive a timely and accurate diagnosis.
70	Action on Hearing Loss	Statement 2 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement **We recommend that the following sentence should be added to the end of the paragraph:**

ID	Stakeholder	Section	Comments
			"Adults with physical disabilities and sensory loss should receive accessible communication and information to participate fully in discussions about dementia treatment and care [see NHS England's Accessible Information Standard]"
71	Alzheimer's Research UK	Statement 2	We recognise that diagnosis of dementia can take place in several clinical settings. For uncomplicated and straightforward cases where there are no unusual signs or symptoms there is justification for dementia to be diagnosed in primary care or other non-specialist settings. This then frees up capacity at specialist memory clinics. However, the arrival of new treatments for dementia are likely to heighten the need for more rapid and accurate dementia subtype diagnosis. The recent NICE clinical guideline (NG97) stated that CSF analysis and PET scans would help to diagnose a dementia subtype and knowing more about the dementia subtype would change management. The option to access these diagnostic approaches, where appropriate, should be supported within the quality standards.
72	Alzheimer's Society	Statement 2	**We recognise that it is important that people with suspected dementia are referred to a specialist for diagnosis, particularly as this can be important for a diagnosing the subtype, which should be key to informing treatment and care. However the consultation documents do not seem to present evidence that suggests this is not already happening in practice.** If this is already happening in practice, then an alternative QS would have greater impact in driving improvement, and resulting in higher quality of care for people with dementia. It would also be useful for this QS to consider that in some cases diagnosis in primary care may be appropriate. For example, in a case where the diagnosis is clear, and a GP has sufficient training and knowledge to diagnose, and where there may be a long wait for the local memory clinic service, it may be appropriate to diagnose in primary care.
73	Berkshire Healthcare NHS Foundation Trust	Statement 2	Statement 2 does not take into account that many GP surgeries do not have access to GPs with specialist expertise in assessing and diagnosing dementia so the "default" would be secondary care memory clinics but this is not always appropriate for patients new to the area e.g. those who have moved into a nursing home with advanced dementia and do not need specialist services to "confirm" the diagnosis. Many GPs are well placed to confirm the diagnosis in this scenario but would not identify as being GPs with specialist expertise in assessing and diagnosing dementia. Berkshire Healthcare Memory Clinics have an established arrangement with GPs (admittedly with variable success) where GPs have been given advice on how to diagnose dementia in such cases. These GPs may not identify as having specialist knowledge.
74	The British Psychological Society	Statement 2 (Definitions of terms)	We recognise that a list of health professionals who may contribute to an accurate and timely diagnosis is not intended to be exhaustive but we believe that this may be a missed opportunity to emphasise the importance of thorough neuropsychological assessments for some people experiencing, or reporting, cognitive changes. The

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			Memory Services National Accreditation Programme (MSNAP) states as a type 1 standard that 'the service has access to in-depth assessment of occupational functioning and neuropsychological assessment as required' (standard 3.5.13). Similarly, the BPS's Faculty of Psychology of Older People's guidance on 'Cognitive assessment of people who may be developing dementia' (Collerton & Damone, 2014) highlights that when basic cognitive assessments are inconclusive people will need an advanced, hypothesis-driven neuropsychological assessment. Such in-depth assessments will use reliable estimates of life long levels of intellectual ability, and a range of up to date assessments of memory, attention, executive function, perception, and language in order to clarify clinical uncertainty. This guidance also clearly articulates the level of expertise required to administer a range of neuropsychological assessments (Collerton & Damone, 2014; page36).
75	The British Psychological Society	Statement 2 (Definitions of terms)	The Standard states that, "The key issue is to ensure that dementia specialists are involved, both for advice and diagnosis and to ensure appropriate access to support and treatment after diagnosis". We have concerns that this standard does not fully recognise the variability in service delivery models nationally, not all of which ensure access to support after a diagnosis. There are serious ethical concerns with providing a diagnosis but no follow up support. It is recognised that good quality services should be holistic and person centred in their approach to ongoing support (Burns & Buckman, 2013). The introduction of this standard could, with the right emphasis, not only ensure that diagnosis is done well but also that follow on support services are adequate and effective. We would be welcome this.
76	Cognitive Disorders Group of the Association of British Neurologists	Statement 2	In the guidance Cognitive Neurology/disorder clinics should be included alongside the other specialist clinics
77	The College of Optometrists	Statement 2	It is essential that once someone is diagnosed with dementia they continue to regularly see their optometrist for eye examinations. This allows the optometrist to manage any visual impairment, something that the government-funded 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*) led by the College of Optometrists has shown is more common in people with dementia. It is important that the patient and their general health, including vision, is not forgotten. This is especially important in dementias that initially involve predominantly visual symptoms, such as Posterior Cortical Atrophy. The successful management of visual impairment can also improve the quality of life of people with dementia. Dementia and sight loss develop independently, but both dementia and the main causes of sight loss are age-related. The ageing population trends 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. 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.

ID	Stakeholder	Section	Comments
			Detecting and correcting impaired vision and refractive error can improve quality of life and reduce related co-morbidities among the dementia population. 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. The College of Optometrists would recommend commissioners to include a full visual assessment in their dementia care pathways.
78	Dementia Clinical Network NHSE; London	Statement 2	Need to consider for people with advanced dementia for example in a care home; it may not be appropriate for patients to attend a specialist dementia diagnostic unit as a diagnosis can be made by a GP in primary care, for example, using the DiADeM Tool . We have completed a GP led care home diagnosis project. Need to also consider that some people do not want to attend a memory service, however are happy to attend a GP appointment. In these cases GPs could gain specialist advice from the memory assessment service.
79	Dementia UK	Statement 2	Q1 Where is the involvement of family in this Statement? Frequently people who are living with the symptoms of dementia are not able to give an accurate history of the symptoms and how it affects their everyday living due to a combination of denial, fear and lack of awareness. This can lead to a lack of understanding about how dementia really affects the person and their family and in some cases to an inaccurate diagnosis. Families also need to be aware of the referral and diagnosis pathway. Q2 The measure here could include time from referral to receiving an assessment and also time to diagnosis. Q3 The resources for specialist assessment vary from county to county and hence the time to be seen, assessed and diagnosed. This is particularly problematic for people living with young onset dementia who may need an out of county referral to a specialist dementia diagnostic service where the time waiting for an appointment, assessment and diagnosis may be prolonged.
80	The Lewy Body Society	Statement 2	Comments on Standard 2 – diagnosis We know that Lewy body dementia is under-diagnosed. Currently, only 6 per cent of people identified as having dementia are diagnosed with LBD, yet autopsies find that 10-15 percent of dementia patients have LBD pathology.1 Some clinical studies have found 15-20 per cent of dementia patients had clinical symptoms consistent with LBD. Other evidence has shown that although the clinical picture is consistent with LBD the autopsy data shows a mixed pathology e.g LBD and Alzheimer's disease. Although there is currently no simple test for LBD, careful clinical evaluation of the patient and their symptoms can form the basis of a reasonably confident diagnosis. Access to a timely and accurate diagnosis is a constant concern for the families who contact us. Without a correct diagnosis, patients and families do not get the right information and support about how to live with the condition. This can be devastating, especially when an incorrect diagnosis causes additional anxiety and a failure to manage particular symptoms of LBD.

ID	Stakeholder	Section	Comments
			As a carer (for her husband of 48 years, who now has a LBD diagnosis) recently told us: “It was Alzheimer’s disease for 4yrs, until I asked for another her opinion. It's been a battle getting a proper diagnosis.” Another told us: “My husband was eventually diagnosed with DLB 2 years after being told, following an MRI scan, that he didn't have Parkinson's Disease. And that was that. No follow up or suggested further diagnostic services. Given the close links between Parkinson's and DLB this should have been a logical first step. We missed out on therapies and treatments that would have improved the quality of both our lives. His diagnosis came about because I began keeping a blog and made a self diagnosis that was supported by the NHS consultant at last. I knew nothing about DLB then - hadn't heard of it but 1 https://www.alzforum.org/news/conference-coverage/dementia-lewy-bodies-research-ready-clinical-trials now am gaining knowledge and understanding through experience and research. A further glitch we have had is that, in this area, (Wirral), Neurological services and movement disorders are dealt with by different and quite seperate NHS Trusts. One is fairly on the ball but the other is over stretched and waiting times are appalling.” If dementia patients are given a wrong diagnosis, they may not get the correct treatment, which can be dangerous, or even life threatening. Delusions and hallucinations are often present with LBD. If patients have not been recognised as having LBD and are given antipsychotics (not recommended) then they can suffer a severe reaction to this class of drugs. In addition, people with DLB cannot tolerate the anticholinergics often given to the elderly for urinary incontinence. In a further example, sleep problems (REM sleep disorder) affect almost all LBD patients. There is a safe medicine for treating REM sleep disorder that can make a big difference to the quality of life of people with LBD and their carers. We therefore support the current guidance that anyone with suspected Lewy body dementia receives a referral to a specialist service for appropriate investigations and diagnosis. We do not consider that sufficient funding is currently available for access to specialist dementia services and would like to see these services given a greater priority. The Lewy Body Society would support a target for the minimum time period between referral and diagnosis for dementia, as is the case with other conditions, to encourage transparency and accountability.
81	NHS England	Statement 2	The diagnosis of dementia via a specialist service is already common practice and referral from primary care embedded but can still be improved. This standard reflects the proposed quality improvement. The data collection is already in place and easily accessed. The exclusion of reversible causes is reasonable for acute causes and depression with increased awareness but sensory impairment is not currently routinely assessed before referral from primary care, anticholinergic burden is becoming more recognisable as a cause but it’s impact has not been highlighted. These 2 areas could improve with this quality improvement. There are some areas that have looked at anticholinergic burden of their own volition, screening with a scoring system and reviewing at risk patients, but not locally supported by medicines management teams.

ID	Stakeholder	Section	Comments
			The time to assessment and time to diagnosis varies across the country and it may be worth considering standards to reduce these to acceptable timescales (a year is far too long). The current wait in my area is 3-6 months from GP to see a nurse for initial assessment, then a diagnostic assessment by a consultant 3 months later (who can initiate treatment straight away). Interestingly locally they do not routinely request brain imaging due to capacity issues in radiology. The vascular dementia patients are discharged back to primary care and Alzheimer's kept under review for another 6-12 months. Workforce is in place and the briefing notes indicate that waits have not increased overall so there is capacity but backlog needs to be addressed. The increased numbers referred will not be a significant increase on the numbers already being referred so there should not be workforce implications unless the assessment process changes. (PS)
82	NHS England	Statement 2	It is not clear how this statement would support the stated outcome of 'self-reported or carer reported quality of life for adults with dementia' (which relates to the living and supporting well aspects of the dementia well pathway). The Statement focuses on a specific aspect of diagnostic process (which supports diagnosing well in the dementia well pathway). The quality measures might be hard to establish with any level of accurately. 'Referral to Memory Assessment Services' data could be obtained through the Mental Health Services Data Set, but this only accounts for secondary care. Primary care needs to be considered. The previously piloted indicator NM65 could potentially be used. However, the definitions would need to be assessed. For measurement of current or total performance, the dates for those who have a record of attendance at a memory assessment service up to 12 months before entering onto the dementia register would need to be confirmed. The currently used definition 'Memory Assessment Service' would need to be changed to 'specialist dementia diagnostic service' as in the consultation document. (CF)
83	Roche Products Ltd & Roche Diagnostics Ltd	Statement 2	The diagnosis standards include specification of referral to a specialist dementia diagnostic service. It is important that early diagnosis and screening is included specifically within the prodromal phase of the disease. It is valuable to consider educating specifically around the prodromal phase and the potential benefits of early referral and potential treatment before clinical symptoms present. Consideration for supporting the system to enable earlier detection would be required. There is an opportunity here to highlight the automated amyloid ß and tau biomarker protein assay. These rapid universally available cerebrospinal fluid (CSF) assays are available for routine use as an alternative or addition to PET scan and would make access to early diagnosis easier. Practicalities of increased demand on the healthcare system for CSF sample taking for biomarker

ID	Stakeholder	Section	Comments
			screening for the benefit of early diagnosis or progression should be discussed both in respect of the current climate and should a disease modifying therapy (DMT) become available.[1-3]
84	Roche Products Ltd & Roche Diagnostics Ltd	Statement 2	Variation exists in performance of the ⅔ diagnosis target across CCGs. Some areas in England fall short of the 2/3rd diagnosis rates set e.g. West Somerset at 45.1% or City of London 48.3%.[1] Each CCG area in England should be achieving the dementia diagnosis rate target by 2020. There should be a focus on consistent delivery of this goal so that the health system is be better placed to give people with dementia the right treatment at the right time. This should include assessing if any clinical trials could be appropriate. [4]
85	Royal College of General Practitioners	Statement 2 P9 and 11	Referral to Specialist Diagnostic Service: circa 80% of people are referred to a Memory Assessment service. Other services diagnosing dementia are; Primary Care led service for a dementia diagnosis in Primary Care by GPs who have undergone specific training, learning disability services, Neurology services, geriatricians In the latest Dementia Guideline the recommendation is not just for a dementia diagnosis but for documentation of subtype
86	Royal College of General Practitioners	Statement 2 P9	In the latest Dementia Guideline the recommendation is not just for a dementia diagnosis but for documentation of subtype
87	Royal College of General Practitioners	Statement 2 P10	Outcome: Unclear why QoL is the outcome here as does not directly relate to statement. Need to document subtype of dementia (see previous comment) and access to treatment (pharmacological / non-pharmacological, support (including receiving appropriate benefits) and advance care planning as outcome as these areas are what give QoL Also for Carer outcomes: record name on Carer's register and Carer has a Health Check
88	Royal College of General Practitioners	Statement 2 P10	Health Care Professionals: Investigate potential reversible causes of cognitive decline and measure outcomes: can measure number of cases of depression identified and treated; can measure anticholinergic burden of repeat medications and replacement with medications with lower cholinergic burden
89	Royal College of Nursing	Statement 2 (statement)	Diagnosis - Referred to specialist dementia diagnostic service: This standard could be achievable, however, there will need to be further workforce development to ensure all people with dementia receive this service. Where this type of service exists, it would not be difficult to obtain measurement data. For example, Dorset seems a good example where a 'dementia pathway' exists that people can follow to obtain a dementia diagnosis from a specialist service.
90	Royal College of Psychiatrists	Statement 2	This is an important quality standard but there are resource implications to allow for effective implementation which need to be proactively encouraged and highlighted.
91	Royal College of Speech and Language Therapists	Statement 2 Page 10	We recommend that you add speech and language therapists to the list of healthcare professionals. SLTs have a key role in helping inform differential diagnosis of people who present with a prominent language disorder; for example, frontotemporal dementia, primary progressive aphasia and language presentation of Alzheimer's disease.

ID	Stakeholder	Section	Comments
92	Royal College of Speech and Language Therapists	Statement 2 Page 11	Please add that SLTs work in memory clinics to support people with early stages of dementia
93	Royal College of Speech and Language Therapists	Statement 2 Page 11	In the equality and diversity section In considering modified ways of communicating please add consideration of people's understanding and communication.
94	Tide	Statement 2	Is anything missing or could it be improved? • We have had cases where people have been referred to a specialist dementia diagnostic service and found not to have dementia. In these cases we are hearing that although the traits and issues that led to the referral still exist they are not offered an alternative route to follow. E.g. a GP nurse informed one family member; "Your mother doesn't have Dementia; it's just old age". What she (the nurse) may have meant is unclear and the family simply took this statement at face value. • Is there a time limit on the referral to a specialist? I pointed out to the gp that my dad had signs of dementia and they just said it was his age for a long time until they took it seriously eventually • It does give a time limit within which assessment should begin and how long it takes to receive a diagnosis. The diagnosis should be clearly explained, its implications, possible progress etc where known. • Should include the following: people once diagnosed should have access to others with a diagnosis to enable peer support Also: carers should have access to assistance in navigating health and social care systems • There are some real gaps ie follow up to diagnosis is patchy and the experience of people living with dementia and opportunity to remain well with meaningful activity is seldom there...I can elaborate! • GP's identifying people with suspected dementia is not as effective as it could be. Some have specialist dementia support workers attached to their surgeries but this is still hit and miss.
95	Action on Hearing Loss	Statement 3 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement. **We recommend that the following should be added to last sentence in the first paragraph:**

ID	Stakeholder	Section	Comments
			"Adjustments should be made to ensure that all people with dementia can work with their named care co-ordinator to plan their care, with access to an advocate if needed, ***in line with NHS England's Accessible Information Standard."***
96	Alzheimer's Research UK	Statement 3	We support the role of named care coordinators in terms of supporting people with dementia and their carers, however the significance and impact of dementia as one of several multimorbidities, and the associated challenge of medication optimisation, is not sufficiently recognised in the proposed Quality Standards. As we stated in our response to the topic engagement consultation the quality standards could build on the existing NICE guidance on multi-morbidities (NG56) to consider how high dementia care may benefit other conditions and vice versa including the challenges of medication optimisation in people with cognitive impairment (which may affect adherence to cognitive enhancers). Furthermore, the responsibility to consider dementia within the context of other health conditions should not just be the responsibility of the named care co-ordinator.
97	Alzheimer's Society	Statement 3	**We support QS3,** Adults with dementia have a named care coordinator. We believe this is a priority for improvement. This is important to help maintain good health and quality of life, and avoid or delay crises. This could be delivered for example by referral into Alzheimer's Society's Dementia Connect service.
98	Berkshire Healthcare NHS Foundation Trust	Statement 3	This ideally sounds good, but is totally impractical and where will the funding come from to resource it? There is no way this will happen. There might be someone to provide signposting and care coordination will only be available for complex cases.
99	Berkshire Healthcare NHS Foundation Trust	Statement 3	The term Care Coordinator suggests CPA, yet many people with dementia will not be open to mental health services. Suggest Care Navigator as an alternative descriptor, but unless this is someone already involved in a person's care, resourcing this will be challenging. Some people with dementia may only be in regular contact with their GP or District Nurse. Would need a significant increase in the number of Dementia Care Advisors if they were to fulfil the role described in this standard.
100	The British Psychological Society	Statement 3 (Outcomes)	Ensuring that adults with dementia have a named care coordinator is a sensible plan and could improve quality of care. The current outcomes suggested are self-reported or carer-reported quality of life. In order to be confident that the outcomes are measuring the construct being evaluated, quality of life needs to be defined more clearly, and appropriate measures chosen carefully. We recognise that there are considerable difficulties with the existing measures of quality of life in dementia. International work has identified quality indicators that are appropriate to monitor psychosocial care in dementia (Vasse et al., 2012). More recently attempts are being made to develop quality of life outcome measures that are co-designed by those completing them. For carers this has resulted in SIDECAR (www.decideproject.co.uk) and for people living with dementia work is underway developing a tool as an offshoot of the IDEAL project. There also exists considerable complexity with accepting proxy measures of quality of life in place of self-report in relation to dementia. It is well documented that proxy reporters tend to report quality of life as being lower in

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			relation to the person living with dementia's self report (Rand & Cailes, 2015) and that this discrepancy increases as dementia progresses (Novella et al., 2001). We would therefore recommend caution in accepting proxy measures as an alternative to self-report.
101	Carers Trust	Statement 3	We welcome the inclusion of "adults with dementia having access to a care coordinator". We believe this will also help unpaid carers of people with dementia. Carers Trust's Retirement on Hold [https://professionals.carers.org/retirement-on-hold] report, about the needs of older carers, set out the need for a care coordinator, so we are pleased to see this principle applied to people with dementia. We believe having a named care coordinator will help carers and people with dementia better navigate the health and social care system.
102	Carers Trust	Statement 3 (Rationale)	Carers Trust welcome NICE's recognition that having a single named care coordinator will help the person with dementia. The role of the care coordinator as set out in the rationale should relieve some of the challenges that carers of people with dementia tell us they face. However, the recognition needs to extend to include support for carers too, and that this named care coordinator needs to work with the unpaid carer as an equal partner in care, for as long as the unpaid carer wants to continue in their caring role. Carers provide the vast majority of care and will be able to share information that is important to the care of the person with dementia. It's important that the care coordinator listens to the unpaid carer and involves them in the care planning of the person with dementia. By involving carers in care planning, and sharing information with carers, health and social care service will improve the care provided to the person with dementia. It is also important that the care coordinator is able to make arrangements for respite for carers, to allow them to take a break from caring.
103	Carers Trust	Statement 3 (Definitions of terms used in this quality statement)	The role of the named care coordinator should be strengthened to ensure that carers are identified by them and involved in decision making. For example, as part of the actions that the named care coordinator will be taking, the guidelines should set out that the care coordinator will: • "involve the person's family members or carers (as appropriate) in support and decision-making **as equal partners in care"** As a professional who will have regular interaction with the person with dementia, the care coordinator should also be expected to identify unpaid carers.

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			Carers Trust believe that one of the activities that the care coordinator should be expected to undertake should be: "**identify the carer(s) of the person with dementia.**" By identifying carers, the care coordinator should then trigger the appropriate assessment, and support for the carer. This would also help reinforce Quality Statement 7 regarding support for carers.
104	Carers Trust	Statement 3 (Quality Measures)	As the named care coordinator's role should also include support for carers, this should lead to the lives and support for carers improving as a result. The quality measure for this statement should reflect this and be added to the Quality Standards. The outcome would read: "Carer reported quality of life of carers of people with dementia" The data source would read: "local data collection, for a survey of carers of people with dementia".
105	The College of Optometrists	Statement 3	See our comment 1 above. The training and support provided to named care coordinator would be critical to the success of this statement and we recommend to ensure the named care coordinator is fully aware of the patient's need to have regular sight test and to raise awareness on how good vision will help patients with dementia live better, and possibly slow their decline. It is important to reassure carers and patients that people with dementia are generally able to undertake all the key elements of an eye examination, and to advise those with dementia, and their carers, of their eligibility for NHS funded sight tests to be performed either at home or in a community practice.
106	The College of Optometrists	Statement 3 (rationale)	See our comment 2 above. We suggest amending the sentence "people with dementia often have other long-term conditions, such as cardiovascular disease and diabetes" by adding "vision impairment". The sentence would read as, "people with dementia often have other long-term conditions, such as cardiovascular disease, **vision impairment** and diabetes". The PrOVIDe study finds that the prevalence of presenting visual impairment was 32.5% and 16.3% for visual acuity worse than 6/12 and 6/18 respectively. This is generally higher than in comparable data from prevalence studies on the overall population (after adjustment for age and gender).
107	Dementia Clinical Network NHSE; London	Statement 3	Can we consider the term of care coordinator, as many services use the term Care Navigator or Dementia Navigator. The term care coordinator in mental health services has specific meaning in relation to implementation of care programme approach
108	Dementia Clinical Network NHSE; London	Statement 3	One example of a service that has implemented Dementia Navigators is the Islington Memory Service where all patients with Dementia remain under the service and are followed up either by a clinician if they require medication reviews or by Dementia Navigators for further sign posting and support.

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109	Dementia Clinical Network NHSE; London	Statement 3	Consider adding to this statement '..and that everyone living with dementia has a care plan'. This is already measured through NHS digital from primary care data
110	Dementia Clinical Network NHSE; London	Statement 3	This could be measured locally but might be difficult measuring as the care coordinator may sit within different services (even within the same CCG) e.g. Memory Services, Voluntary sector and primary care.
111	Dementia Clinical Network NHSE; London	Statement 3	The London Memory Audit (2016) which looked at 590 referrals across 10 services in 2016, found that overall 66% of people were referred to a Dementia Advisor. This varied between services from 49-94%.
112	Dementia UK	Statement 3	Q1 This should read "Adults with dementia **and their family** have a named care coordinator". The family need this as much as the person with dementia. Having this named care coordinator can help families (including the person with dementia) live as well as possible with the diagnosis, receive support when needed and so prevent crises. The named care coordinator needs to be trained in dementia and be someone the family can approach directly. It needs to be clearly explained to people diagnosed with dementia and their family what the scope of the role is. Q2 Agreed Q3 There will need to be many more named care coordinators to ensure this works effectively. They should be from a variety of backgrounds e.g. Tier 1 workers giving advice and signposting - e.g. navigators, advisors. Tier 2 workers giving more bespoke input- e.g. support workers, groups, befrienders. Tier 3 workers dealing with complex cases- e.g. specialist dementia nurses (Admiral Nurses).
113	NHS England	Statement 3	The named care co-ordinator is a pivotal role but who this is, or should be, and the prerequisite skills required has not been set out. The concept does not seem to have been adopted from my local experience and my impression is that these have not been considered a priority. The default position seems to be the GP. The local arrangement in my area is shared care with the patient being discharged to the GP and reviewed 6 monthly (alternate nurse/GP) and referral back if there are difficulties. I would argue that the GP should not be the care co-ordinator. There is a historical element to those patients who have had dementia for several years and are now end stage. These have often not had contact with dementia services initially and are exclusively under the care of GP. Data collection should be straightforward as set out by the statement but maybe a survey of health care professionals involved in the care of the patient and their experience of working with the co-ordinator could be ascertained. Funding and workforce implications are most likely to impact those who have not historically resourced the role sufficiently (which I think is the majority) (PS)
114	NHS England	Statement 3	To measure this statement, the definitions used would need to be considered. It is possible that the previously piloted NICE indicator NM64 could be used, however, the definition would need to be adjusted. The NM64 definition 'the % of patients with dementia with the contact details of a named carer on their record' would need to be amended to 'the % who have a named health or social care practitioner responsible for coordinating their care', as stated in the consultation document. (CF)

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115	Nottinghamshire County Council	Statement 3	Social Care Response: We no longer have named Care Coordinators who remain with individuals for long periods of time. The move has been towards intervention ways of working (i.e. short-term, targeted work).
116	Nottinghamshire County Council	Statement 3	Social Care Response: In the future it may be possible to have access to health systems to see if there is a health coordinator. It can't just be a name but rather a person actually coordinating care. Quite often individuals are named without actively engaging with individuals. Issues may arise due to staffing levels and the way teams currently operate as well as data collection and sharing.
117	Royal College of General Practitioners	Statement 3 p12 and P 13	Make clear that his "Named co-ordinator" should be for the holistic care of that patient i.e. dementia plus their long term co-morbidities Data Source: person should be specifically identified on the Care Plan
118	Royal College of Nursing	Statement 3 (statement)	Named Care Coordinator: Does the use of the term mean registered professional which is indicated in the examples, please could this be clarified?
119	Royal College of Nursing	Statement 3 (measure)	This standard may be difficult to measure as in reality there can be multiple professionals involved in the care of someone living with dementia. Single morbidity services may be involved for example cardiology but they do not always have the expertise to manage the dementia element of a person's care. Not all people living with dementia have a social worker involved and even when they are involved, once care is arranged, very few people maintain contact with a social worker. With challenges facing primary care, it is more difficult for a general practitioner or practice nurse to do this. In clinical practice, we are aware that very few people living with dementia have a single coordinating health or social care professional.
120	Royal College of Psychiatrists	Statement 3	This should be an important and useful quality indicator that should be easy to implement and monitor.
121	Royal College of Speech and Language Therapists	Statement 3 Page 13	Please specify allied health professionals in the section on health and social care practitioners. Allied health professionals such as speech and language therapists are a key provider of care and support to people with dementia and their families and should be added.
122	Royal College of Speech and Language Therapists	Statement 3 Page 15	In the equality and diversity section Please change the reference from speech difficulties to speech and language difficulties
123	Tide	Statement 3	• GP's should be the ongoing care coordinator but they don't • Unsure what or who would be 'a named care coordinator' e.g. NHS? • Quality Standard 3 Adults with dementia should have a named care coordinator. Since the people with dementia have other conditions such as cardiovascular disease, diabetes, sight and/or hearing

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			loss and motor difficulties it is inappropriate to devolve monitoring multiple co-morbidities to social care workers. All coordinators should be health care practitioners and preferably registered health care professionals. "The person with dementia can develop and review a care and support plan with their named practitioner. This will enable a person centred care" It would be helpful if there was some indication of frequency of reviews here. **Based on your lived experience, is this the quality of service/support you currently receive?** • No not really! I had access to training / information about dementia (as a carer). No such thing as a 'care coordinator' or choice of meaningful activities for PWD
124	Action on Hearing Loss	Statement 4 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement. **We recommend that the following should be added to second sentence in the paragraph:** *"Any information provided should be accessible to people with additional needs, such as physical, sensory or learning disabilities, **in line with NHS England's Accessible Information Standard.**"*
125	ADMP UK	Statement 4 P16	Quality statement Four: Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences. We welcome the focus of this statement on choice, following diagnosis. We are concerned however, that neither dance nor dance movement therapy are mentioned as options, especially since there is evidence to suggest that these interventions may have high uptake amongst people with dementia and may contribute towards wellbeing. Music therapy is included as an intervention that can contribute to wellbeing. It is unclear and concerning that dance movement therapy is not also mentioned here. Examples of evidence missing: Hill, H. (2009). Dancing with Hope: Dance therapy with People with Dementia. In The art and science of dance/movement therapy (pp. 194-207). Routledge. Coaten, R. (2001). Exploring reminiscence through dance and movement. Journal of Dementia Care, 9(5), 19-22. Duignan, D., Hedley, L., & Milverton, R. (2009). Exploring dance as a therapy for symptoms and social interaction in a dementia care unit. Nursing times, 105(30), 19-22.

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			Palo-Bengtsson, L., & Ekman, S. L. (2000). Dance events as a caregiver intervention for persons with dementia. Nursing inquiry, 7(3), 156-165. Guzmán-García, A., Mukaetova-Ladinska, E., & James, I. (2013). Introducing a Latin ballroom dance class to people with dementia living in care homes, benefits and concerns: A pilot study. Dementia, 12(5), 523-535. Lazarou, I., Parastatidis, T., Tsolaki, A., Gkioka, M., Karakostas, A., Douka, S., & Tsolaki, M. (2017). International ballroom dancing against neurodegeneration: a randomized controlled trial in Greek community-dwelling elders with mild cognitive impairment. American Journal of Alzheimer's Disease & Other Dementias®, 32(8), 489-499. Hamill, M., Smith, L., & Röhricht, F. (2012). 'Dancing down memory lane': Circle dancing as a psychotherapeutic intervention in dementia—a pilot study. Dementia, 11(6), 709-724.
126	Alive	Statement 4	Under the section 'What this means for different audiences' the paragraph on Adults with dementia gives only two examples of 'suitable activities'. A list of two seems very reductive and insufficient to recognise the range of people's needs, interests and mobility; it should include the list further down for 'Activities to promote wellbeing'.
127	Alzheimer's Society	Statement 4	**We support QS4,** Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences. We believe this is a priority for improvement.
128	Association for Family Therapy and Systemic Practice	Statement 4	Equality and diversity – activities should also take into account cultural and religious preferences
129	The British Dietetic Association	Statement 4	Under 'source guidance', we feel Dementia Training Standards Framework https://www.hee.nhs.uk/our-work/dementia-awareness/core-skills requires listing. This highlights that 'the importance of food and drink is based on the emerging evidence base that links a reduction in mealtime eating and behavioural abilities with decreased nutrition, hydration and reductions in quality of life. Conversely, socialisation and other person-centred mealtime interventions can enhance the pleasure of eating and mealtime abilities and lead to improved nutrition and hydration.' To support quality improvement in this section, activities to promote wellbeing need to include; opportunities for mealtimes as a positive experience that acknowledge the health benefits and pleasure of food and choices, food nutrition reminiscence, food theme days etc. The rationale is meeting the basic human right to have access to adequate food within a positive environment which simulates all the senses (taste, touch, sight, smell, audio) to positively affect nutritional status. As activities which encompass this are broader than 'baking', we would suggest that 'baking' be removed and replaced with 'therapeutic food related activities'. The rationale for this can be found in Appendix 9: Nutrition and hydration and oral health references (page 90) of the above.
130	The British Psychological Society	Statement 4 (rationale)	We welcome the inclusion of activities to promote wellbeing as a priority and would like to draw attention to 'A Guide to Psychosocial Interventions in Early Stages of Dementia' (BPS, 2014) which provides a comprehensive

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			review of psychosocial interventions for dementia including their evidence base. The document is currently in the process of being updated.
131	The British Psychological Society	Statement 4 (Outcomes)	Similar issues exist with measurement as those that are highlighted above in comment number 4.
132	Carers Trust	Statement 4	Carers Trust would like to see “with the involvement of their carers” included in this statement. The new statement would, therefore, read: “Adults with dementia are given, **with the involvement of their carers,** a choice of activities to promote wellbeing that is tailored to their preferences. We know that carers provide the vast majority of care, and carers should be involved in the care planning for the person with dementia for as long as they choose to be.
133	Dementia Clinical Network NHSE; London	Statement 4	Considering the evidence base should providing CST and Psychoeducation for carers be included instead of this statement. There is currently significant variation in the commissioning of these services in London.
134	Dementia Clinical Network NHSE; London	Statement 4	Not sure how data could be collected on ‘choice of activities to promote wellbeing’ as people access activities from different sources and this is very personal and dependent on premorbid personality and interests.
135	Dementia UK	Statement 4	Q1 Agreed but would add here that family supporters/carers also need to be involved with this as they often have a valuable input into these activities either by giving suggestions, encouraging the person to attend and possibly taking them there. There are also a range of activities that the person and their family may wish to engage in together e.g. walks, physical activities, social groups, singing for the brain, cinema and peer group support. The family supporter/carer may also benefit from having their need for activities noted to promote their well-being and to enable them to continue with supporting their family member. Respite/ break from caring can come into this Statement. Q2 and Q3 Needs to include family supporter/carer in this. Also not all activities need to be dementia related with adaptations everyday activities can be used not just dementia groups e.g. dementia friendly screenings at cinemas, attendance at gyms and swimming pools, meal and chat social groups, art and craft groups, walking groups
136	NHS England	Statement 4	The evidence and rationale to promote activities and improve wellbeing is good and the standard reflects the key areas. The data collection will be more difficult and would mainly be through survey unless specifically asked and recorded at review and in care plans. There is large variation in activity provision and their quality so this data would reflect the former but maybe not so much the latter. My experience is that the provision is poor, more so for those living at home. They have to attend centres for their activities and there are not sufficient resources available. Ironically the provision is better when in nursing homes but I would argue that although beneficial the impact would be better for those less dependent. The potential barriers are both financial, workforce and infrastructure ie having appropriately trained and resourced practitioners in appropriate settings (with the attending logistical implications). (PS)

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137	NHS England	Statement 4	Accurate measurement of this statement would be dependant on what the ‘activities to promote wellbeing’ are for each local area and how they would be recorded in a care plan. (CF
138	NHS England		Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences’ this standard has the potential for significant system implications, it is difficult to determine form the standard who this would apply to, who would commission the services required and who would provide such services. (SC)
139	Royal College of General Practitioners	Statement 4 P16	People with dementia are supported to continue to do activities that support their wellbeing as well as given access to other activities that may help them with cope with the illness and tailored to their needs
140	Royal College of General Practitioners	Statement 4 P16 & 17	Quality Measures and Outcomes: QoL outcomes should be measured here. Other possible outcomes include lack of depression
141	Royal College of Nursing	Statement 4 (statement)	Although we are aware of a few services that offer specific tailored interventions for people living with dementia, these appear rare. We are however, aware that some third sector organisations provide some interventions so it would be important to review any data those organisations may have.
142	Royal College of Psychiatrists	Statement 4	We agree with this standard and feel that commissioners should ensure resources are available to support it.
143	Royal College of Speech and Language Therapists	Statement 4 Page 17	We would welcome the following amendments in the rationale to ensure all recommendations maintain person-centred: “Understanding the activities that a person thinks are **enjoyable,** suitable and helpful…**will foster motivation** for the person to engage with the activities offered.”
144	Royal College of Speech and Language Therapists	Statement 4 Page 17	Please specify allied health professionals in the section on health and social care practitioners. Allied health professionals such as speech and language therapists are a key provider of care and support to people with dementia and their families and should be added.
145	Royal College of Speech and Language Therapists	Statement 4 Page 18	In the equality and diversity section Please add people with communication needs.
146	Sunrise Senior Living UK	Statement 4	This statement does not support the opportunity for rehabilitation to improve well-being and function
147	Tees Esk and Wear Valleys NHS Foundation Trust	Statement 4 (statement)	There is perhaps a need to look at funding and accountability to follow engagement in activities as many voluntary agencies see themselves only as referring agents only.
148	Tees Esk and Wear Valleys NHS Foundation Trust	Statement 4 & 6 (statement)	There needs to be more focus on non-pharmacological interventions.

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149	Tide	Statement 4	Identifying the existence of a choice of activities to promote wellbeing that are tailored to the preferences of someone with dementia is a massive task. We have had issues around the sharing and storing of such information. E.g. Gwent Dementia Road Map. **Based on your lived experience, is this the quality of service/support you currently receive?** • There are some real gaps ie follow up to diagnosis is patchy and the experience of people living with dementia and opportunity to remain well with meaningful activity is seldom there...I can elaborate! • No not really! I had access to training / information about dementia (as a carer). No such thing as a 'care coordinator' or choice of meaningful activities for PWD
150	Action on Hearing Loss	Statement 5 (Rationale)	**The Quality Statement that adults with dementia should receive a structured assessment considering other causes of distress before starting pharmacological treatment is welcomed.** As highlighted in Comment 2, research shows that hearing loss can be misdiagnosed as dementia or make symptoms of dementia appear worse. Ensuring hearing loss is properly diagnosed and managed will therefore have an important role to play in managing distress in adults with dementia.
151	Action on Hearing Loss	Statement 5 (What the quality statement means for different audiences; Health and social care professionals)	**This paragraph should be changed to include sensory loss as an example of clinical cause of distress in adults with dementia.** Health and social care practitioners should be aware of how unsupported hearing loss may be causing distress and exacerbating other behaviours such anxiety and other mental health problems. Unaddressed hearing loss is linked with depression, anxiety and other mental health problems.[5] For example, research shows that hearing loss **doubles the risk of developing depression.**[6] Given the increasing body of evidence demonstrating the relationship between hearing loss, cognitive decline and dementia (see Comment 2), it is likely that adults with dementia will be at even greater risk of poor mental health. Eliminating unsupported hearing loss as a clinical cause of distress in adults with dementia is therefore crucial for effective treatment and care. **We recommend that the following wording should be added to the second sentence in the 'health and social care professionals' paragraph.**

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[5] Eastwood et al, 1985. Acquired hearing loss and psychiatric illness: an estimate of prevalence and co-morbidity in a geriatric setting. British Journal of Psychiatry, 147: 552–556; Garnefski & Kraai, 2012. Cognitive coping and goal adjustment are associated with symptoms of depression and anxiety in people with acquired hearing loss. *International Journal of Audiology*, 51: 545–550; Mulrow et al, 1990. Quality-of-life changes and hearing impairment. A randomized trial- Ann Intern Med. 1;113(3):188-94; National Council on Aging, 2000. The consequences of untreated hearing loss in older persons. *Head and Neck Nursing*, 18(1), 12-6;

[6] Saito et al, 2010. Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese

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			"As part of the assessment, they check for any clinical or environmental cause of distress, for example, pain discomfort, delirium, ***unsupported sensory loss****, inappropriate care, infection, boredom, noise or temperature, using appropriate assessment tools and involving other professionals if needed"*
152	Action on Hearing Loss	Statement 5 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement. **We recommend that the following sentence should be added to the end of the paragraph:** ***"Adults with physical disabilities and sensory loss should receive accessible communication and information to ensure they are able to participate fully in discussions about dementia treatment and care, in line with NHS England's Accessible Information Standard"***
153	ADMP UK	Statement 5 and 6	Quality statement five: Adults with dementia have a structured assessment before starting nonpharmacological or pharmacological treatment for distress. Quality statement six: Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each health and social care review We welcome both of these quality statements. We are concerned however that dance movement therapy and the other arts therapies are not mentioned here as viable non-pharmacological options. As mentioned before, evidence stemming from reviews such as the dementia Cochrane review (Karkou and Meekums 2017; Lyons, Karkou, Richards et al 2018; Kiepe, Stockigt and Keil 2012) and other systematic reviews in arts therapies (Beard 2012; Schmitt and Frolich 2007; Cowl and Gaugler 2014) suggest that although further research is needed, dance movement therapy could be an effective intervention for dealing with distress amongst adults and older people with dementia. Examples of evidence: Karkou V, Meekums B. Dance movement therapy for dementia. Cochrane Database of Systematic Reviews 2017, Issue 2. Art. No.: CD011022. DOI: 10.1002/14651858.CD011022.pub2. Lyons, S., Karkou, V., Roe, B., Meekums, B., & Richards, M. (2018). What research evidence is there that dance movement therapy improves the health and wellbeing of older adults with dementia? A systematic review and descriptive narrative summary. The arts in psychotherapy, 60, 32-40. Kiepe, M. S., Stöckigt, B., & Keil, T. (2012). Effects of dance therapy and ballroom dances on physical and mental illnesses: A systematic review. The Arts in Psychotherapy, 39(5), 404-411.
154	Alzheimer's Society	Statement 5	**We recognise that carrying out an assessment with people with dementia for distress is important before starting non-pharmacological or pharmacological treatment, as it is vital to identify the cause of**

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			distress, and to address this directly where possible. The impact of not identifying the cause can lead to poorer outcomes, including inappropriate use of anti-psychotics. However the consultation documents do not seem to present evidence that suggests this is not already happening in practice. If this is already happening in practice, then an alternative QS would have greater impact in driving improvement, and resulting in higher quality of care for people with dementia. We would also suggest that a QS of greater value in ensuring an appropriate course of action to address distress would be training of health and care professionals in understanding of distress in people with dementia and how to treat it.
155	The British Psychological Society	Statement 5 (rationale)	While we are pleased to note a shift in language to describe 'managing distress' as opposed to the previous term of behavioural and psychological symptoms of dementia it does raise an issue of whether distress is routinely recognised and whether tools exist to measure this. Applied clinical research in England shows that families referred by their GP for specialist help did not receive this - their needs were 'hidden' (Manthorpe et al., 2018) since specialist NHS providers did not have tools to identify the challenges that families faced. Similarly, when those with clinically significant behavioural symptoms were offered help there were no reductions in behavioural symptoms coping or related distress over 6 months (Moniz-Cook et al., 2017). We have previously called for action in (i) the delivery of what is known to work i.e. biopsychosocial individually formulated interventions (Holle et al., 2016) and (ii) sustained training and support of family and staff carers by specialist trained mental health practitioners who have access to multi-professional medical and psychological professionals within relevant teams and pathways of care (Moniz-Cook et al., 2012). We therefore recommend that the standard is extended to include a personalised formulation of the distress following on from an appropriate assessment. We would also like to ensure that behaviours which could be seen as coping practices in the context of dealing with memory loss, often in strange and alienating environments, are not over-pathologised. It is not just the use of antipsychotic medication that is problematic in the management of distress in dementia. The use of benzodiazepines is also well documented and associated with can lead to significant harms, including fall-related injuries such as fractures (Rocho, Vozoris, & Gill, 2017).
156	The British Psychological Society	Statement 5 (Outcomes)	We recommend that measuring quality of life should be supplemented with validated measures of distress e.g. the Challenging Behaviour Scale (Moniz-Cook, et al., 2001) or the Neuropsychiatric Inventory (Cummings, 1997) in care home or inpatient settings, or the Revised Memory and Behaviour Problems Checklist (Teri et al.,1992) in family carer situations.
157	The College of Optometrists	Statement 5	See our comments 1 and 2 above. We strongly recommend that the structured assessment includes a full visual assessment.

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158	Dementia Clinical Network NHSE; London	Statement 5	Suggested statement change: 'Adults with dementia who are distressed have a structured assessment and psychosocial and environmental intervention if required.' The importance is that the assessment leads onto a care plan and anti-psychotics are not prescribed unnecessarily.
159	Dementia Clinical Network NHSE; London	Statement 5	This could be measured using data on prescribing anti-psychotic medication as a proxy measure. This information is available monthly via NHS digital.
160	Dementia UK	Statement 5	Q1 Agreed but this should also involve the family supporter/carer as they may be able to add information very useful for a full and accurate assessment. Q2 Agreed. Q3 Families report that when their family member with dementia is distressed it can take many phone calls to get someone to listen to their concerns and there is often a time delay in receiving any specialist assessment and support. By the time they receive help the situation may have escalated causing more distress and could even involve an admission to hospital or a decision made that there is now the need for long term care due to feeling that they can no longer cope. There needs to be more practitioners available who can complete a structured assessment in a timely way to prevent this which could be a cost saving.
161	The Lewy Body Society	Statement 5	Comments on Standards 5 and 6 – treatment and review We support these standards and believe that training and support must be given to medical professionals to ensure they comply with them. Too often, patients with Lewy body dementia and their carers tell us that they don't feel their views are listened too, and that they are not offered the most appropriate treatment. A patient with LBD recently told us: "I get tired of Doctors saying that they know about Lewy Body Dementia, when they clearly don't have a clue. Many keep recommending high doses of medication, when they should realise that we don't cope with high doses of some medication. When my wife tells them they look stunned."
162	MHA	Statement 5 Definitions and outcomes	As the largest provider of music therapy for older people living with dementia, we are pleased to see reference to music therapy within the standard (Statement 4). However, through our experience and research we know that music therapy is more than just an activity, as inclusion within this statement implies. All Health Care Professions Council (HCPC) registered music therapists complete two years' post-graduate study before being able to practice. Research shows that music therapy is an effective treatment for agitation and anxiety (Svansdottir and Snaedal, 2006) - more so than standard care (Raglio et al, 2010) - and prevents medication increases in people living with dementia (Ridder et al 2013). Given this evidence, we believe music therapy should be included as an example of non-pharmacological treatment within Statement 5, along with other appropriate non-pharmacological treatments. Under '*What the quality statement means for different audiences: Health and social care professionals'* should be broadened out to include music therapists, who undertake structured assessments with residents who begin music therapy. As one of the Allied Health Professions, music therapists carry out structured assessments using

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			validated outcome measures and promote the DICE approach (Describe, Investigate, Create, Evaluate) (Kales et al., 2014) across care settings to support people living with dementia and their carers. We believe it is vitally important that non-pharmacological treatments should be given greater priority in the reduction of agitation and distress in people with living with dementia.
163	MHA	Statement 5	Under the *Equality and Diversity considerations*, we believe there should be reference to early onset dementia (below 65 years). We care for people of working age and recognise that a different care approach is needed. Those experiencing earlier onset are more likely to: have young children; have parents with their own caring needs, who are still alive; have a main carer – most probably a partner – who is still working; have mortgage responsibilities; be more physically more active. Additionally, we feel a robust equality impact assessment of the revised standard, with particular regard to people living with dementia and learning disabilities, people from BAME communities and LGBT+ people living with dementia, is essential.
164	Neurology Academy Limited	Statement 5	This is a curious choice of words – I am not sure how 'distress' is defined – I am not sure how 'distress' is defined; I don't think any doctor would start treatment for 'distress'.
165	Neurology Academy Limited	Statement 5	Managing distress We feel this is an odd standard to include. How does a GP define distress and provide treatment ? There is not a clinical diagnosis of distress to our mind it is a symptom
166	NHS England	Statement 5	Managing distress is a key area and the data should be relatively easy to collect by looking at local protocols and anti-psychotic prescribing in dementia patients. Many areas have a specific team set up to address this issue and advise on management to the primary care team. There may be an issue in the delay from the patient's carers highlighting the issue (often to the GP) then this being passed on to the appropriate team then the assessment taking place. Often the behavioural issues are not until later in the progression of the disease and they are not on the active caseload of the dementia team and this can cause delay. There are some provisions for telephone and email advice from the teams to GP. The prescribing of antipsychotics by GPs is not recommended but I would say that given appropriate support those with experience in dementia should be permitted within the workings and subsequent involvement of the dementia team. There are GPs (and ANPs) who have lots of experience in this field who know what needs to be done but have to delay until a specialist review. (PS)
167	NHS England	Statement 5	A clear definition of what a structured assessment / multifactorial assessment is and how it would be recorded would need to be established to measure this statement. In addition, the pharmacological and non-pharmacological treatments would need to be listed and how they are recorded would need to be confirmed.(CF)
168	Parkinson's UK	Statement 5	It is unclear how the term 'distress' is defined, and a term unlikely to be used in a clinical setting to treat people in a nonpharmacological or pharmacological sense. We recommend finding an alternative term to describe the behaviours set out in the 'Rationale' for the statement, and to do this in consultation with people experiencing such behaviours and clinicians.

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169	Royal College of General Practitioners	Statement 5 P20	The assessment should first exclude physical causes of distress (earache, toothache, long toenails, eye conditions such as glaucoma) before looking at a structured assessment for behavioural and psychological symptoms of dementia such as anxiety, apathy, agitation, depression etc
170	Royal College of General Practitioners	Statement 5 P21	Additional outcomes could include: documentation of regular ear, eye, dental and feet checks adequate hydration – fewer urinary tract infections, episodes of delirium
171	Royal College of Nursing	Statement 5 (statement)	Adults with dementia have a structured assessment before starting treatment: NICE may want to include a recommendation for liberty protection safeguards to be considered at this stage.
172	Royal College of Nursing	Statement 5 (measure)	There is greater awareness of non-pharmaceutical interventions and increasing gathering of evidence for this. We are aware that in Dorset, they undertake audits of the use of pharmaceuticals for people (living with dementia who are experiencing symptoms of distress) in their specialist services and this means these people would have had a structured assessment. Whilst there may be evidence of obtaining data for people with dementia who are see by specialist services, it could be challenging to obtain data for people seen in general hospitals or in primary care.
173	Royal College of Nursing	Statement 5 (statement)	We note that pain is mentioned in the measure for statement 5, but consider that there could be a specific standard on managing pain or the inclusion of the word ‘pain’ in statement 5? Pain in this client group presents challenges in terms of assessment and treatment. A standard document like this could recommend the use of pain assessment tools such as the Bolton Pain Assessment Tool and give a steer on safe pain management e.g. avoiding medication that increases risk of falling.
174	Royal College of Psychiatrists	Statement 5	The indicated outcome measure of antipsychotic prescribing is inadequate to capture the standard set out.
175	Royal College of Speech and Language Therapists	Statement 5 Page 21	It is important to include in this standard the issue that distress and the behaviours listed can also be caused by difficulties with communication and it is imperative this is also included as a potential cause, and thereby examined in a structured assessment.
176	Royal College of Speech and Language Therapists	Statement 5 Page 21	Please specify allied health professionals in the section on health and social care practitioners. Allied health professionals such as speech and language therapists are a key provider of care and support to people with dementia and their families and should be added
177	Sunrise Senior Living UK	Statement 5	This statement might be difficult to deliver if service providers are not responsible for carrying out the structured assessment but instead must have arrangements in place for referring to the health or social care professional to do the assessment. The demand on the h&sc professionals could be very high and they may not know the individual as well as the service provider does
178	Tide	Statement 5	• A definition of the word 'distress' is needed. Does it mean agitation caused by constipation, or another resident in a care home, or does it mean psychotic behaviour such as hallucinations and delusions, or does it mean restlessness caused by boredom, which can result in aggressive

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			behaviour? Non-pharmacological interventions need to be explained - a hand massage? Vitamins? Chiropractor? - Quality Standard 5 Adults with dementia have a structured assessment before starting non pharmacological or pharmacological treatment for distress. This assessment should also be restricted to registered health care professionals since it is unlikely that a social care worker would be qualified to carry out an assessment of a list of triggers which are with the exception of boredom all health related.
179	Action on Hearing Loss	Statement 6 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement. **We recommend that the following wording should be added to the second sentence in the paragraph:** *"Healthcare professionals caring for adults with dementia should establish the person's cognitive status, and if they have any speech, language or communication needs,* ***in line with NHS England's Accessible Information Standard****;"*
180	Action on Hearing Loss	Statement 6 (Equality and Diversity Considerations)	**A reference to NHS England's Accessible Information Standard should be added to this section.** As highlighted in Comment 5, including references to NHS England's *Accessible Information Standard*[2] will help ensure equality and diversity issues receive appropriate consideration in the context of this Quality Statement. **We recommend that the following wording should be added to the sentence in this section:** *"Offer of training and support for carers of adults with dementia need to take into account any physical or mental conditions, and learning or physical disabilities that make it difficult to access training and support****. In this regard, health and social care professionals should refer to NHS England's Accessible Information Standard****"*
181	Alzheimer's Society	Statement 6	**We recognise the importance and benefits of advance care planning, and this happening early, whilst people with dementia still have capacity, and with ongoing opportunities to review. However, advance care planning is very complex, and these conversations can be difficult to have and can cause anxiety or distress. It requires sufficient time for an in-depth discussion.** Offering the opportunity to review these decisions at every care review is not always feasible, considering the time that should be taken to discuss these important decisions, and also considering the other aspects of care

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			required to be covered in the review also. Even though ‘offering the opportunity‘ does not mean the discussions taking place at every review, to explain what ‘advance care planning’ means itself takes time, and people with dementia may not easily recall previous discussions and decisions. Offering this opportunity at every review may result in advance care decisions being made without the appropriate understanding, or this being done at the expense of other vital parts of the care plan. It is important that these conversations are carried out properly, and not as a ‘tick box’ exercise. We would suggest that it is more important that advance care planning is carried out by staff with the appropriate training in having these discussions so that they are done properly, and that the appropriate time is dedicated to this also.
182	Berkshire Healthcare NHS Foundation Trust	Statement 6	Advanced Care Planning – agree this should be done as early as possible but stating that it should be completed at the point of diagnosis could be too prescriptive for some people – particularly if they are having difficulty coming to terms with the diagnosis itself.
183	The British Dietetic Association	Statement 6	See comment below
184	The British Psychological Society	Statement 6 (rationale)	We believe that people having the opportunity to discuss advance care planning, including conversations about end of life is an important priority. Recent work conducted by the Life Story Network on people living with dementia has suggested that end of life conversations are framed as important conversations rather than difficult conversations (End of Life Care and Post Bereavement Support Shifting the Conversation from Difficult to Important, 2018). Despite this it is well recognised that staff often do not feel confident or competent in discussing death and dying with people living with dementia (Lee et al., 2017). We would therefore recommend that if this quality standard is to be met in a meaningful way considerable investment will be needed in supporting staff to carry out these discussions.
185	Carers Trust	Statement 6	Carers Trust would like to see “with the involvement of their carers” included in this statement. “Adults with dementia have the opportunity, **with the involvement of their carers,** to discuss advance care planning at diagnosis and at each care review” We know that carers provide the vast majority of care, and carers should be involved in the care planning for the person with dementia. Adding the involvement of carers into this quality statement would better align Quality Statement 6 with the rationale behind Quality Statement 2, which states, “The benefits of a timely diagnosis include early consideration of mental capacity and advance care planning, knowing what to expect, and enabling families and carers to make plans” It is important that carers are seen as equal partners in care and their voice is heard when care planning.

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186	Cognitive Disorders Group of the Association of British Neurologists	Statement 6	We have reservations about the wisdom of always including advance care planning at diagnosis because patients may have very mild problems and an uncertain prognosis. Patients with very mild problems may progress very slowly. We would therefore recommend that the statement is kept as it is but with a second sentence “the concept and need for advance care planning should be introduced at an early but appropriate time by the health professional”. This should make it clear that clinical judgement has a role to play. The method of measuring as laid out in “process” would need to be changed also.
187	The College of Optometrists	Statement 6	The PrOVIDe study finds that the primary cause of visual impairment worse than 6/12 was cataract, which is treatable with surgery in suitable patients. Most people with dementia interviewed during the PrOVIDe study said they would want surgery to correct cataract if required. We recommend that a decision about referral for cataract surgery should take into account the need to try and do so while the person still has the capacity to consider the decision, consent to the procedure, and cope better with the recovery process after surgery.
188	Compassion in Dying	Statement 6 (Rationale)	We recommend changing the sentence ‘As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on…’ to ‘As dementia is a progressive condition, it is important for people to be able to make **and document** wishes and decisions about their future care…’. It is important that wishes are documented so that health and social care professionals know how to care for the person and make decisions in their best interests. Documenting wishes supports best interests decision making as outlined in NICE guidance ‘Decision-making and mental capacity’.
189	Compassion in Dying	Statement 6 (Rationale)	We recommend adding the sentence “Specific refusals of treatment can be recorded in an Advance Decision to Refuse Treatment, or someone may give a person they trust the ability to make decisions on their behalf by registering a Lasting Power or Attorney, which are both legally binding documents.” after the sentence “This is known as Advance Care Planning.” Without a legally binding Advance Decision to Refuse Treatment or a registered Lasting Power of Attorney someone with dementia may still be given treatment that they would not have wanted, so it is critical health and social care professionals are reminded of the specific tools that people have available to them under the Mental Capacity Act.
190	Compassion in Dying	Statement 6 (Quality Measures, Outcomes (a))	The word ‘encouraged’ should be replaced by ‘supported’ so the sentence reads ‘Proportion of adults with dementia who feel **supported** to make decisions about their future care.’ Feeling supported may be easier to measure than feeling encouraged and sits better within this quality standard as some people may feel encouraged to make decisions, but not feel supported to do so. Feeling supported would be a better indicator of how this quality standard is working.
191	Compassion in Dying	Statement 6 (service providers)	In this section, it would be useful to add that service providers should ensure not only that systems are in place for adults with dementia to have early and ongoing opportunities to discuss advance care planning, but also that

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			there are systems in place so that advance care plans, or evidence of these discussions, can be shared between professionals. We know that there are currently issues with healthcare professionals not being able to effectively share advance care plans (e.g. an advance decision to refuse treatment) because the systems in place used by the different professionals vary. For example, a GP might struggle to share an advance care plan with the local ambulance service/paramedics, which can lead to people receiving treatments such as CPR, even if the person has refused this in a legally binding way. In an FOI conducted by Compassion in Dying [1], only 46% of the CCGs (96 out of 207) reported that GP practices in their area have systems for recording the existence of a person's Advance Decision. This was reinforced by callers to Compassion in Dying's information line. One caller said "My GP said it was not procedure to retain a copy of my Advance Decision with my medical notes." [1] https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/
192	Compassion in Dying	Statement 6 (health and social care professionals)	It is important that health and social care providers give adults with dementia opportunities to discuss advance care planning. However, it is also essential that health and social care providers have knowledge of how to document wishes in a legally binding way (Advance Decisions to Refuse Treatment, Lasting Powers of Attorney) and have knowledge of organisations they can signpost to for further information and support, such as Compassion in Dying. We suggest this is added to this section.
193	Compassion in Dying	Statement 6 (Definitions)	We suggest that Do Not Attempt Resuscitation (DNAR) orders are added to this section. Preferences about resuscitation are part of advance care planning so should be discussed alongside the other points suggested.
194	Compassion in Dying	Statement 6 (Definitions)	The bullet point 'their preferences for place of care and place of death' should be replaced with 'their place of care, place of death and other aspects of care the person considers a priority'. In a 2018 YouGov poll, people were asked about what was important to them when thinking about their end of life. Respondents were twice as likely to say 'being involved in decisions about my care' than they were to say 'dying at home'. 76% respondents did not rank being able to die at home as one of the top three factors that would be important to them. While place of care and place of death are often used as a key performance indicator of end-of-life care, it is important that discussions around advance care planning are not unnecessarily restrictive in scope.
195	Dementia Clinical Network NHSE; London	Statement 6	In London we are able to measure this through number of Coordinate My Care records (digital urgent care plan)
196	Dementia UK	Statement 6	Q1 Agreed but this should read "Adults with dementia **and their family** have the opportunity to discuss advance care planning **after** diagnosis and at each health and social care review". If family are not involved in this it can

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			lead to potential misunderstandings, distress and disagreements as the person loses the capacity to be able to say what it is they want. Q2 For some people at the time of diagnosis is not the time to have the advance care planning conversation this is something that the care coordinator should discuss at a time suitable for the person and their family. Everyone should be offered the chance to discuss advance care planning throughout their journey with dementia. On admission to hospital or a care home a copy of the advance care plan should be made available so that the MDT can ensure any advance wishes are respected. Some people living with dementia and their family decide they do not want to have this discussion at any point in the journey and this should be respected. They should be given a contact persons details so they can contact them when they feel able to discuss and make an advance care plan. There could be an electronic advance care plan that all health organisations could access. Q3 This reinforces the need for a named care coordinator who follows the person and their family throughout their progression with dementia.
197	Neurology Academy Limited	Statement 6	This is excessive to me – at diagnosis there is so much to discuss that it is not appropriate to start discussing advance care planning; this entails careful and detailed discussion with a lot of sensitivity – some care reviews might be short and therefore it would not be appropriate to raise such a topic at 'each' care review
198	Neurology Academy Limited	Statement 6	Advanced care planning Giving the diagnosis of dementia is overwhelming and the standard to include discussions at this point to begin ACP discussions is excessive. We would suggest separate appointments where this could be done in a more supportive and structured fashion when the initial shock of the diagnosis has been absorbed.
199	NHS England	Statement 6	Advance care planning should be early and ongoing and part of the dementia care pathway, the standard reflects this and the data collection should be straightforward. My impression is that this is not done as early as it should (locally it is not discussed in the memory clinic at diagnosis). The difficulty seems to be when to have the discussion and health professionals seem to struggle with when is best, the most positive push for this in the past was when it was highlighted to be part of a care plan. This is another role that seems to be left for the GP to undertake. (PS)
200	Nottinghamshire County Council	Statement 6	Social Care Response: Advanced care planning is not routinely part of social care reviews by the reviewing. This may take place on an ad hoc basis where social work or CCO involvement is available. Most social care practitioners will not feel confident in talking about end of life needs and will delegate this to health. Carers have indicated that they need support to plan for the future – specific advice on power of attorney, how to discuss future care planning and end of life with the person they care for while they have capacity to do this. Please note, this support is most valued shortly after diagnosis – at this stage the person with dementia is unlikely to be receiving social care as their condition is not advanced enough to be causing significant impairment. Advice on advance care planning may therefore be better promoted through information and advice services rather than the assessment/review process.

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201	Nottinghamshire County Council	Statement 6	Social Care Response: Reviewing plans at regular intervals would be time consuming and impact upon social work caseloads and therefore staffing levels. Fluctuating Mental Capacity over the course of the person's dementia pathway may impact on ability for this to take place particularly in the later stages of dementia. There would be a requirement to train staff around these possibly difficult conversations, how to start them and what to include. There are also issues around service user and carer acknowledgement of disease progression and their willingness to participate in any such discussions of future needs.
202	Parkinson's UK	Statement 6	We support the need for discussions on advanced care planning from diagnosis onwards. Clinician's we have engaged with have raised concerns about the coordination of advanced care planning between services and the need for greater clarity around which clinicians should have ultimate responsibility for the advanced care planning process. For example, an advanced care planning discussion may happen at diagnosis in a memory clinic with a person before transitioning to GPs for ongoing care reviews, where it may be unrealistic given the time available for GPs to discuss advanced care planning at 'each' care review. We recommend that oversight for the delivery and recording of advanced care planning discussions is made the responsibility of the 'named care coordinator' (set out in quality statement 3) and the statement provides greater clarity on when these conversations should be held.
203	Royal College of General Practitioners	Statement 6 P23	At the time of Diagnosis is not the most appropriate time to have an in depth discussion about Advance Care Planning as the person with dementia can be too shocked to concentrate on other broader issues. It is important to have a follow-up discussion soon after diagnosis about Advance Care Planning, preferably in the person's home
204	Royal College of General Practitioners	Statement 6 P24	Outcomes should include: number of people with Lasting Power of Attorney for Health, Lasting Power of Attorney for Welfare Advance Statements Advance Decisions; end of life care considerations No mention is made of needs of specific groups e.g. Young Onset Dementia, people with Learning Disability
205	Royal College of Nursing	Statement 6 (measure)	We are not aware of work for advance care planning specifically for people living with dementia but there is increasing work for people living with frailty, with dementia being a Frailty marker. Perhaps with suitable system changes it may be possible to obtain measurement data for this quality marker.
206	Royal College of Psychiatrists	Statement 6	We fully support this standard and agree with the outcome measures.
207	Royal College of Speech and Language Therapists	Statement 6 Page 24	It would be helpful to delineate between the clauses in the rationale: 'before their communication deteriorates or they lack the capacity to do so; there is a risk that this second clause may be misunderstood as lacking the ability to communicate which is very different to lacking mental capacity. We would recommend amending to; "before their communication deteriorates, or they lack the mental capacity."

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208	Royal College of Speech and Language Therapists	Statement 6 Page 24	Please specify allied health professionals in the section on health and social care practitioners. Allied health professionals such as speech and language therapists are a key provider of care and support to people with dementia and their families and should be added
209	Royal College of Speech and Language Therapists	Statement 6 Page 25 and 26	We welcome the consideration of people's communication needs and their level of understanding in the equality and diversity section. Speech and language therapists are the only trained professionals who are assess someone's communication needs and should be referenced accordingly.
210	The Society & College of Radiographers	Statement 6	The Society and College of Radiographers believes the importance of gaining permission to share and actually sharing that information about advance decisions (when permission is given) should be stressed. For example, a person who experiences claustrophobia may wish to make an advance decision not to undergo any MRI scans – if this information was shared with an imaging department then alternative arrangements for a CT scan could be made etc.; enabling services to continue to provide person-centred care for all patients and service users.
211	Tees Esk and Wear Valleys NHS Foundation Trust	Statement 6	Discussing advanced care planning is often not appropriate at the diagnostic appointment when the patient might feel that they have been hit by a bullet, and they need time to digest information.
212	ADMP UK	Statement 7	Again, we would like to endorse this statement as good practice. We would like however to highlight the value of training carers on the non-verbal and emotional communication that can take place with persons with dementia. The literature presents several examples of how this can take place as suggested following references. The contribution of dance movement therapy towards such as training needs to be acknowledged. Examples of evidence: De Vries, K. (2013). Communicating with older people with dementia. *Nursing older people*, *25*(4). Melhuish, R., Beuzeboc, C., & Guzmán, A. (2017). Developing relationships between care staff and people with dementia through Music Therapy and Dance Movement Therapy: A preliminary phenomenological study. Dementia, 16(3), 282-296. Kowarzik, U. (2013). Opening doors: Dance movement therapy with people with dementia. In H Payne (ed) Dance Movement Therapy. London: Routledge, 37-50
213	Alzheimer's Society	Statement 7	**We support QS7, Carers of adults with dementia are offered education and skills training. We believe this is a priority for improvement.**
214	Association for Family Therapy and Systemic Practice	Statement 7	"Education and skills training" does not necessarily include a support element (which is part of the rationale, and which is arguably more important than learning skills as an individual carer). Skills training may also convey an implicit message that carers' skills are not good enough (when the issue may not be this, in some cases, but the fact of feeling stressed and overwhelmed leading to difficulty keeping going with the skills they do have). We welcome the acknowledgement that carer education is more beneficial in groups, and we feel this is precisely because people have the opportunity to be in some way part of a group or community, rather than remain as isolated individuals who "need more skills".

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			“Support and education (including useful skills)” might be better phrasing. Support should include social and emotional support (such as access to e.g. therapy, counselling, peer-support, co-ordinator for carers, etc.) and practical support (such as respite care, information about financial assistance, befriending and volunteer services, carers associations, carer assessment etc.) as well as education
215	Association for Family Therapy and Systemic Practice	Statement 7	Equality and diversity – should also include cultural or religious factors which might make access more difficult
216	Berkshire Healthcare NHS Foundation Trust	Statement 7	Measurement of this standard is suggested as a proportion of Carers who have had a Carers Assessment. This would imply that Carers who decline a social care assessment of their needs are not equally entitled to psychoeducation. Sometimes it is through education that Carers agree to a Carers assessment. Would also be difficult to measure as it is currently defined because Carers assessments are recorded on Social Care systems and education is provided by a range of other services. Suggest revising the denominator.
217	The British Dietetic Association	Statement 7	Carers of adults with dementia can find supporting with eating and drinking highly stressful, and dietitians and speech and language therapists often have little capacity to offer supportive nutritional education or skills training. In addition, advice and guidance obtained from other sources can be conflicting or based on national public health policy which is unlikely to be appropriate. Carers need to be able to recognise potential malnutrition or dysphagia and they need to be able to access specialist advice from appropriately trained healthcare professionals when they need it - Registered Dietitians for nutrition or other health care professional e.g. Speech and Language Therapists for dysphagia. Abdelhamid et al (2016) noted that eating and drinking difficulties are a major source of ill health and stress for people living with dementia and for their carers. Addressing these difficulties was identified as one of their top-ten research priorities by people with dementia and their formal and informal carers. Under ‘what the quality statement means for difference audiences’, the workforce support from Registered Dietitians and Speech and Language Therapists needs to be included. These Allied Health Professionals are a valuable source of evidence-based information and resources. The rationale is to enable understanding of the need for a balance between healthy living (a nutritionally balanced diet and providing the opportunity for those living with dementia to enjoy the food and drink of their choice (preference or cultural etc.) but also recognising that this groups nutritional needs may be different from general population/healthy eating/ prevention messages particularly as the conditions progresses. Papachristou, Hickey, and Iliffe (2015) completed a qualitative study where they interviewed twenty informal care givers. This study found four main themes which were important to informal care givers. These include: • direct food-related information (written material, and training) • direct food-related informal support services (lunch clubs) • indirect food-related formal support services (respite care and help in the home)

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			• no services required (because of confidence in managing food-related processes and no change in dementia progression and food responsibility) Further research is required to establish the best ways to support people who have dementia, their informal and formal care givers with regards to managing nutritional changes related to dementia experienced over time. Under 'source guidance', we feel Dementia Training Standards Framework https://www.hee.nhs.uk/our-work/dementia-awareness/core-skills References: Abdelhamid A, Bunn DK, Copley M, Cowap V, Dickinson A, Howe A, Killett A, Poland F, Potter JJF, Richardson K, Smithard D, Fox C and Hooper L (2016): Effectiveness of interventions to directly support food and drink intake in people with dementia: systematic review and meta-analysis. BMC Geriatrics 16:26 Bunn DK, Abdelhamid A, Copley M, Cowap V, Dickinson A, Howe A, Killett A, Poland F, Potter JJF, Richardson K, Smithard D, Fox C and Hooper L (2016): Effectiveness of interventions to indirectly support food and drink intake in people with dementia: Eating and Drinking Well IN dementiA (EDWINA) systematic review. BMC Geriatrics 16:89. Papachristou, Hickey, and Iliffe (2015) Dementia informal caregiver obtaining and engaging in food-related information and support services. *Dementia* . Vol 16, Issue 1, pp. 108 - 118
218	The British Psychological Society	Statement 7 (Definitions)	In order for carers to be able to attend support services, adequate support will need to be made available for the person that they are caring for as well. Without this support, many carers will be unable to leave the person living with dementia alone and therefore be unable to attend the support.
219	Carers Trust	Statement 7	Carers Trust welcome the inclusion of "**Quality Statement 7: Support carers"** as one of the broad quality statements in these standards. The quality statement itself currently reads "Carers of adults with dementia are offered education and skills training". Carers Trust would like to see the inclusion of "support" in this quality statement. This would better reflect the aim of the quality statement and ensure providers are aware that this statement is about supporting carers. Carers Trust also believe that "**information and advice**" would better reflect the aim of this statement, rather than "education and training."

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			Carers are not paid care support workers, therefore, Carers Trust believe that the terms “education and training” do not reflect the support unpaid carers should be receiving. By using “information and advice”, instead, NICE would be better reflecting the provisions in the Care Act which set outs that caring is a choice, and that carers should be able to choose which aspects of care they provide Although these standards will also apply to non Local Authority providers, the use of “information and advice” will better reflect, and make the Standards closer aligned to, the duty on local authorities, contained in the Care Act, to provide a comprehensive information and advice service. The quality statement would then read, “Carers of adults with dementia are offered **support**, **information** and **advice**”
220	Carers Trust	Statement 7 (Rationale)	Carers Trust welcome the rationale behind the Quality Statement. It rightly recognises the mental and physical stress that many carers of people with dementia report, as well as the challenges they face balancing this with other responsibilities and leading the life they want to. We welcome that NICE recognises this may impact on carers’ mental and physical wellbeing. The Care Act guidance defines “wellbeing” as encompassing “control over day to day life.” This includes how carers are enabled to continue with other responsibilities as listed in the current Quality Statement – such as work, caring for children, their own health and financial issues. This also includes the carers’ social and economic wellbeing, and their ability to continue living the life they want to lead. In the final Quality Statement, the rationale should be expanded to include a carer’s ability to have control over day to day life. In addition to the above, Carers Trust would also like to see the risk of loneliness being highlighted specifically. We know that all carers face increased risk of loneliness, and that – for multiple reasons – carers of people with dementia are of particular risk of facing loneliness. We also know that loneliness can negatively impact an individual’s physical and mental health. We, therefore, would like to see this risk highlighted in the rationale (and later on in the definitions used) to ensure that service providers are aware that they need to take steps to combat potential loneliness amongst carers of people with dementia.
221	Carers Trust	Statement 7 (Structure)	Following on from the above, subsequent Quality measures should include “support”, “information” and “advice” in the subsequent sections. For example Structure a) Evidence that education and skills training are available for carers of adults with dementia” should be re-worded to read: “Evidence that **support, information** and **advice** training are available for carers of adults with dementia”

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222	Carers Trust	Statement 7 (Process)	Similarly, the "process" should read: "Proportion of carers of adults with dementia having a carers' assessment who have a discussion about **support, information** and **advice"**.
223	Carers Trust	Statement 7 (Definitions of terms used in this quality statement)	Carers Trust welcome the provisions set out about what this support would include. We believe it is crucial that carers of people with dementia are given information about the condition, are advised on how to care for someone with dementia, and how to look after their own health and wellbeing as well as the other provisions set out in this section. The relevant points under "Definitions of terms used in this quality statement" should also be adapted to reflect the changes we believe NICE should make set out above. Therefore, these would then read: • **information** about dementia, its symptoms and the changes to expect as the condition progresses • **advice on** developing personalised strategies and building carer skills • **information and advice** to help them provide care, including how to understand and respond to changes in behaviour • **advice** to help them adapt their communication styles to improve interactions with the person living with dementia If a carer expresses a desire to have more formal training on any of the above, then this should be provided as this would be tailored to their needs – as per the aims of this quality statement. This would help NICE better reflect the rationale behind the Quality Statement and make clear to service providers and commissioners that this statement is about supporting carers to maintain their own health and wellbeing.
224	Dementia Carers Count	Statement 7	This statement might be hard to measure because: - Family carers might not live in the same locality (data collection area) as the person with dementia for whom they care and therefore not think to register themselves as carers **The carer might not be registered as a carer with their GP because they might not yet identify themselves as a carer. Indeed, as much as we use the term 'carer' in our communications, we use terms that describe the relationship to the person with dementia eg 'are you a wife, husband, daughter, friend [etc] that supports or cares for a person with dementia?'**
225	Dementia Carers Count	Statement 7	The quality statement does not define the content or quality of the education and skills training that should be made available to family carers. Some services might meet one or two elements of the quality standard whereas we believe that Dementia Carers Count core course for family carers is likely to be one of the only services that meets all of the elements of the quality standard AND developed and delivered by qualified and experienced

ID	Stakeholder	Section	Comments
			allied health professionals. It will therefore be difficult to meaningfully measure education and training services available to carers
226	Dementia Carers Count	Statement 7	Quality services such as the Dementia Carers Count education and skills training courses are available to every family carer in the UK and are currently delivered in Birmingham and Swindon. Some carers organisations send their carers onto our residential course eg Brent Carers sent a minibus with 4 of their family carers to one of our courses and are sending another group of carers in May. How will data on this service be collected?
227	Dementia Carers Count	Statement 7	We are encouraged to know that NICE is working towards carers having good support to enable them to manage the stresses and demands of caregiving and to fulfil their role and that this includes both support for the specific challenges of caregiving and support to address their own needs. However, achieving this requires more than education and skills training. Resilience building is just as important, and this requires carers to live in dementia friendly communities and to be able to access a telephone helpline as well as counselling, coaching, peer support and respite.
228	Dementia Carers Count	Statement 7	There seems to be an assumption that carers of adults with dementia all have carers' assessment. Carers who have attended our courses frequently report that have not accessed a carers assessment. Using the proportion of carers of adults with dementia having a carers' assessment who have a discussion about education and skills training as a measure may not be may not reap sufficient or accurate data.
229	Dementia Carers Count	Statement 7	What the quality statement means for different audiences Service providers – Charities are not included in this list even though Charities currently provide a significant amount of services to family carers of people living with dementia.
230	Dementia Clinical Network NHSE; London	Statement 7	Suggest that statement is changed to 'Carers of Adults with dementia are offered psychoeducation and skills training intervention' to align with evidence base and NICE guidelines.
231	Dementia Clinical Network NHSE; London	Statement 7	An example of a Psycho education intervention is START (STrAtegies for RelaTives).
232	Dementia UK	Statement 7	Q1 Whilst education and skills training is important there is also the need for adequate specialist advice, support and regular breaks from their caring role. Q2 To focused on measuring education and skills training needs to have more on provision of specialist advice, support, and regular breaks. Not sure how education and skills training alone will improve carers quality of life! Q3 As stated in the comments for Statements 2-6 family supporters/carers need to be included every step of the way when a family member is diagnosed with dementia as they are the people providing the bulk of the care and support which "saves" the health and social care budgets.
233	The Lewy Body Society	Statement 7	Comments on Standard 7 – training and support for carers It is a huge challenge for health professionals to provide education and support for carers when the symptoms can vary so much between different types of dementia. A single programme for carers which did not have significant content about dementia sub-types would fail to meet the needs of Lewy body dementia carers.

ID	Stakeholder	Section	Comments
			We appreciate that the draft standards says that the training should be tailored to the needs of the carer. It goes on to list a number of ways in which carers' needs might vary – for example in relation to their employment status – but does not mention the different types of dementia. Again, we believe that a more explicit mention would ensure that the needs of Lewy body dementia carers are more likely to be met.
234	NHS England	Statement 7	The carer support standard reflects the key areas and helpfully pushes the carer health further up the agenda. The data collection for this should be easy to collect. The training and education is ongoing, crisis support and respite care can be difficult to put in place with pressures on the resources in social care. The carers assessment is not widely taken up despite it being mentioned at the dementia review and could be promoted especially if there are more services and help available to signpost from the assessment (employment rights, mental health, community connectors etc). But obviously this will take time and resources with health professionals in primary care, but little additional training. Generally respite and crisis care is managed acutely when the situation has deteriorated significantly when it could have been managed earlier but resources generally preclude/frustrate this.(PS)
235	Nottinghamshire County Council	Statement 7	Social Care Response: Locally, research undertaken/commissioned has identified support for carers of this with dementia as a need, including: • Dementia JSNA Chapter (2016 refresh) • Personal Budgets and Dementia project • 'Nottinghamshire County Council: Services for Carers' Recent consultation with carers has identified that having information and guidance to prepare them for the future is important, however this is not limited to education and skills training in the traditional sense, instead they have identified that they would also value: • Self-managed information and resources (library books, internet resources, e-learning) • Access to helplines/tailored personal advice • ALL health and social care practitioners consulting and involving carers in health discussions • Support to plan for the future – specific advice on power of attorney, and how to discuss future care planning and end of life with the person they care for while they have capacity to do this This support is most valued shortly after diagnosis when carers need support to understand their situation and the person with dementia has capacity to make decisions about their future. At this stage, it is unlikely that the person with dementia will be receiving social care as their condition is not advanced enough to be causing significant impairment and the carer will not yet have a formal assessment of their needs from the local authority.

ID	Stakeholder	Section	Comments
			Therefore, support needs to be promoted through universal information and advice services and primary care networks rather than through the local authority's assessment/review process.
236	Nottinghamshire County Council	Statement 7	Social Care Response: It is unlikely that training delivered in the traditional way will achieve this quality standard – there are not the resources to reach all carers. It is important that support is not linked closely to the carers assessment – this is for those where caring is having/likely to have an immediate impact on carer's wellbeing and support needs to be targeted at an earlier stage, in order to prevent caring having this impact. The Council is currently re-commissioning all carer support services, to provide an offer with a greater emphasis on prevention and a range of resources to promote self-help. Current dementia support services (Compass) focus only on carers of those with moderate/severe dementia and other carers can access advice and support through a generic carers support service. Dementia support services will be re-commissioned during 2019/20, to provide a service focused on early intervention, including advice, support and some training as well as referral to national resources such as those provided by Carers Trust. This reflects feedback from local carers that they would value support at an earlier stage, and also the need to reach more carers. It will not be possible to provide a more intensive support service/training programme to carers of those with dementia without additional resources, given the projected increase of around 50-60% in the numbers of carers with dementia within the next 15 years (national projections from health and social care data).
237	Roche Products Ltd & Roche Diagnostics Ltd	Statement 7	As specified in these standards, it is essential that carers have adequate support and training to enable them to manage the high demands in their role. This should include education of available treatments which addresses both potential benefits and safety considerations. This is critical as carers play a role in treatment decisions.
238	Royal College of General Practitioners	Statement 7 P27	Need to specify that this applies to Informal Carers
239	Royal College of General Practitioners	Statement 7 P27	Quality measures should include inclusion on Carer's register, offer of respite care
240	Royal College of Psychiatrists	Statement 7	We fully support this standard and agree with the outcome measures.
241	Royal College of Speech and Language Therapists	Statement 7 Page 29	Training should involve advising, supporting and training families and carers in effective ways to promote safe swallowing, reduce risk of aspiration and enable nutrition and hydration needs to be met.

ID	Stakeholder	Section	Comments
242	Royal College of Speech and Language Therapists	Statement 7 Page 30	Please specify allied health professionals in the section on health and social care practitioners. Allied health professionals such as speech and language therapists are a key provider of care and support to people with dementia and their families and should be added
243	Tide	Statement 7	Quality statement 7 Carers of adults with dementia are offered education and skills training Replacement care costs without means testing and minimal administration should be provided by the Local Authority if required.
244	Action on Hearing Loss	Additional area	A Quality Statement should be added on the importance of addressing deafness and hearing loss in adults living with dementia. This Statement is needed to ensure health and social care professionals are fully aware of the crucial role hearing aids and good communication can play in supporting adults with dementia to stay healthy. An increasing body of evidence suggests that hearing loss is associated with cognitive decline and dementia.7 People with mild hearing loss are at twice the risk of developing dementia; with a 3-fold increase for those with moderate hearing loss and 5-fold the risk for those with severe hearing loss.8 Hearing loss not only is associated with the risk of onset dementia, but also accelerates the onset of cognitive decline.9 Hearing loss can be misdiagnosed as dementia or make symptoms of dementia appear worse.10 Evidence also suggests ensuring hearing loss is properly diagnosed and managed may reduce the risk of people developing dementia in future. For example, a recent study identified hearing loss as the largest modifiable risk factor for dementia. If removed, the study states that 9% of dementia cases could be prevented.11 Early research also suggests that hearing aids might reduce the risk of cognitive decline and the onset of dementia.12

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[7] Lin FR et al, 2011. Hearing loss and incident dementia. *Archives of Neurology*, 68 (2), 214-220; Lin, et al, 2013. Hearing loss and cognitive decline in older adults. *Internal medicine*, 173 (4), 293-299; Gurgel et al, 2014. Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. *Otology & Neurotology*. 35 (5), 775-781; Albers et al, 2015. At the interface of sensory and motor dysfunctions and Alzheimer's disease. *Alzheimers and Dementia Journal*, 11 (1), 70–98. Deal, et al, 2017. Hearing impairment and incident dementia and cognitive decline in older adults: the health ABC study. *The Journals of Gerontology*, 72 (5), 703-709.

[8] Lin FR et al, 2011. Hearing loss and incident dementia. Archives of Neurology, 68 (2), 214-220; Lin

[9] Lin, et al, 2013. Hearing loss and cognitive decline in older adults. *Internal medicine*, 173 (4), 293-299; Gurgel et al, 2014. Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. *Otology & Neurotology*. 35 (5), 775-781

[10] Burkhalter CL, Allen RS, Skaar DC, Crittenden J and Burgio LD, 2009. Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviors. *Journal of American Academic Audiology*, 20 (9), 529-38.

[11] Livingston et al, 2017. Dementia prevention, intervention, and care. *The Lancet*. Available at: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6 .

[12] Amieva 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; Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. *PLoS ONE,* 10 (3): e0119616; Deal 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), 680-90.

ID	Stakeholder	Section	Comments
			Early intervention and on-going support for hearing loss may have an important role to play in reducing both the risk and impact of dementia. For example, Action on Hearing Loss estimated that properly diagnosing and managing hearing loss in people with dementia could save the NHS £28 million per year by supporting older people to remain independent for longer.[13] Although more evidence is needed to confirm what impact hearing aids might have on dementia, NICE's recently published Hearing Loss in Adults: Assessment and Management Guideline[1] states that hearing aids have the potential "to improve functioning and quality of life, and this could delay the progress of dementia or improve its management. The Guideline recommends that adults with diagnosed or suspected dementia should be referred to their audiology service for hearing assessment, because hearing loss is a comorbid condition. The Guideline also states that adults in this group should be reassessed every two years, if they have not previously been diagnosed for hearing loss. However, despite this, research shows that many more people could benefit from hearing aids than are currently doing so. For example, evidences suggests that only two-fifths of people who need hearing aids have them.[14] Adults with dementia may find it even more difficult to seek help for their hearing loss and get the most out of their hearing aids due to communication or memory problems. More also needs to be done to improve awareness of hearing loss and hearing aids amongst health and social care professionals supporting adults with living dementia. For example, it is estimated that over 80% of older people living in care homes need support for their hearing loss to maximise their independence and wellbeing,[14] but this often goes undiagnosed or isn't properly managed.[15] People who are deaf living with dementia may require specialist care and support that recognises the importance of good communication and/or takes account of the unique values and culture of the Deaf community. For example, people who are deaf may require a specialist support worker who is trained to

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Maharani et al, 2018. Longitudinal Relationship Between Hearing Aid Use and Cognitive Function in Older Americans. *Journal of the American Geriatrics Society*; Ray et al, 2018. Association of cognition and age-related hearing impairment in the English Longitudinal Study of Ageing. *JAMA Otolaryngology–Head & Neck Surgery*, 144 (10), 876-882.

[13] Action on Hearing Loss, 2013. *Joining Up*. Available from: https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/joining-up-report/

[14] NHS England, 2016. Commissioning services for people with hearing loss; a framework for Clinical Commissioning Groups (CCGs). Available from: https://www.england.nhs.uk/wp-content/uploads/2016/07/HLCF.pdf

[15] Echalier, 2012. *A World of Silence*. Available from: http://www.actiononhearingloss.org.uk/-/media/ahl/documents/research-and-policy/reports/care-home-report.pdf

ID	Stakeholder	Section	Comments
			communicate in British Sign Language (BSL). Evidence suggests that poor communication or lack of awareness of Deaf culture in care homes could lead to social isolation and deterioration in health and wellbeing.16
245	Alive	Additional area	People receive care from staff appropriately trained in dementia care – Alive still sees many instances in the 350 care settings we work in annually of poor staff understanding of the needs of people living with dementia. With a continuing shortage of care staff, this should remain a national priority for improvement. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships. This is essential to wellbeing, but this is something that is all too often neglected in the case of people living with more advanced dementia. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing. The exclusion of this measure is short-sighted, as the more people who can access appropriate services to maintain health and wellbeing, the less need there will be for medication or intensive health interventions. Hospital inpatients living with dementia have access to a liaison service – there is continuing evidence of shortcomings in hospitals' ability to meet the needs of people living with dementia and this should remain a national priority for improvement. People can participate in a review when their needs or circumstances change – dementia is a progressive disease and changing needs need to be monitored and reviewed regularly. People can access independent advocacy services – carers and people living with dementia are often left to fend for themselves, and independent advocacy is important form of support.
246	Alzheimer's Research UK	Additional area	We are concerned that statements around staff competence and skills have been removed. Given that many people with dementia access care in a range of clinical and care settings, it is crucial that all health and care staff across the NHS have consistent skills and competencies. This approach is also important in terms of considering multimorbidities as outlined in comment 3. Dementia Training Standards Framework outlines the skills and competences expected for various health and care practitioners.
247	Alzheimer's Research UK	Additional area	Given that recruitment of people to dementia studies is a well-recognised challenge in the field, we would highlight the need for the Quality Standards to promote research opportunities across the NHS and care sector including independent contractors (e.g. GP surgeries, care homes and community pharmacies) and are disappointed that this is not mentioned within the standards. This is despite the Dementia Clinical Guidelines (NG97, paragraph 1.1.11) stating that people with dementia should be informed of potential research studies they could be involved with.

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[16] Hunt et al, 2010. *Older people who use BSL – preference for residential care provision in Wales*. Manchester: University of Manchester; Parker et al, 2010. 'My Mum's Story' A Deaf daughter discusses her Deaf mother's experience of dementia. *Dementia*, 9(1), 5-20.

ID	Stakeholder	Section	Comments
			There are recognised benefits and reasons why people choose to take part in research, which benefits 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 memory clinics, doctors or other appropriate services. • Research will lead to outcomes that could benefit those taking part or future generations. • There is also good evidence that organisations that actively engage in research achieve better clinical outcomes across the organisation as a whole.
248	Alzheimer's Society	Additional area	**We believe there is strong evidence that dementia training for health and care professionals is a key area for quality improvement, and should be included as a QS.** From the stakeholder feedback table, 12 stakeholders that responded to the consultation suggested training, and yet it has not been included despite having more stakeholder support than several others that have resulted in QSs. We would disagree that 'people with dementia receive care from staff appropriately trained in dementia care' comes under the category of '*no longer considered national priorities for improvement'* (page 2 of the QS draft document). Appropriate dementia training is included as a commitment within the Prime Minister's Challenge on Dementia, which sets out key national priorities for dementia. Training in dementia is important so professionals can meet individuals' needs, which are complex and can be hard to understand without training. Staff must be equipped with skills to confidently deliver person-centred care. The Dementia Training Standards, commissioned by the Department of Health and developed by Skills for Health, Skills for Care and Health Education England, recommends professionals involved in direct care for people with dementia should be trained to Tier 2 as defined by the framework. Yet we have found evidence of staff without sufficient dementia training, and poor quality care as a result. For example, through our Fix Dementia Care reports, we have found: • Only 2% of those surveyed said all hospital staff understood the needs of people with dementia, and almost 60% of people we surveyed felt the person with dementia they know wasn't treated with dignity or understanding while in hospital. We found evidence of poor care, including discharge at inappropriate hours, use of excessive force including being handcuffed to the bed, visits from family members and carers being denied, people not being changed after incontinency, resulting from the lack of knowledge of staff in how to appropriately identify or meet the needs of people with dementia.

ID	Stakeholder	Section	Comments
			- In homecare, only 2% of people affected by dementia say homecare workers have enough dementia training, and 86% of homecare workers believe that dementia training would help them to provide better care. We found consequences of poor care included emergency admission to hospital from failing to identify infections, missing medication, and care workers refusing to make further visits to someone with dementia as they felt so unprepared and helpless. Training is measurable, as the Dementia Training Standards Framework sets out the three tiers of dementia training, and locally areas could record the number of staff receiving training to each of the tiers. Training is underpinned by NICE guidance, included in recommendation 1.13 of the dementia guideline. Though the document provides an explanation for not including training as a QS: '*Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased training. However, training may be referred to in the audience descriptors*' this would be a change, as the current QS does include training. We would suggest that as training requires improvement and would drive up quality of care, it should be a QS.
249	Alzheimer's Society	Additional area	**There are several other QSs that have been removed, and appear under a heading '*no longer considered national priorities for improvement*' (page 2 of the draft QS doc) that we would disagree with.** Most notable of these are: - People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area - People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
250	Alzheimer's Society	Additional area	**We would also propose the addition of a quality standard on use of person-centred, holistic care plans, developed in partnership with the person with dementia.** This is important because the needs of a person with dementia are complex and also change over time as the condition progresses. Person-centred planning is vital to ensure the right support is delivered at the right time to maintain health, independence and quality of life, and to avoid or delay crises, and plans should be recorded in a care plan. The Dementia Statements reflect things that are important to people with dementia, and care plans developed in partnership with the person with dementia can help meet the statement, '*We have the right to be*

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			respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future'. We frequently hear from people that report not receiving the support they need. In our Turning up the volume report 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. This suggests that whilst statistics from NHS Digital report around 65% of people with a diagnosis of dementia have a care plan that has been put in place or reviewed over the past 12 months, these may not always be fit for purpose. It may be that care plans are not sufficiently person-centred or developed in partnership with the person with dementia. Data collection measures could include people with dementia being partners in the development of their care plan, and people with dementia and carers having a copy of their care plan.
251	The British Psychological Society	Additional area	The priority highlighted in 2010 that 'people with dementia receive care from staff appropriately trained in dementia care' underpins many of the other quality standards identified. There remains however, doubts as to the effectiveness of models of dementia training in improving the care received by people living with dementia, in particular transferring classroom learning to workplace settings (Surr et al., 2017). An extensive review of the training literature and available evidence has led to the development of a clearer set of principles guiding dementia training (Surr & Gates, 2017) including an audit tool which providers can use to monitor and evaluate their training - Dementia Training Design and Delivery Audit Tool (DeTDAT) (available at: https://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/#study-outputs). It seems therefore, premature to remove training as a priority when it is only now we have clear evidence on the most effective ways to actually deliver it in a way that will have maximum impact.
252	Carers Trust	Additional area	The support available to carers should include access to respite. NICE has set out that one of the statements from 2010 quality standards that "are no longer considered a national priority for improvement" is: "Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia." By excluding this, NICE risks carers not accessing the respite they need and therefore risking their own health and wellbeing. We know that access to respite care is important for carers' physical and mental wellbeing. Access to respite is key to supporting carers maintain their own health and wellbeing, and we know that carers do not have consistent access to good quality respite care. NICE should be promoting access to respite by carers and this is crucial to providing the support they need.

ID	Stakeholder	Section	Comments
			We urge NICE to reinstate this expectation under Quality Statement 7 as part of the support carers can expect to receive.
253	Dementia Clinical Network NHSE; London	Additional area	Consider prescribing memantine for people with moderate Alzheimer’s Disease and offer people with severe Alzheimer’s disease, memantine. This could be measured through primary care records. This would be an important quality statement to add as this is a change in prescribing in primary care (as most specialist services discharge 6 months after diagnosis) and implementation of this will need supporting and monitoring
254	Dementia Clinical Network NHSE; London	Additional area	All services that provide care or support people living with dementia should provide staff with person centred care training.
255	Dementia UK	Additional area	Q1 Whilst education and skills training is important there is also the need for adequate specialist advice, support and regular breaks from their caring role. Q2 To focused on measuring education and skills training needs to have more on provision of specialist advice, support, and regular breaks. Not sure how education and skills training alone will improve carers quality of life! Q3 As stated in the comments for Statements 2-6 family supporters/carers need to be included every step of the way when a family member is diagnosed with dementia as they are the people providing the bulk of the care and support which “saves” the health and social care budgets.
256	Dementia UK	Additional area	The Quality Statement (*staff appropriately trained in dementia care*) from 2010 quality standards has been left out as not being a national priority, There is still widespread evidence from people living with dementia, families, Care Quality Commission reports and reports from other organisations that this is still not happening consistently. In some hospitals and services there is often the mistaken belief that a Dementia Friends awareness session is training and therefore staff do not consistently receive any further training on dementia. Training in dementia should still be a national priority to prevent the poor standard of care and support still being given to people living with dementia, and their families. The 2010 Quality Statement regarding carers receiving short breaks or respite is still relevant and should remain a national priority as carers often do not have access to this due to the financial pressures of both local authorities and families and also paucity of provision in many areas. Carers “save” health and social care spending whilst caring for their family member at home and so whilst respite/ breaks are not universally given in the form that families need, it should remain a national priority. The 2010 Quality statement on acute care should also remain as a national priority: "People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health"- There should be liaison services within each hospital setting that specialists in dementia - we know that

ID	Stakeholder	Section	Comments
			1 in 4 hospital beds are occupied by someone with dementia and the evidence base states that people with dementia have poorer outcomes in hospital. Having access to specialist teams within the hospital who work the people with dementia and their family from admission to discharge should definitely still be considered a priority.
257	Department of Health and Social Care	Additional area	However, we believe that it would be appropriate to maintain the quality standard relating to training in the 2010 standards People with dementia receive care from staff appropriately trained in dementia care, as the Dementia 2020 Challenge highlights the importance of dementia training for health and social care staff, particularly at tier 2 and tier 3 levels.
258	The Lewy Body Society	Additional area	Our overall response to the draft quality standard In general, we support the draft quality standard and believe that it does focus on the key areas for quality improvement. However, we feel that there is too little focus on the sub-types of dementia, with a risk that there may be a lack of recognition of the diversity of experience of people living with different types of dementia. We note the comments made by Parkinson's UK in the initial stakeholder exercise that informed the draft standard about the need to improve diagnosis of dementia with Lewy bodies and Parkinson's dementia, and welcome the evidence that they provided. Others also referred to sub-types. For example the Royal College of Psychiatrists said: "People with non-Alzheimer's form of dementia should also have access to improved assessment and treatments (e.g. vascular disease, lewy body disease…) with some access to subtype specific treatment pathways." We welcome this statement in the narrative of the briefing paper: "Stakeholders felt that identifying a dementia subtype in a specialist diagnostic service is a quality improvement area, as knowing the subtype will determine how dementia is managed. Getting a diagnosis in the right setting also allows for planning services and coordinating care." However, it isn't clear in the draft standard how this view from stakeholders has been responded to. The issue of dementia sub-types may be implicit throughout the entire standard – for example personalised care plans would of course be dependent on the type of dementia – but we believe more explicit acknowledgements of the types of dementia would be helpful. We are also disappointed to see that training is no longer considered a national priority for improvement. We believe that while there has been an improvement of awareness about dementia generally, and training is now more fully embedded across the health and care sector than it was when the quality standard was last revised, there is still a need for further training on dementia sub-types. We hear very regularly from patients, and the carers of people with Lewy body dementia, that they come into contact with professionals (particularly in primary and social care) who do not have knowledge of Lewy body dementia. This appears to be backed up by the evidence provided by the Alzheimer's Society, Alzheimer's Research UK and others in the briefing paper.

ID	Stakeholder	Section	Comments
259	MHA	Additional area	**Does this draft quality standard accurately reflect the key areas for quality improvement?** Partly - we are pleased to see recognition for the skills and education needs of carers of people living with dementia. However we are disappointed that the 2010 statement *'People with dementia receive care from staff appropriately trained in dementia care'* will no longer be considered a national priority. In our experience, while great achievements have been made in the training of health professionals, training of social care staff – by suitably qualified and experienced trainers - needs continued focus, particularly those in domiciliary care and supporting organisations. We believe there should be continued national commitment to ensure a range of staff are trained in dementia care and this should continue to be reflected in the standard.
260	MHA	Additional area	We are also disappointed that the 2013 statement '*People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support'* is no longer considered a national priority. The message that this statement conveys is not apparent in any of the new standards and we feel 'choice and control' needs great emphasis either by re-adopting this statement as a priority or embedding the message clearly throughout the new statements.
261	MHA	Additional area	We are disappointed that the 2013 statement '*People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships*' has also lost national priority status. In the context of the national recognition that tackling loneliness has been given (e.g. the Government's Loneliness Strategy) we believe this statement should be reinstated. The Alzheimer's Society report that over a third (35%) of people living with dementia said they have felt lonely recently (Turning Up the Volume report, May 2017) and a third of people living with dementia also said they had lost friends following a diagnosis. People living with dementia who experience loneliness should be given support to maintain their existing relationships and develop new ones. From our experience in treating people living with dementia with music therapy, we know first-hand how important relationships are and how music therapy can be a used to enable the individual to reconnect with relatives and friends and connect with care staff, improving their all-round wellbeing and care.
262	MHA	Additional area	We are disappointed that the 2010 statement '*People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area*', has been deprioritised. Although it is covered in part by the new Statement 6, we feel it is vitally important that a person diagnosed with dementia is fully informed about their condition, treatment and what support is available in a local area and that this should be explicitly outlined.
263	National Institute for Health Research, Clinical Research Network.	Additional area	*Insert new statement:* "Those with concerns that they have a diagnosis of dementia should be informed of research opportunities at all stages of condition about research studies they could participate in." Although this is difficult to measure directly, there are a number of surrogates that could identify variations in practice: 1) the number of patients in a given area that have been recruited into research studies, information available via the National Institute for Health Research Clinical Research Network.

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			2) the number of people in a clinic, Trust, or GP surgery that have undergone the Join Dementia Research (JDR) Awareness Tool training. 3) records on the number of approaches made to patients regarding invitations to Join Dementia Research, and to inform patients on research opportunities. By increasing the numbers involved in research, new approaches to slowing, halting and even preventing cognitive deterioration will be found to be effective. Background In addition to identifying advances in dementia care, participation in research is also correlated with positive outcomes: there is also evidence that patients receive improved care from research-active institutions (such as Jonker et al, published in Journal of Evaluation in Effective Clinical Practice, February 2019), and report a positive experience of participation in research (CRN Patient Experience Survey 2018). Research activity has been accepted as a marker of being well-led in the Care Quality Commission's inspection framework (September 2018) and in the national patient experience survey for acute trusts. Increasing the numbers of people participating in dementia research and joining the register Join Dementia Research are key targets in the Government's 2020 Dementia Challenge. Join Dementia Research - www.joindementiaresearch.nihr.ac.uk - provides real-time matching of a registrant through information provided to relevant studies based on inclusion and exclusion criteria. It thus provides information on all relevant studies, regardless of location. The JDR Awareness Tool is being disseminated in March 2019 and will provide a measure of those who has successfully completed the training. This measure will also provide support to the Dementia 2020 Implementation Plan (Annex 2: Roadmaps to 2020 Delivery): "All relevant staff able to signpost interested individuals to research via 'Join Dementia Research'."
264	Parkinson's UK	Additional area	We believe this quality standard must include a statement on dementia training for health and social care professionals, we recognise the previous standard included a statement on this, however dementia training for staff remains a key area of quality improvement. For dementia care to improve health and social care professionals require the skills and knowledge needed to provide a person-centred approach to care. An Alzheimer's Society survey of people with dementia on hospital care found just 2% (Alzheimer's Society (2016) 'Fix Dementia Care: Hospitals') of respondents felt that hospital staff understood people with dementia's specific needs, and as a result led to poor quality care. This was also found to be the case for those receiving homecare where only 2% (Alzheimer's Society (2016) 'Fix Dementia Care: Homecare') of people with dementia said that homecare workers have enough dementia training, and 86% of homecare workers said dementia training would enable them to deliver improved care.

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			Research commissioned by Parkinson’s UK carried out by Firefly Research and University of West of Scotland into care for people with Parkinson’s dementia and dementia with Lewy bodies in care homes found the majority of care home staff reported a low level of awareness of Parkinson’s related dementia which was in part due to a lack of training on these subtypes of dementia. With care home staff finding hallucinations and delusions, reactions to medication for hallucinations, unusual sleep disturbance, distress or behaviour that staff find challenging as particularly difficult to handle given the lack of training. Dementia training and education for all staff working with people with dementia is a recommendation (1.13) in the recently updated NICE Guidance on dementia (NG97). As well as forming a key commitment in the Prime Minister’s Challenge on Dementia making it a national priority. It is also measurable as the Dementia National Training Framework includes three tiers of dementia training which could be tracked locally by the number of staff who have completed each tier of training.
265	Public Health England	Additional area	It is unclear how specific housing for people living with dementia (and their carers) will be addressed within the new standards
266	Public Health England	Additional area	Respite care for carers should be included in the guideline: this is an important aspect of enabling carers to continue with their caring role over a long-term period, and may not be picked up through a carer’s needs assessment
267	Tide	Additional area	• I think some of the statements from the previous 2010 quality standard should be included in the new changes. Such as: People with dementia receive care from staff appropriately trained in dementia care. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia. If it’s national then there’s a better chance of being accessible to all rather then select few. • Education for communities so that a more inclusive experience is available for people living with dementia and their carers • I do not understand why some of the 2010 and 2013 standards are no longer considered national priorities. If the aspiration is 100% or 0% and the standards are still required at the local level then the national standard cannot have been achieved. If localities can choose whether or not to implement this standard there is a danger of producing post code lotteries which are generally considered to be unfair and discriminatory. I am particularly concerned with the statement from 2010

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			“People with dementia receive care from staff appropriately trained in dementia care” should remain a national priority. It would be interesting to see the evidence that NICE is relying on to assert that this no longer needs to be a national priority. I am also concerned about the 2013 standard “People with dementia are enabled with the help of their carers to maintain and develop their involvement in and contribution to their community. Socialization is an important part of a person’s identity but for people with dementia it can be difficult and stressful. There is very little provision of appropriately modified social opportunities. The statutory services should be required to consider providing suitable venues and travel arrangements to allow people with dementia to socialise in a low stress and physically understanding environment. • REHABILITATION RE-ENABLEMENT therapeutic services physio ot speech and language therapists. More therapy intervention in the community to avoid hospital admissions. This would also give personal skill training for carers to encourage retaining independence. Care plans should include an annual examination of sight and hearing and corrective aids supplied where possible. You can be isolated in a crowded room if you can’t hear or see. • Access to help with home care/ Access to suitable care home provision/access to suitable end of life care. More help for carers and suffers, understanding of a practical nature from local authority run care services not learning from a Book but by organisation who have lived experience and knowledge from carers and suffers! • Help for the carer not just teaching as everyone is different, you need an ear to listen more than anything • I am challenged with the significant number of individuals diagnosed with Alzheimers without full testing and consideration of other conditions with the subsequent 'buy in' to the medical condition by family and carers • More needs to be done for carers of people with dementia. • Everyone with Alzheimers and their carers deserve the best care and support regardless of the area that they are from and treated on an individual basis. • Person centred holistic care needs an experienced multidisciplinary team. In the community working with the family teaching them the skills needed to support their relatives.

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			• Involvement of speech and language therapists in supporting people with dementia is not early enough. Linking with pharmacy in the community and assisting in reminding in the taking of medication is poor.

Registered stakeholders who submitted comments at consultation

- Action on Hearing Loss
- Association for Dance Movement Psychotherapy UK
- Alive
- Alzheimer’s Research UK
- Alzheimer’s Society
- Association for Family Therapy and Systemic Practice UK
- Association of British Neurologists
- Berkshire Healthcare NHS Foundation Trust
- British Psychological Society
- British Dietetic Association
- British Geriatrics Society
- Carers trust
- College of Optometrists
- Compassion in Dying
- Dementia Carers Count

- Dementia UK
- Department of Health and Social Care
- Lewy Body Society
- London Dementia Clinical Network, NHS England
- MHA
- National Institute for Health Research
- Neurology Academy
- NHS England
- Nottinghamshire County Council
- Parkinson’s UK
- Public Health England
- PJ Care
- Roche
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Occupational Therapists
- Royal College of Physicians
- Royal College of Psychiatrists
- Royal College of Speech and Language Therapists
- Skills for Care

- Society and College of Radiographers
- Sunrise Senior Living UK
- Tees Esk and Wear Valleys NHS Foundation Trust
- Tide