National Institute for Health and Clinical Excellence

Care of people with Dementia
Scope Consultation Table
14 March – 13 April 2012

Row	ID	Stakeholder	Order No	Section	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	003	Bournemouth University	General		The scope is comprehensive and a positive move forward for dementia care.	Thank you.
2	005	Gloucestershire Hospitals NHS Foundation Trust	General		Positive document	Thank you.
3	005	Gloucestershire Hospitals NHS Foundation Trust	General		Would need to review content of the guideline as it evolves regarding application of the social care standard within Acute Care Setting and who this would apply to i.e. roles & responsibilities, state that it is intended for the social care sector, then that it will also apply to all hospital areas.	Thank you for your comment. Alignment with the published dementia quality standard will be made clear at consultation. The group is keen to ensure integration of support delivered by social and health care.
4	005	Gloucestershire Hospitals NHS Foundation Trust	General		Need to ensure consultation with all providers from Independent Care Sector and Social Care providers.	Thank you for your comment. NICE has published a list of the registered stakeholders who we will contact at consultation. Any organisations wishing to comment are able to register as stakeholders via the NICE website
5	005	Gloucestershire Hospitals NHS Foundation Trust	General		Would welcome the opportunity to comment on the guideline documents as it evolves.	Thank you for your comment. Consultation on the draft quality standard will commence in August 2012.
6	006	Carers Trust (formally The Princess Royal Trust for Carers)	General		There needs to be a clear link in each section to carers otherwise the ability and capacity of service providers to achieve the requirements identified in SCIE Implementing the Carers (Equal Opportunities) Act 2004 will be compromised.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be more apparent in the draft quality

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						standard.
7	006	Carers Trust (formally The Princess Royal Trust for Carers)	General		The requirements of the Equalities Act will be achieved more comprehensively by the inclusion of carers, many older members of the BME community are heavily reliant on family carers to access any health or social care services.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be more apparent in the draft quality standard.
8	009	British association of social workers	General		It is felt that the scoping exercise is excellent, albeit challenging in its breadth.	Thank you.
9	009	British association of social workers	General		The involvement of a wide group of stakeholders in the scope is welcomed, particularly carers / lay members	Thank you.
10	010	College of Occupational Therapists	General		The College of Occupational Therapists welcomes the development of the social care quality standards on the care of people with dementia. We have the following comments to make at this stage.	Thank you.
11	011	NHS Sheffield	General		Thanks, I'll comment as a doctor and a carer - I would want to say that giving good care to someone with Dementia is immensely challenging and at times very distressing. Carers need a lot of support and this needs to be ongoing - often funding is for short-lived interventions, other than basic caring which is ongoing but is often dependent on the personal qualities of individual carers who "go the extra mile" to improve people's quality of life. People with Dementia and their carers - both unpaid/family and paid in all settings, need ongoing support and training to deal with the day to day difficulties. Staffing levels need to be appropriate - currently they are often not enough to ensure time for someone as an individual and quality of life through personal interactions that are not rushed. There also need to be ready access to senior staff to deal with crises and enough staff to reduce stress and crises, and to allow time out after stressful interactions. There needs to be regular meaningful activities. As more people with Dementia are assessed as "Care", rather than "Nursing need", more people with Dementia are cared for in Care Home settings with fewer staff. The effect of this on the person, staff and other residents is often not acknowledged, and can be detrimental to them all. This guidance needs to address this, and must not shy away from	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard. The group also agrees that the training of staff and appropriate staffing levels are vital to delivery of high quality care. Your comments will be considered when developing the quality statements and measures.

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					making us face up to the plight of our elderly, and their families.	
12	013	Hampshire County Council Adult Services Department	General		Given that these standards are to be social care standards, overall they do not well reflect a social model perspective as they have an over emphasis on assessment rather than support planning to meet outcomes defined by people with dementia and their carers. It still feels a bit like a health service document or dated social care one..	Thank you for your comment. The Topic Expert Group acknowledged that a social model of care should be better reflected.
13	014	Royal College of Speech and Language Therapists	General		There is a lack of focus on dysphagia (eating, drinking and swallowing problems	Thank you. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
14	015	Tunstall Healthcare	General		Tunstall welcomes the selection of dementia as one of the first areas to be selected as a social care quality standard. A range of recent reports have demonstrated that care for people with dementia varies greatly across the country and the quality standard should be used to set out for commissioners how to commission high quality care services for people with dementia. The financial cost of dealing with dementia has been estimated to be £17 billion a year and given the ageing population and difficult fiscal position of the Government finances expected in the coming years, a new approach to how we care for people with dementia is needed with the focus being on shifting care into more cost-effective settings in the community, through using services such as telecare. The development of the standard should reflect this. Tunstall welcomes the focus in the scoping document on a range of care settings particularly people's homes, including assisted living accommodation and residential care homes. The quality standard should look at ways to bring high quality care closer to the individual and their carer and telecare can play an important role in this. Telecare sensors can help support people with dementia in a number of ways by managing risks to independence caused by their condition, including: Raising alerts following wandering (40% of people with dementia wander)– through use of property exit sensors and bed occupancy sensors	Thank you for your comment. The quality standard will apply to people living with dementia in their own home. The Topic Expert Group will consider the importance of assistive technologies and adapting environments when developing the quality statements and associated measures..

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					Managing falls – through bed occupancy sensors and inactivity monitors Environmental concerns – flood detectors, temperature extreme sensors, carbon monoxide detectors and a natural gas detector Personal health and medication issues – medication reminders, enuresis sensors, epilepsy sensors Support for carers – all sensors linked to a carer pager or pillow vibrator It will be important in developing the standard that the statements within it are measurable and supported with clear and definable outcome measures that can be used to assess the performance and effectiveness of services. The measures developed should also be included in other frameworks to measure commissioner performance, particularly the Adult Social Care Outcomes Framework (ASCOF) and where there is cross over with health, measures should be included as joint indicators in the NHS Outcomes Framework and the Commissioning Outcomes Framework. This will help incentivise improved performance by commissioners and allow commissioner performance to be benchmarked across the country. There is a welcome focus on co-ordination between health and social care in the scoping document and in order that this is delivered it will be important that the social care quality standard aligns with the healthcare standard and both seek to drive high quality care which improves outcomes for users and delivers efficiencies for commissioners.	
15	016	Sue Ryder	General		We welcome this draft scope, but hope that it effectively builds on, rather than duplicates, the standards as set out in the dementia quality standard June 2010. Evidence that there is synergy between the two quality standards needs to be demonstrated.	Thank you for your comment. The method to best show alignment between the two products is being examined.
16	016	Sue Ryder	General		Further consideration needs to be given to the different ways in which people with dementia, their families and carers access support. The standard needs to recognise the different delivery methods. For example, increasingly there is encouragement for the establishment and development of self sustaining support networks, supported by the voluntary sector. People often draw on informal support and advice from the internet, blogs, email and advice lines.	Thank you for your comment. The Topic Expert Group recognises the importance of appropriate information provision and signposting of services. Your comments will be considered when drafting the quality statements and associated measures.
17	018	Action on hearing loss	General		We welcome the outlined proposals to develop a social care quality standard in dementia and, in particular, the focus of the standard on	Thank you.

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					personalised services and the need to integrate health and social services.	
18	018	Action on hearing loss	General		We strongly welcome the inclusion of recognition and response to the symptoms of sensory loss in the section on assessment and diagnosis. Ineffective management of hearing loss can make the symptoms of dementia worse and/or appear worse. Similarly, the effective management of hearing loss can improve the quality of care experienced by people with dementia. Therefore, it is essential to take into account the impact of hearing loss both at the time of assessment and diagnosis of dementia but also throughout the period while care is being delivered. We have covered our response to this in more detail in the relevant sections.	Thank you for your comment.
19	021	Alzheimer's Society	General		• Alzheimer's Society welcomes the comprehensive nature of the scope. Many of the areas and activities that will be considered support the commitments in the Prime Minister's challenge on dementia, launched on the 26th March 2012. The challenge is an ambitious programme of work to push further and faster to deliver major investments in dementia care and research by 2015, building on the work of the National Dementia Strategy (2009). • In particular the challenge covers: o Increasing diagnosis rates through regular checks for over-65s o Financial rewards for hospitals offering quality dementia care o A dementia care and support compact signed by leading care home and home care providers o Promoting local information on dementia services o Ensuring that communities are working to help people to live well with dementia • It is vital that the pilot social care quality standards on dementia reflect and support the Prime Minister's commitments. The Society therefore supports the fact that the scope: o Covers all stages of the dementia journey from possible symptoms through diagnosis to end of life. o Emphasises personalised care, with recognition of the importance to engage and actively participate in meaningful activities and be involved in the community. o Recognises the importance of de-stigmatisation	Thank you for your comment. The draft quality standard will show appropriate links to the relevant policy context.

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					o Involves people with dementia in service improvement o Recognises the need to support informal carers • Some of the comments below also highlight ways in which the scope can further support the delivery of major improvements in dementia care.	
21	022	Royal college of nursing	General		The Royal College of Nursing welcomes proposals to develop this quality standard. It is very timely. The aim and objective of this scope is appropriate.	Thank you.
22	022	Royal college of nursing	General		As with comments on 3.3.1 c, the standards should drive the message around maintaining the person's rights as an integrated member of the community	Thank you for your comment. The Topic Expert Group recognises the importance of maintaining involvement in the wider community. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
23	022	Royal college of nursing	General		In view of the current financial climate, it would be helpful to know if budget will be set aside for the implementation of this care standard.	Thank you for your comment. This topic is a pilot quality standard being developed by NICE. Availability of additional funding is not within NICE's control.
25	026	Royal college of general practitioners	General		The scope seems wide and relevant. We would be keen to see the socially excluded being part of this scope and you have mentioned people with Learning disability. The needs of ethnic minorities also needs special mention. It is also highly relevant that end of life matters is included.	Thank you for your comment. The group recognises the importance of including all groups of people who may need special consideration. People from ethnic minorities would be included in "people with characteristics covered by the Equality Act 2010". The group also recognises the importance of end of life care, your comment will be considered when developing the quality statements and associated measures.
26	029	Foundation	General		The FTN is pleased to comment and share our member trusts' views on	Thank you for your comment.

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		Trust Network			this quality standard: improving the dignity, quality and effectiveness of care for patients with dementia is a priority for both providers and commissioners, and reflecting the provider voice in shaping and improving these services is essential for delivering better care to patients. The key driver for quality improvement is the board of the provider organisation as it is ultimately accountable for the delivery of high quality care - setting quality objectives, tracking performance and benchmarking against its peers to learn and develop. The draft scope of the standard NICE has provided is comprehensive and focuses on the most important areas. Based on feedback from members and the results of the recent Foundation Trust Network Elderly Care Services Benchmarking study we have provided comments on specific sections below.	
27	030	Inner North West London Primary Care Trusts	General		The scope for the Standards covers the main areas that people with dementia and their carers often talk about, but doesn't appear to make a distinction about support across the full spectrum of dementia conditions, the sub-types, (such as Korsakoffs and Pick's) and the unique difficulties that patients/people with dementia and their carers experience as their individual condition deteriorates.	Thank you for your comment. The scope does not distinguish between sub-types of dementia. Where differences in quality of care occur between sub-types, this will be examined by the expert group.
28	030	Inner North West London Primary Care Trusts	General		There needs to be adequate ongoing support from community services to prevent unnecessary admission into care homes, and this must address the needs of people with needs at the severe end of the spectrum. People who do not have physical frailties, but who are at risk in their own homes, may need better partnership working across health and social care services (especially from MH trusts) in order to remain at home for longer, and more must be done to support social care to provide assistive technology and the necessary monitoring and support for people living alone.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
29	030	Inner North West London Primary Care Trusts	General		There is a nod to personalisation, but from experience people with dementia and their carers struggle with this, and there should be a clear indication to ensure people have appropriate local information to support any decision around personalisation	Thank you for your comment. The group acknowledges that the quality standard should address personalisation of support. The Topic Expert Group will consider your comment when developing the quality statements and associated

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30	034	Parkinson's UK and the Lewy Body Society (LBS)	General		We note from the background documentation that the intention of the Quality Standard is to represent good practice that is not currently being delivered consistently by social care professionals and providers and support the aim to address unacceptable variations in delivery. This is a key aim of Parkinson's UK's "Fair Care campaign" as people are subject to a postcode lottery of services, in some cases of unacceptable quality. We are concerned about the process by which social care QS will be used to drive up the quality of local services and whether social care QS have the potential to be used as a benchmarking tool to hold local providers to account. Social Care QS do not appear to feed into an accountability system, unlike Health QS which, along with the NHS Outcomes Framework are being used to develop the NHS Commissioning Outcomes Framework (COF). The NHS Commissioning Board, will use the COF to measure the health outcomes and quality of care (including patient reported outcome measures and patient experience) achieved by clinical commissioning groups. The COF will allow the NHS Commissioning Board to identify the contribution of clinical commissioning groups to achieving the priorities for health improvement in the NHS Outcomes Framework, while also being accountable to patients and local communities. It will also enable the commissioning groups to benchmark their performance and identify priorities for improvement. In this manner, the Health QS will input into an accountability framework, which will be scrutinised by a central body to ensure local clinical commissioning groups are commissioning the appropriate services for the local population. It is unclear how the Social Care QS will inform the adult social care commissioning outcomes framework (ASCOF) to help local authorities report on outcomes they are delivering on social care. The ASCOF is not a national management tool and government will not seek to set targets or manage the performance of councils in relation to any of the measures in the framework. Given the lack of an equivalent	Thank you for your comment. The quality standard will contain audience descriptors, detailing what the quality statements mean to each audience. We are working with our partners to identify how they may be integrated in the health and social care accountability frameworks in the future.

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					accountability framework overseen by a central body, we are concerned that providers and commissioners will not have to consider the social care QS with the necessary regard needed to drive up standards, in the way that is envisaged for health counterparts. Our suggestion is that the Scope should include an introductory section about how the QS may be used by different stakeholders. For example, individuals may wish to use the QS to determine whether they are receiving a high quality service, and commissioners may use the QS as a mechanism to drive up the standards of services in their area. Potential stakeholders include: o Individuals wanting to buy a service (self funders and those who have direct payments/personal budgets) o Individuals in receipt of services o A carer for someone in receipt of services o Social care professionals o Provider/managers of services o Healthwatch organisations o Health and Wellbeing BoardsDirectors of Adult social services o Local authority commissioners	
31	034	Parkinson's UK and the Lewy Body Society (LBS)	General		It is notable the scope document doesn't propose a section to define social care. It seems at present the scope of the QS will be very much focussed on personal care although this may not be what is envisaged. The QS must ensure that it includes that people with dementia must have the opportunity to live an independent life. We make some suggestions for where additional, ancilliary services and activities should be included in scope in detailed comments, but a general comment would be for the QS to reflect upon the Law Commission's suggested definition of adult social care and the outcomes that social care should aim to achieve. The recommendation in its review of adult social care law is: *Community care services (however named) should be defined in the statute as any of the following provided in accordance with the well-*	Thank you for your comment. The Topic Expert Group agrees that the quality standard should help promote opportunities to live an independent life. Your comment will be considered when drafting the quality statements and associated measures.

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					being principle: *(1) residential accommodation;* *(2) community and home-based services;* *(3) advice, social work, counselling and advocacy services; or* *(4) financial or any other assistance.* *The statute should set out the following list of outcomes to which the wellbeing principle must be directed:* *(1) health and emotional well-being;* *(2) protection from harm;* *(3) education, training and recreation;* *(4) the contribution made to society; and* ***(5) securing rights and entitlements.***	
32	035	Care Quality Commission	General		We know that NICE is well aware of the need for clarity between social care quality standards and other quality initiatives but we think further clarification may be needed on how the pilot adult social care quality standard on dementia would fit alongside the existing quality standard on dementia, published in 2010. Both appear to be relevant across health and social care sectors. Is the intention to have one all encompassing quality standard to cover all health and social care settings, or to separate them out more clearly into two distinct documents? For example, the inclusion of hospital emergency departments within a social care quality standard may cause some confusion unless there is a clear rationale.	Thank you for your comment. The method to best show alignment between the two products is being examined.
33	035	Care Quality Commission	General		In response to the consultation question about how the scope could be changed to better promote equality of opportunity relating to age, disability, gender, gender identity, ethnicity, religion and belief, sexual orientation or socio-economic status - there could be an overarching statement that says that services should have due regard to eliminating discrimination and advancing equality of opportunity on these grounds. More detail could then be embedded in the 'areas and activities' section.	Thank you for your comment. The group will consider your comments when drafting quality statements and associated measures.

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34	035	Care Quality Commission	General		A number of equality bulletins were produced by one of our predecessor organisations. We have attached these for your information. It may be helpful to cross reference to these where appropriate, or to use some of the helpful check lists found at the back of the documents. The equality bulletins were felt to be well received by the adult social care sector at the time they were published and could prove useful in making the NICE pilot quality standard meaningful within this sector. Sections 3.3.1b) personalised care, and 3.3.1c) delivery of care, may particularly benefit from reference to these equality bulletins where appropriate.	Thank you for your comment. These have been shared with the NICE technical team for consideration.
35	035	Care Quality Commission	General		The National Dementia Strategy has been cited as a reference in the policy context Appendix 1. Will a more explicit link be made between the final quality standard and the National Dementia Strategy once published?	Thank you for your comment. Relevant policy context is examined during the development of all quality standards. The method of linking to the National Dementia Strategy will be examined once the draft quality standard has been developed.
36	035	Care Quality Commission	General		More emphasis could be given to the importance of sharing data between services on people's history, not only clinical notes, so that personalised and effective care can be delivered, especially if people have lost the direct ability to communicate their needs and wishes. This could potentially fall within both/either sections 3.3.1c on delivery of care or 3.3.1d on organisation of services.	Thank you for your comment. Your comments will be considered when drafting the quality statements and associated measures.
37	036	Chartered Society of Physiotherapy	General		AGILE welcome the scoping of Social Care standards for people with Dementia and hope this will contribute towards the dignity and care agenda for people with Dementia	Thank you.
39	038	NTW NHS Foundation Trust	General		I am a Clinical Psychologist involved in the assessment of more complex presentations of those with a query of dementia. Many of the people I meet with find themselves diagnosed with the controversial diagnosis of 'Mild Cognitive Impairment', MCI (not all of whom later convert to a dementia) Having read through the consultation document I could not find a mention of this group (or the more recent term of "cognitive impairment not otherwise specified') and their needs. Those finding themselves in this MCI category may find themselves in a very difficult position of uncertainty (will this or won't this convert to a dementia for example),	Thank you for your comment. The scope has been amended for clarity. The quality standard will be for people living with probable or diagnosed dementia. It is envisaged that a number of statements will apply to people before a formal diagnosis of dementia. Your comments will be considered when drafting the quality statements and associated measures

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					living with changes in their cognitive functioning, but frequently without the service support to help them make sense of this. This may also be a growing group as we look to the identification of dementia at earlier stages in the process.	
40	001	Lost Chord	General	General	In the light of growing concern for the over prescribing of antipsychotic drugs, would it not be appropriate to include some discussion/ research into alternative therapeutic approaches particularly music which is often the only successful stimuli in the care of people with dementia at all stages of the disease.	Thank you for your comment. The Topic Expert Group will consider your comment when drafting the quality statements and associated measures.
41	025	Registered Nursing home association	3		The need is for a practical guide to identify the key aspects of dementia care that are missing in day to day provision, not to re-emphasise the need for care planning. In other words we must concentrate the standard on the essential elments which need to be implemented. I our view that is to move away from task based care to truly "personalised care", and then to go on and define the essential elements of that care ie taking and active use of life histories, the provision of meaningful activity for each and every person living with dementia on a 24hrs a day basis, and the reality of every day choices and risk taking by that person.	Thank you for your comment. Quality statements are intended to be aspirational, but achievable, markers of high-quality care. Comments will be welcome at consultation on whether the draft quality statements are truly markers of high quality.
42	025	Registered Nursing home association	3.1		It must be recognised that "task based care" is no longer deemed acceptable.	Thank you, your comment will be considered.
43	029	Foundation Trust Network	3.1	populati on	The proposed scope for the quality standard sets out that people without suspected or diagnosed dementia will not be covered by the standard – we would be grateful for clarity on how the standard will relate/address older patients who present with delirium but may not have suspected dementia.	Thank you for your comment. The quality standard is not intended to address the care of people with delirium.
44	007	Age UK	3.1.1		The standard needs to provide a definition of 'formal' care services. This is necessary because some elements of service provision are publicly funded but arranged by individuals (for example, through the use of direct payments) and it is not clear whether care assistants employed by a budget holder would be covered under this definition.	Thank you for your comment. This section of the scope has been amended to make it simpler.
45	007	Age UK	3.1.1		There is a group of people who are not covered that should be – those who have suspected or diagnosed dementia but who are not eligible for formal social care services. There are many older people who do not receive Local Authority funded care services because their needs are	Thank you for your comment. This section of the scope has been amended to make it simpler.

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					not high enough for them to qualify. They nevertheless might have suspected or diagnosed dementia and could choose to fund services privately. They should be covered by the standards. We suggest that section 3.1.1 b is reworded to read 'people with suspected or diagnosed dementia who access social care support and who are not funded by their Local Authority'.	
46	021	Alzheimer's Society	3.1.1	a) and everywhere the word "suspected" is used.	Use of the word "suspected" is potentially stigmatising. "Suspected" has negative connotations and is more usually associated with crime than health. "Possible dementia" or "Indications or possible symptoms of dementia" would be an alternative, neutral way of saying it. Or as in Section 3.3.1 a) "people with symptoms suggestive of dementia".	Thank you for your comment. The language has been altered.
88	018	Action on hearing loss	3.1.1		Population We welcome inclusion of people funding their own care. As local authorities tighten their eligibility criteria this group of people will increase in number. It is essential that the quality standard covers this group.	Thank you for your comment. This section of the scope has been amended to make it simpler.
47	034	Parkinson's UK and the Lewy Body Society (LBS)	3.1.1	a	The Standard must be applicable to all types of dementia recognising that different dementias affect people in different ways and require different types of treatment, care and support. Parkinson's UK and the Lewy Body Society draw NICE's attention particularly to Parkinson's Disease Dementia (PDD) and Dementia with Lewy Bodies (DLB). The prevalence of PDD and DLB among people aged 65 years or more of 0.3 per cent and 0.7 per cent respectively, together accounting for about 20 per cent of all dementia DLB is the second most common type of dementia after Alzheimer's Disease (AD), contrary to the National Dementia Strategy's description of it as 'rare'[1]. The clinical features of the Lewy body dementias (DLB and PDD) differ from AD (Lennox, 2012). In the early stages, while memory may be relatively intact, someone with a Lewy Body dementia may have:	Thank you for your comment. The quality standard will present markers of high quality care for all people with dementia. Areas focussing on people with sub-types of dementia will be examined and the Topic Expert Group will consider your comments when drafting quality statements.

[1] Department of Health (2009). Living well with dementia: A national dementia strategy for England. Department of Health, London.

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					○ Brief periods of confusion alternating with periods of lucidity, against a background of gradually worsening cognitive decline ○ Fluctuating cognitive performance and vigilance: periods where the person stares blankly into space and shows apathy and excessive daytime sleepiness ○ Visuo-perceptual difficulties which result in impaired task performance and imprecise recognition of surroundings ○ Visual hallucinations ○ Disrupted sleep, especially REM-sleep behaviour disorder (in which the person shouts and lashes out during vivid dreams) ○ Delusions ○ Anxiety. In addition, people with DLB can be particularly susceptible to neuroleptic drugs which can escalate parkinsonian symptoms, even causing death. As Lewy Body Disease progresses, up to three quarters of people with DLB show symptoms of parkinsonism including reduced facial expression, difficulties in maintaining balance and moving, especially slowness in moving and rigidity.	
48	024	Dementia care matters	3.1.1		People from seldom heard groups do not appear to be wholly represented in the stakeholder list e.g.: refugee and traveller communities. What strategies are in place to ensure their participation?	Thank you for your comment. We have consulted with colleagues from our Patient and Public Involvement team and our colleagues at the Social Care Institute for Excellence, as well as having discussions with the Topic Expert Group, to ensure that a wide range of organisations are invited to register as stakeholders. We cannot guarantee to notify all organisations that may have an interest in a topic but we do try to ensure that as many organisations are invited as

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						possible. We would welcome any suggestions for organisations that should be invited to register. Please note that we cannot compel organisations to register as stakeholders but we do try to encourage them as much as we can. If you are aware of any such organisation, please feel free to send them the link to the NICE website where they can register as stakeholders to take part in the consultation.
105	021	Alzheimer's Society	3.1.1	a	The Society suggests inserting after "self-funding their own care" "and/ or receiving Personal Budgets (including Direct Payments)".	Thank you for your comment. This section of the scope has been amended to make it simpler.
50	027	Social Care Institute for Excellence	3.1.1	c	Population: "Unpaid carers of people with suspected or diagnosed dementia". I would like to see this amended to: "Paid and unpaid carers of ...." There are only 3 headings in this scope: Population, Settings, and Areas and Activities. Neither of the latter two suggest people. This denies the pivotal importance of the human relationships between people with dementia and their paid carers (inc. domiciliary workers; including people who may be both family members and paid carers through the use of personal budgets). It is the paid carers that are the primary target of these QSs, and they are not automatons that are just an aspect of the 'setting'. Research suggests this is not just about training needs, it is also about caring for and supporting paid workers.	Thank you for your comment. The section 'population' defines the recipients of support for whom the quality standard will propose markers of quality. People employed by organisations to provide care would not generally be considered as a member of the 'population' section. They would be part of the services in place to deliver the quality standard. This does not mean their pivotal relationship and the impact on the person with dementia will not be examined in the development of the quality statements.
20	021	Alzheimer's Society	3.1.1 d) and 3.3.1 a)		• Younger people with dementia should be defined as under 65 years of age. • People from Black and Minority Ethnic communities should be included within this list	Thank you for your comment. The group has not limited 'younger people' to 'less than 65', though it is accepted that this is a general

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					The Society welcomes the inclusion of equalities. The protected characteristics under the Equality Act 2010 should be specified in detail as they may not be well known and the needs of people with dementia with each of the characteristics or a combination of two or more may differ	definition. People from ethnic minorities would be included in "people with characteristics covered by the Equality Act 2010". For brevity, the scope does not list the various groups protected by the Equality Act 2010. However there is a hyperlink that readers can use if interested.
51	002	Kent and Medway partnership trust	3.1.1	d	I would have liked Parkinson's Dementia and Alcohol dementia's included in this subgroup. The needs of these groups are high with high level of carer burden.	Thank you for your comment. The quality standard will present markers of high quality care for all people with dementia. Areas focussing on people with sub-types of dementia will be examined and the Topic Expert Group will consider your comments when drafting quality statements.
52	003	Bournemouth University	3.1.1	d	People with dementia and their family members living in remote and rural communities experience distinct issues and require special consideration. Including rurality specifically would ensure this rather neglected population needs are taken into account. It may be useful to specify other marginalised groups such as LGBT and BME communities.	Thank you for your comment. The scope has been amended to include "people facing barriers to accessing services". The group is keen to ensure the other marginalised groups are given special consideration. These groups were included in the term "people with characteristics protected by the Equality Act 2010".
53	010	College of Occupational Therapists	3.1.1	d	As homeless people have been identified as part of the inclusion criteria, would people from seldom heard groups also include gay, lesbian and bisexual people with dementia, and BME groups?	Thank you for your comment. The group is keen to ensure the other marginalised groups are given special consideration. These groups were included in the term "people with characteristics protected by the Equality Act 2010".

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54	019	Association of British neurologists	3.1.1	d	With respect to the subgroups of people with suspected or diagnosed dementia who may need special consideration (especially younger people) we believe that Neurology input to the Quality Standard would be particularly helpful. These individuals are often cared for by neurologists and are more likely to suffer from different causes of dementia than the elderly population. They may have disorders which lead to other neurological problems (eg. Epilepsy, Physical Disability) or are associated with early behavioural features (Frontotemporal Lobar Degeneration), and social care input will need to be tailored to their specific problems.	Thank you for your comment. The group recognises the importance of ensuring that all groups of special interest be examined. The scope has been amended accordingly to reflect the wide variety of people who may need special mention.
55	031	Bradford Dementia Group	3.1.1	d	We suggest you add people from BME communities, immigrant groups, refugees, asylum seekers	Thank you for your comment. The group is keen to ensure the other marginalised groups are given special consideration. These groups were included in the term "people with characteristics protected by the Equality Act 2010".
56	032	Dementia UK	3.1.1	d	Other subgroups that might need special consideration could include: - People with rare types of dementia (eg Pick's) - People with other long-term conditions, alongside their dementia, which may be affected by living with dementia – bearing in mind the projected growth in the population of people living with 3 or more long-term conditions - People with alcohol-related dementia whose needs can be difficult to meet in generic services for people with dementia.	Thank you for your comment. The quality standard will present markers of high quality care for all people with dementia. Areas focussing on people with sub-types of dementia will be examined and the Topic Expert Group will consider your comments when drafting quality statements.
57	034	Parkinson's UK and the Lewy Body Society (LBS)	3.1.1	d	The sub-groups of people with suspected or diagnosed dementia who may need special consideration should include people with complex co-morbidities. For people with PDD/DLB, particular problems directly related to Lewy Body Disease may include: o Gait and balance difficulties leading to difficulty with transfers and mobility o Repeated falls o Autonomic problems such as fainting caused by low blood pressure upon rising o Unexplained sweating or coldness	Thank you for your comment. The quality standard will present markers of high quality care for all people with dementia. Areas focussing on people with sub-types of dementia will be examined and the Topic Expert Group will consider your comments when drafting quality statements.

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					○ Constipation, urinary or sexual problems ○ Difficulty swallowing, choking, or a weak voice In addition, the standard should take into account the needs of people with dementia and other conditions frequently seen in older patients, such as diabetes, heart disease, arthritis, high blood pressure, pulmonary disease and osteoporosis. Given the difficulties people with dementia have in communicating about pain, diagnosis and management of pain should be specifically covered within the QS.	
58	035	Care Quality Commission	3.1.1	d	We welcome the inclusion of the seldom heard groups outlined within the scope.	Thank you for your comment. Other respondents felt the term seldom-heard groups to be limited. We have amended the scope to reflect that the throughout the process we examine all groups who may have a special interest.
59	016	Sue Ryder	3.1.1		We agree with the groups to be covered by a, b, and c.	Thank you.
60	016	Sue Ryder	3.1.1		To point d we would like to add the following: people from seldom-heard groups, for example and including homeless people, travellers and prisoners. We believe prisoners' access to appropriate care should be represented in the groups, rather than settings. We would also like to add those with dual diagnosis where dementia is an individual's secondary condition.	Thank you for your comment. The group recognises the importance of ensuring that all groups of special interest be examined. The scope has been amended accordingly to reflect that the wide variety of people who may need special mention.
61	027	Social Care Institute for Excellence	3.1.2	a	Would then be amended to add 'or their carers'.	Thank you for your comment. Amendments to this section have been made. The exclusion in 3.1.2 negates having to also exclude "their carers".
62	009	British association of social workers	3.1.2 And 3.1.2		I am sure the group have considered the complexities of defining dementia and it is hoped that a broad concept is considered – people who have cognitive / emotional problems linked to degeneration, brain damage etc. There are particular issues around people with mental health problems who are older where diagnosis and patients are batted	Thank you for your comment. The quality standard will present markers of high quality care for all people with dementia. Areas focussing on people with sub-types of dementia

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					around, particularly within and between psychiatry and older people's medicine. It is requested that consideration is given to an emphasis on the social model, rather than medical model. In practical terms this may mean that a person is deemed to have dementia if they have behaviours which have social consequences for them and their carers.	will be examined and the Topic Expert Group will consider your comments when drafting quality statements. The Topic Expert Group acknowledged that a social model of care should be better reflected.
63	007	Age UK	3.2		There is no mention of GP services and practices in this section. They should be included as a setting where people with dementia can expect to receive high quality care.	Thank you for your comment. The setting section has been amended to include primary care.
64	017	National Skills Academy for Social Care.	3.2		We would suggest another 'setting' of **hostels**, which links in with the homeless as one of the groups that need special consideration. Some people are able to stay in hostels for longer than a few nights, which gives them greater access to care if they have suspected or diagnosed dementia.	Thank you for your comment. The scope has been amended to include community settings to capture settings such as hostels.
65	022	Royal college of nursing	3.2		To have consistent approach – the standard of services given or structured should adhere to a national approach and be equally available in all NHS settings or NHS funded care. One of the reasons to be considered is staff turnover – in some of the settings providing care for people with dementia, staff turnover can be high, with people working in various settings of care within a short space of time. It is therefore important to have consistent standard.	Thank you for your comment.
66	022	Royal college of nursing	3.2		What about the homeless? There is an increasing number of older adults who are homeless.	Thank you for your comment. The list given in section 3.2 is illustrative only and not restricted to only the examples given
67	031	Bradford Dementia Group	3.2		We suggest you add respite	Thank you for your comment. The list given in section 3.2 is illustrative only and not restricted to only the examples given.
68	032	Dementia UK	3.2		Hospitals are rightly included but this is not the only part of the NHS where a quality standard for dementia might be needed – primary care and secondary mental health settings could also be included.	Thank you for your comment. The setting section has been amended to include primary care, secondary and tertiary care.
69	034	Parkinson's UK and the Lewy	3.2		Given that the QS acknowledges the importance of opportunities to engage and actively participate in meaningful activities and be involved	Thank you for your comment. The scope has been amended to include

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		Body Society (LBS)			in the community [3.3.1b)], settings that should fall within the scope of the QS should also include community transport services The QS should also cover services specifically targeted at people with dementia and their supporters, including 'Memory Cafes' (bearing in mind that while a 'Memory Café' may be targeted towards clients affected by AD, it may not as geared up to support people with DLB (with its non-memory symptoms).	community settings.
71	016	Sue Ryder	3.2	A,b	Agree	Thank you.
72	016	Sue Ryder	3.2	c	Point c, day care, needs further clarity and detail. We would like this point to be headed Community Support, with sub headings that outline particular support, including day services, remote support, informal support networks, befriending.	Thank you for your comment. This section is not intended to describe the many settings and locations that care for people living with dementia. It is illustrative in its detail.
73	016	Sue Ryder	3.2	f	We would prefer to see prisoners represented in 3.1 d) rather than prisons be distinct settings.	Thank you for your comment. Prisoners may be covered in section 3.1.1 by the subsection "people facing barriers to accessing services". The group will consider your comments during development of the quality statements and associated measures.
74	015	Tunstall Healthcare	3.2	Settings-people's homes	It is currently estimated that 150,000 people with dementia live alone, and many of those living in their own homes rely on support from an elderly carer who may have their own health issues. Ensuring people with dementia have access to the right levels of care and support at home, will be crucial if the standard is to be a success. The majority of older people would like to stay in their own home where possible and the development of services such as telecare can help keep people with dementia safe whilst living independently. Safeguarding people with dementia whilst ensuring their independence should be a major objective of the standard. **Case Study** Barbara is in her 80s, has moderate dementia and lives alone. She had been walking away from her home during the night and her family had been keeping a close watch on her and escorting her home on	Thank you for your comment. The quality standard will apply to people living with dementia in their own home. The Topic Expert Group will consider the importance of assistive technologies and adapting environments.

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					occasions. In addition she had been leaving pans on the cooker unattended. This was causing a great deal of stress for the family. A telecare package was installed including a property exit sensor which sent an alert to the 24 hour Careline. The operators managed to reassure Barbara and encourage her to shut the door and come back into the house 87 times in a three month period. Only on three occasions were the family called out. A saving of approx £34,000 has been made in this case, by allowing Barbara to stay at home for a further 16 months before she had to enter a nursing home.	
75	015	Tunstall Healthcare	3.2	Settings-Residential care homes	Ensuring people with dementia in residential care have access to telecare services will also be important for delivering improvements in the quality of services. **Case Study** A recent report by North Yorkshire County Council and St Cecilia's, an independent residential care provider in Scarborough, highlighted the positive impact of telecare on people with dementia living in a residential care setting. Telecare was provided to 21 residents at the home between June 2009 and August 2010. Telecare equipment and a nursecall overlay system with docked handsets were installed. The specific equipment used was 18 enuresis sensors, 7 bed occupancy sensors, 1 chair occupancy sensor, 2 falls detectors, 3 door exit sensors and a nursecall overlay with docking handsets. Out of the 21 residents with severely challenging behavioural problems, 20 still have telecare in place today. Telecare manages issues such as night time checks, floods, falls, incontinence and security for entry to and exit from the building (particularly in adverse weather conditions). Key benefits • Highlighted the positive impact of telecare on people with dementia living in a residential setting • Assistance to staff, helping them feel supported in their role and enabled them to be more productive	Thank you for your comment. The quality standard will apply to people living with dementia in their own home. The Topic Expert Group will consider the importance of assistive technologies and adapting environments.

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					• Telecare has also alleviated the need to carry out frequent "just in case" checks, for example in the event of enuresis, which can limit a person's behaviour or cause anxiety *"I am positive that telecare has helped staff to make more productive use of their time. It has even enabled us to accept residents with higher care needs."* Mike Padgham, Dementia home owner and chair of the ICG Key outcomes of the work were: • Residents' care needs were supported effectively without limiting their choice • Staff were trained, supported and encouraged to consider telecare as a tool to deliver a better quality of care; both by being able to react when necessary and knowing when to respect the residents own space and time • Telecare has been embraced as a standard component of supporting the residents' best interests in their environment • Residents skin integrity improved due to the installation of enuresis sensors • Greater efficiencies in the use of staff time to deliver quality time with residents	
76	003	Bournemouth University	3.3		Events leading up to a diagnosis are extremely important for those with dementia and their families. Including pre diagnosis, including speed of receiving a diagnosis, improving the 'maze' many people with dementia report to a clear pathway and common protocols would be a useful activity to consider. It is also vital to promote sustained post-diagnostic support over time to limit crisis situations.	Thank you for your comment. The group recognises the importance of the events leading up to diagnosis. Your comments will be considered when developing the quality statements and associated measures.
77	012	Wigan Council	3.3		We agree that all areas identified are essential in measuring quality of good dementia care	Thank you.
78	034	Parkinson's UK and the Lewy Body Society (LBS)	3.3		With the scope's focus on "care" there are areas and activities which are currently missing. These include: 1. Advice, information and brokerage which is particularly important given the confusing nature of social care, multiple providers and the	Thank you for your comment. The Topic Expert Group recognises the importance of information provision and signposting, and will

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					means testing throughout. A number of studies have shown that the needs of self-funders for advice and information have been particularly neglected. 2. Funding of care: social care unlike the NHS is means tested and wrangling over funding and charges impacts on the person's experience of care. Moreover with the move to personal budgets there is an even greater emphasis on people managing their own finances for care. Good quality care services should be clear on people's rights and entitlements, explicit on what is means tested and what is not; those paying for care need to have clear information on charges and fees. For this particular client group there should be clear signposting to the NHS continuing care funding system where someone's needs appear to be primarily health needs: evidence that is coming into Parkinson's UK suggests people are rarely told about NHS continuing care despite clear indications that they would be eligible. This is common in hospital discharge scenarios. 3. Aids and adaptations to the home are not "care" services but are vital in helping someone remain independent and should be within the scope of the standard.	consider your comment when developing the quality statements and associated measures. The quality standard will apply to people living with dementia in their own home. The Topic Expert Group will consider the importance of assistive technologies and adapting environments.
80	004	British pain society	3.3.1		As it has been suggested that pain prevalence increases to 80% in the care home population we would like to see the addition in c) of pain assessment using a recognised pain scale (Abbey or DOLOPLUS) as proposed by the BPS guidelines http://www.britishpainsociety.org/pub_professional.htm#assessmentpop This is in accordance with the proposal that pain is recognised as the 5th vital sign.	Thank you for your comment. The Topic Expert Group recognises the importance of pain management and will consider your comment when developing the quality statements and associated measures.
81	007	Age UK	3.3.1		Consideration of quality must also refer to the breadth of provision available through Local Authorities. Many older people are not able to access local care and support services, which causes major difficulties and creates unmet need. One of the markers of a quality service for someone with suspected or diagnosed dementia should be their ability to access support at all stages of their condition, including low level preventative services.	Thank you for your comment. The Topic Expert Group will consider variations in access and provision when developing the quality statements and associated measures.
82	008	Nutricia UK	3.3.1		Reference should be made to the training of staff in the nutritional needs	Thank you for your comment. The

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					of people with cognitive impairment and possible dementia and how to meet these individual's nutritional needs in the best and most appropriate way. Also staff need to be trained on how to nutritionally screen and how to manage those who are at risk of malnutrition – reference NICE CG32	Topic Expert Group have identified that training needs of staff are of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. Nutritional Support in general is currently being covered by a separate Quality Standard that is in development
83	008	Nutricia UK	3.3.1		Individuals, as outlined in CG 32, should be screened for malnutrition risk in all care settings and the appropriate/right nutritional care management plans put in place depending on malnutrition risk.	Thank you for your comment. The Topic Expert Group will consider nutritional care when developing the quality statements and associated measures.
84	012	Wigan Council	3.3.1		In addition we suggest that standards relating to skills/experience and ongoing training and development of staff need to be included.	Thank you for your comment. The Topic Expert Group have identified that training needs of staff are of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
85	012	Wigan Council	3.3.1		In addition we suggest promotion of a 'Dementia Champion' within services.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
86	012	Wigan Council	3.3.1		In addition we suggest that standards are included regarding Medication – knowledge about low dose anti psychotics and awareness of care staff regarding timeliness of reviews of antipsychotic medication/ etc.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
87	013	Hampshire County Council Adult Services Department	3.3.1		It is not clear where support planning and agreeing outcomes sits in this section	Thank you for your comment. The Topic Expert Group wishes to ensure the quality standard incorporates enablement,

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						personalisation and shared decision making.
89	022	Royal college of nursing	3.3.1		Therapeutic support – include the arts	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. Detailed reference to the appropriate types of support will be made in the draft quality standard.
90	024	Dementia care matters	3.3.1		Seems to include strategies for including people with dementia in making decisions about the future and implementing care plans. Specific reference to including people with dementia in designing their care plan would reinforce the theme of participation.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
91	024	Dementia care matters	3.3.1		"Providing opportunities for people with dementia to self-manage" This statement seems to over-ride the person's right to self-manage. Taking the focus away from `provision' of opportunities and moving towards a statement on enabling the person to self-manage seems more person-centred.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
92	024	Dementia care matters	3.3.1		"Caring for people with dementia with dignity, respect, kindness and compassion": This is a generic statement, rather than a dementia specific one. The statement needs to represent a recognised, valid and reliable model of dementia care which encompasses these generic principles in a dementia specific way e.g. person-centred and relationship focussed care. The statement needs to be supported by reference to the observation and measurement of a person's wellbeing and qualitative experience once the person's capacity to evaluate and express their own experience verbally begins to become impaired.	Thank you for your comment. The Topic Expert Group agrees that these themes should be incorporated throughout the quality standard.
93	024	Dementia care matters	3.3.1		"Safeguarding people with dementia including balancing safety with personal liberty, mental capacity and positive risk taking" The respect for a person with dementia's autonomy and agency could be strengthened here by acknowledgement of the variations in capacity associated with the different presentations of dementia. The concepts of variation and, therefore flexible responses to need, ought to be a recognised key	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.

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					component in the standards on safeguarding decision making processes.	
94	024	Dementia care matters	3.3.1		"Opportunities for the involvement of people with dementia in service planning (etc.)..." This needs to be strengthened by imposing an expectation e.g.: People with dementia are enabled to…. . A suggested addition to this bulleted list to enhance participation for people with dementia is to ensure they are able to choose to be involved in the training and education of paid and unpaid carers as trainers and educators as well as participants.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
95	024	Dementia care matters	3.3.1		"Managing differences in the views of people with dementia and their unpaid carers": This appears to imply that the relationship needs to be managed / controlled by an external body. Accepting there are complex family dynamics and responses to changes in a person's experience of dementia, some reference to `supporting compromise'; `arbitrating'; `advocating'; `providing person-centred counselling' would place more emphasis on the respect for personhood, relationship and citizenship.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
96	024	Dementia care matters	3.3.1		Support for unpaid carers needs to include the provision of training in person-centred and relationship focussed approaches. This needs to parallel the principles underpinning training and education for paid support staff (and people with dementia) in order to cement the support partnership and create consistency for the person with dementia as their dementia progresses.	Thank you for your comment. The Topic Expert Group have identified that training needs of carers is of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
97	024	Dementia care matters	3.3.1		End of life care also needs to include care specific to people with dementia from seldom heard of groups, with parallel support and information for their unpaid carers (taking into account the differences in life experiences, actual care need and world views that often exist between e.g.: LGBT people; homeless people etc.. and their family members who may become their unpaid carers).	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
98	033	Lundbeck UK	3.3.1		Dementia is a syndrome which also affects behaviour from early through to the late stage of the illness (WHO 2012). Also behavioural abnormalities are often the precipitant to care homes. The behavioural and psychological symptoms profoundly affect the quality of life of people with dementia and their carers (WHO 2012). Assessment and diagnosis should therefore also take into account behavioural symptoms, in addition to the cognitive impairment which has been	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.

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					included in the scope. Ref: Dementia: A Public Health Priority. Available at: http://www.who.int/mental_health/publications/dementia_report_2012	
99	028	British Society of Gerodontology	3.3.1		This must include a dental examination and the need to assess the oral health for people with dementia and the likelihood of the dental condition affecting behaviour: Guidelines for the Development of Local Standards of Oral Healthcare for People with Dementia – Funded by the Department of Health. http://www.gerodontology.com/guidelines.html Poor oral care and an increase in oral disease can lead to changes in eating habits that may be because of a non-functional dentition, pain and discomfort or ill fitting dentures; as well as affecting self-esteem because of compromised aesthetics.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
100	028	British Society of Gerodontology	3.3.1		This should include an oral healthcare assessment to ensure appropriate early intervention is possible General health and comfort are closely linked with oral health in the terminal stages of progressive neurogenic diseases (PND) such as dementia. Poor oral health can impact on: • diet and nutrition, • oral and general comfort, • cognition, • behaviour change, • quality of life • and life expectancy • Aspiration pneumonia risk is significantly increased by oral factors such as: • decayed teeth, • periodontal disease and the presence • of various decay-causing organisms in saliva Good oral health can improve the quality of life and prolong it by reducing the likelihood of aspiration pneumonia.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.

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					It is well recognised that oral health is likely to decline as AD progresses. The impact of the disorder, especially in the latter stages, leads to poor oral hygiene with an increase in: • periodontal disease, • higher levels of decay (both coronal and cervical) There is a greater incidence of other dental problems. These include: • difficulty wearing dentures, • the inability to comply with oral care and • the inability to carry out oral hygiene procedures	
101	006	Carers Trust (formally The Princess Royal Trust for Carers)	3.3.1	a	Concerns are often first expressed by family and carers, this should be reflected in this section to ensure early and swift action. Especially crucial if the person with dementia lacks insight into their condition.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
102	014	Royal College of Speech and Language Therapists	3.3.1	a	Assessment and diagnosis Some individuals who exhibit a progressive aphasia or progressive apraxia which will consequently be associated with a generalised dementing condition. Other progressive language disorders do not have cognitive decline. Differentiation needs to be made within the scope between (diagnosing) those with and without more generalised cognitive decline.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
103	014	Royal College of Speech and Language Therapists	3.3.1	a	Add : The recognition and response to dysphagia (eating, drinking and swallowing problems) experienced by people with dysphagia	Thank you for your comment. The Topic Expert Group recognises the importance of including recognition and response to dysphagia. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
104	018	Action on	3.3.1	a	Areas and activities that will be considered	Thank you for your comment.

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		hearing loss			Assessment and diagnosis Action on Hearing Loss strongly welcomes the inclusion of recognition and response to the symptoms of sensory loss in this section. There is a direct relationship between hearing loss and dementia; people with mild hearing loss have nearly twice the chance of going on to develop dementia as people with normal hearing. The risk increases threefold for those with moderate and fivefold for severe hearing loss. We know that, in the UK, 44% of over 70 year olds have moderate to severe hearing loss and there are around 800,000 people with dementia. This means that there are at least 352,000 people with a hearing loss and dementia. In reality, the link between hearing loss and dementia means that this figure is likely to be much higher. In practice, this means that there exists a large group of older people who have both hearing loss and dementia. Ineffective management of hearing loss can make the symptoms of dementia worse and/or appear worse. Similarly, the effective management of hearing loss can improve the quality of care experienced by people with dementia. Dementia and hearing loss can cause similar symptoms, such as social withdrawal; this means that hearing loss can make the diagnosis of dementia more challenging, and vice versa. Therefore, it is essential that health and social services take an Integrated approach that accounts for both dementia and sensory loss to reach an accurate diagnosis. A different approach will be required depending on the needs of the person – for instance, it may be necessary to take a different approach depending on whether someone has age-related hearing loss or they are profoundly deaf and British Sign Language is their preferred language. Resources are being developed in this area. For instance, as part of the	

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					Deaf with Dementia project, the Deafness, Cognition and Language Research Centre (DCAL) at University College London is working to develop a battery of measures for British Sign Language users suitable for the identification of cognitive changes associated with dementia. Action on Hearing Loss and DCAL are also working together to produce a review of evidence around hearing loss and other long term conditions, including hearing loss. We will be happy to share this with NICE in advance of the development of the social care quality standard around care for people with dementia. Additional challenges stem from the fact that it can be difficult for someone with dementia to complete an audiometric assessment. However, some audiology departments in the UK have adapted their testing procedures so that they meet the needs of people with dementia. It is important that those organisations that provide services to people with dementia work with audiology departments to ensure that this happens systematically.	
106	023	Lilly UK	3.3.1	a	We welcome the inclusion of this important section – assessment and diagnosis – as a key step to ultimately delivering appropriate care. We wish to underline the importance of including access to diagnostic tests or assessments in this section for all patients with suspected dementia, regardless of the setting.	Thank you for your comment.
107	029	Foundation Trust Network	3.3.1	a	It would also be helpful to get clarity on whether the standard will address the information management of diagnosis and assessment information for patients with dementia e.g. • recording of diagnoses on electronic system; • use of present on admission flags; • transfer of information throughout the hospital e.g. using stickers on records to clearly identify patients with dementia during transfers to radiology etc.?	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
108	031	Bradford Dementia Group	3.3.1	a	We suggest you add: What promotes help seeking People with dementia and family cares' experience of assessment and	Thank you for your comment. The Topic Expert Group will consider your comment when developing the

Row	ID	Stakeholder	Order No	Section	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					diagnosis Impact of diagnosis on relationships, family and community Impact of diagnosis on finances, insurance, work, travel	quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
109	032	Dementia UK	3.3.1	a	Assessment and diagnosis could also include a standard on post-diagnostic support. Recognition of symptoms in younger people is important but also people presenting with symptoms of rarer types of dementia.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
110	034	Parkinson's UK and the Lewy Body Society (LBS)	3.3.1	a	Assessment and diagnosis services must be geared up for people with DLB/PDD symptoms. People with dementia have stressed the importance of: o Early diagnosis; o Being informed of the diagnosis (with appropriate information resources to support the diagnosis); o Proactive services (especially GP) Memory Clinics should be equipped to diagnose dementias caused by Lewy Body Disease (LBD) but not all LBD patients will be referred there because their primary problem is not memory failure – as in the case of people with Parkinson's Disease who develop dementia. Neurology (movement disorder), psychiatry and geriatric medicine services are all likely to be involved and there needs to be central coordination of information about people being diagnosed in these different workstreams.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
111	035	Care Quality Commission	3.3.1	a	In response to the consultation question about which particular parts of the scope could affect equality of opportunity – Assessment and diagnosis: in terms of recognition of, and response to,	Thank you for your comment. The Topic Expert Group will consider your comment when developing the

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					symptoms. For example, ensuring that professionals carry out the necessary memory tests and assessments in a way that is meaningful and accessible for people who have a learning disability or for people who do not speak English as their first language, etc. In relation to sexual orientation and gender identity, the sharing of information about the diagnosis with relevant family members, friends and carers can sometimes become an issue, as the question of 'next of kin' can often arise at this point, especially if there have been tensions in the past between the lesbian, gay, bisexual or transgender person and members of the family.	quality statements and associated measures. Issues of particular importance to equality groups will be considered throughout the process.
112	036	Chartered Society of Physiotherapy	3.3.1	a	It would be good to have some recognition of the assessment of the physical capabilities of the person with dementia and specifically the additional challenges that may be faced by those who either are physically impaired or who demonstrate activities such as wandering.	Thank you for your comment. The Topic Expert Group agrees with including recognition of physical capabilities. Your comments will be considered when developing the quality statements and associated measures.
115	016	Sue Ryder	3.3.1	A,b,c	agree	Thank you.
116	009	British association of social workers	3.3.1	b	Flexibility in the frequency and content of assessments. There is a danger that assessment is seen as a formal, "professionally" driven process. It is important that social workers, nurses and others undertake assessments, but it is also equally important that assessments are seen as a shared process with all concerned, and carers – paid and unpaid as well as the service users must have an important input into this. Also that assessment is a process and at best a snap shot at a moment in time, assessment needs to be continuous	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
117	010	College of Occupational Therapists	3.3.1	b	Personalised care - We would suggest the inclusion of some guidance addressing assessment for driving for people with dementia.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
118	015	Tunstall Healthcare	3.3.1	b	Tunstall welcomes the inclusion of flexibility in the frequency and content of assessments in the standard. In order that high quality care for people with dementia is delivered it will be crucial that regular assessments of their condition are undertaken and acted upon.	Thank you for your comment. The Topic Expert Group will consider assistive technologies and telecare when developing the quality

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					As important will be the process whereby people with dementia are assessed for the support and services they will need to improve the quality of their care. All people with dementia regardless of location should have access to the same high quality interventions such as telecare. In order to address this variation there needs to be widespread use of standard assessment tools, such as the FACE telecare assessment and outcome toolset, which incorporates questions about the suitability of users for telecare during the initial assessment. **Case Study** Despite having a higher level of social need than many other English local authorities, Sunderland City Council continues to provide against all four of the Department of Health's Fair Access to Care (FACS) service bands – thereby providing individuals assessed as "critical" through to "low" with care packages aimed at meeting their eligible needs. The council's strong emphasis on continuing to support people with low-level preventative services means that everyone who receives a care service in Sunderland automatically is given a telecare service and anyone not eligible for services under FACS can purchase telecare for a minimum monthly fee. The decision to offer support to people in all levels of need means Sunderland is able to prevent or delay the need for higher intervention. Sunderland continues to support a relatively high level of individuals, particularly older people, helping them to stay in the community through social care and telecare services. **Case Study** Marj lives in a farmhouse with her daughter and son in law. As she had dementia, she was due to go into a permanent EMI placement as was continually walking around the property and leaving taps on in kitchen and bathroom. This was replaced with a : • property exit sensor	statements and associated measures.

Row	ID	Stakeholder	Order No	Section	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					• flood detector • bed sensor • light module • carer pager As soon as an alert is raised, the family would be paged and they would come to mum's aid immediately, wherever they were on the farm. This maintained Marj at home and happy in familiar surroundings. The estimated net annualised cost saving to the authority (excluding client contributions) was £11,625.	
119	017	National Skills Academy for Social Care.	3.3.1	b	b) On personalised care, commissioning will be a key issue. Commissioners need to be enabled to develop the necessary skills for commissioning personalised services, and to commission for outcomes. We agree with the need for proper and extensive co-production with people with dementia, and their carers.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
120	019	Association of British neurologists	3.3.1	b	We feel that personalized care should include recognition of the fact that patients with suspected or diagnosed dementia are at high risk of delirium, and that true personalized care would enable social care providers to provide a dynamic response allowing them to scale up care for relatively short periods of time for people who develop delirium. This would avoid patients waiting in hospital for delirium to settle and might even avoid some hospital admissions altogether.	Thank you for your comment. The Topic Expert Group will consider personalisation when developing the quality statements and associated measures.
121	021	Alzheimer's Society	3.3.1	b	• Personalised Care could include an extra bullet point around the effects of dementia on a person's response to, diagnosis of, treatment decisions about, or treatment for co-morbidities. • The PM challenge on dementia also highlights that people with dementia will be guaranteed a written integrated personalised care plan. This must be mirrored in the social care quality standards. • The second bullet point 'shared decision-making, recognising the person as an individual and acknowledging the changing nature of the condition' contains three essential strands to delivering personalised care, each of which require more emphasis. We would suggest having them as separate points. • In addition, the points can be expanded. Shared decision making must emphasise the importance of the Mental Capacity Act and	Thank you for your comment. The Topic Expert Group will consider personalisation and shared decision making further when developing the quality statements and associated measures.

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					individual care must emphasise the importance of a person's life history and personal culture. The Dementia Care and Support Compact, part of the PM challenge on dementia and signed by leading care home and home care providers, emphasises that there must be a focus on quality of life for people with dementia, as well as quality of care, which involves knowing the person, their life history and their personal culture.	
122	022	Royal college of nursing	3.3.1	b	Need to include the importance of use of life history, biography and life planning	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The draft quality standard will contain further details on appropriate methods and approaches that services can use.
123	022	Royal college of nursing	3.3.1	b	Would prefer: 'outcomes of assessments and implementation of individualised care plans'	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
124	029	Foundation Trust Network	3.3.1	b	Will the standard specifically address how personal preferences of patients are *communicated* to staff e.g. This is Me and similar documents that clearly set out patient preferences?	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The draft quality standard will contain further details on appropriate methods and approaches that can be used.
125	029	Foundation Trust Network	3.3.1	b	Will the standard include advanced care planning as part of needs-specific care planning i.e. care planning discussions anticipating deterioration in patients' condition, decision-making or communication abilities in the future?	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The draft quality standard will contain further details on appropriate methods and approaches that can be used.

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126	032	Dementia UK	3.3.1	b	The bullet point "Results of assessments and implementation of care plans" needs clarifying	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
127	036	Chartered Society of Physiotherapy	3.3.1	b	Add to: '*flexibility in the frequency and content of assessments to account for changes in needs, behaviour and personal circumstances'* to include change in physical abilities	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The Topic Expert Group agrees that the quality standard should address changes in physical abilities.
128	036	Chartered Society of Physiotherapy	3.3.1	b	Add to sustaining capabilities to include sustaining physical and mental capabilities	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The Topic Expert Group agrees that the quality standard should address sustaining physical abilities.
129	036	Chartered Society of Physiotherapy	3.3.1	b	Again, add to opportunities to participate in meaningful activities to incorporate activities to maintain or improve physical activity levels.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The Topic Expert Group agrees that the quality standard should address physical abilities.
133	008	Nutricia UK	3.3.1	b, c,d	Personalised care, Delivery of care, Organisation of services should make reference to individual nutritional needs being assessed and having access to the right nutritional care.	Thank you for your comment. The Topic Expert Group recognises the importance of nutrition and will consider your comment when developing the quality statements and associated measures.
134	014	Royal College of Speech and	3.3.1	B,c	<u>Care</u> There needs to be a greater focus on sustaining communication in the	Thank you for your comment. The Topic Expert Group recognises the

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		Language Therapists			early and medium stages of dementia. There is evidence that early language intervention can sustain / maintain communication skills including word finding.	importance of communication and will consider your comment when developing the quality statements and associated measures.
135	023	Lilly UK	3.3.1	B,c	We believe there should be an explicit statement around Patient management with a focus on working proactively to improve the quality of life of these patients and preventing decline with access to appropriate treatment, regardless of the setting. There are a number of treatments approved by NICE or programmes, such as Memory Clinics, that are proven to be effective in improving quality of life and preventing decline; the personalised care plans should be comprehensive and include access to appropriate treatment, regardless of the setting.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
136	034	Parkinson's UK and the Lewy Body Society (LBS)	3.3.1	B,c	It is not clear what is envisaged in terms of the difference between personalised care (b) and delivery of care (c). Personalised care is enriched by knowing about the individual's personality and history. The QS should include life story work, including work to ensure people have 'banked' life history material before the onset of dementia. The QS should include: o Peer to peer support o Access to people who can act as: o Guides through the health and social care system o Guides/helpers in the local community	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
137	003	Bournemouth University	3.3.1	c	Including the potential use of technology to deliver care, including assessment and delivery of support and services would be a useful addition and reflect current innovations in the UK and beyond.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. It is intended that the quality standard will include methods to enable independence such as assistive technology.
138	004	British pain	3.3.1	c	We welcome these as a general statement and then under 3.3.1	Thank you for your comment.

Row	ID	Stakeholder	Order No	Section	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		society			welcome the section on c) Delivery of care, including: assessment and care of mental and physical health and wellbeing	
139	014	Royal College of Speech and Language Therapists	3.3.1	c	Delivery of care should include the management of feeding and swallowing difficulties commonly found in those with dementia. These may be behavioural or associated with physical difficulty / coordination impairment.	Thank you for your comment. The Topic Expert Group recognises the importance of dysphagia will consider your comment when developing the quality statements and associated measures.
140	014	Royal College of Speech and Language Therapists	3.3.1	c	The last bullet add: Capacity to consent to treatment and care	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
141	015	Tunstall Healthcare	3.3.1	c	Recent reports by the Care Quality Commission and the Alzheimer's Society have highlighted concerns about the way people with dementia are cared for including a lack of dignity, respect, kindness and compassion. It is welcome that the development of the quality standard will explore ways to improve the way people with dementia are treated by those who care for them and the services they use. **Case Study** **Focus on Managing Dementia Care in Nottingham** As part of its commitment to dignity in care, Nottingham City Council pioneered the use of Radio Frequency Identification (RFID) buttons in specialist dementia units to tackle the issue of residents accidentally wearing each other's clothing. A person's clothes are part of an individual's identity, and many older people take pride in their appearance. Unfortunately the ability to choose what to wear can become a problem for people with dementia as lapses in memory can result in people not being able to identify their own clothing. Some residents and family members resorted to writing their names inside their clothing or even sewing in name tags, but both of these techniques are undignified. Nottingham needed a solution that would help residents to remain	Thank you for your comment. The Topic Expert Group agrees that these themes should be incorporated throughout the quality standard.

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					independent, maintain their identity and promote dignity in care. The small RFID buttons are attached to each piece of clothing in a discreet position, and can be programmed to store up to 200 characters of information. This can include the person's name, unit, room number and any private information. Programming and scanning of the buttons is performed by a mobile hand-held reader, which allows staff to quickly identify an individual item of clothing. Clothing from several residents is washed together and individual items are then ironed, scanned and separated, ensuring each resident receives their own clothing. The buttons have been well received by families and carers and the solution promotes individuality, dignity and an overall reduction in anxiety and stress for residents. This innovative solution also enables staff to spend more time caring for residents, instead of searching for clothing or buying replacements. **Case Study** Mary was due to go into a permanent EMI (elderly mentally infirm) placement as she was recently diagnosed with dementia. She was at risk of falls and going out of the house inappropriately putting herself in danger. Plans for a placement were replaced by 10 home care visits of ½ hr per week, a property exit sensor and a fall detector. Mary was where she wanted to be – at home and her family was greatly reassured. The estimated net annualised cost saving to the authority (excluding client contributions) was £9,018.	
142	017	National Skills Academy for Social Care.	3.3.1	c	c) On delivery of care, we would add the need to include leading and managing care delivery, at every level from front line to top management.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
143	018	Action on hearing loss	3.3.1	c	Delivery of care We would recommend inclusion of management of sensory loss in this section. While diagnosis of hearing loss is important, service-providers also need to take particular approaches throughout the period while care is being delivered; for instance, hearing aid management, employing communication tactics and taking steps to minimise background noise. This is implicit in the section on 'assessment of care of mental and	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.

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					physical health and wellbeing'. However, Action on Hearing Loss believes that there should be explicit mention of management of sensory loss – this would draw attention to the high cost of mismanagement of hearing loss for people with dementia, as well as the high level of benefit that can accrue from effective management of hearing loss.	
144	021	Alzheimer's Society	3.3.1	c	• The scope currently does not place sufficient emphasis on the need for professionals who are equipped with the appropriate skills to provide good dementia care. Training for professionals is essential to delivering personalised care that is based on dignity and respect. • This is outlined in the PM challenge on dementia and the Royal Colleges have committed to ensure that all their members are capable and competent in dementia care. It is suggested that a bullet point is added to the delivery of care section to complement this action and ensure that all care is delivered by appropriately skilled professionals.	Thank you for your comment. The Topic Expert Group have identified that training needs of staff are of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
145	022	Royal college of nursing	3.3.1	c	Understanding and recognising behaviours that challenge	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
146	022	Royal college of nursing	3.3.1	c	Suggest re-wording the term *'delivery of care'*. It sounds like being 'done to' - need to refer to relationship centred care and person centred approaches	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
147	029	Foundation Trust Network	3.3.1	c	Members have noted that the standard may wish to: (1) incorporate elements from the developing National CQUIN on dementia; (2) review best practice in the prescribing of anti-psychotic medications for patients with dementia; and; (3) reflect the national challenge to offer dementia screening to all patients aged over 75 to boost diagnosis rates, secure earlier intervention and better treatment outcomes; balancing this against the opportunity costs associated with more active screening.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
148	029	Foundation	3.3.1	c	Will the standard address all staff (i.e. not only clinical staff) treating	Thank you for your comment. It is

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		Trust Network			patients with dignity and compassion e.g. ethos of all staff being responsible for treating patients with care and dignity even if that patient is not under your care and you are just passing the patient's bed?	envisaged that where appropriate the quality standard will apply to all staff.
149	031	Bradford Dementia Group	3.3.1	c	We suggest you add: Informed and skilled workforce, cognisant of special circumstances of migrant workers	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
150	032	Dementia UK	3.3.1	c	Delivery of care seems to be a key area on which to focus a quality standard but the suggestions included are few and vague. The list needs to be longer and more comprehensive, including things such as: - A focus on enablement in care delivery - The need for flexibility in services - Peer support models - Cognitive Stimulation Therapy - Continuity and relationship-building in personnel approaches - A trained workforce - Partnership approaches in working with family carers (shared care models)	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
151	034	Parkinson's UK and the Lewy Body Society (LBS)	3.3.1	c	This comment could sit within either b) or c) but there should be an absolute focus on the: • Time given for care i.e. good quality should never mean 15 minutes to get someone up, washed and dressed. For those with Parkinsons' and Lewy Body dementia mobility issues make this almost impossible, yet we know of packages of care commissioned at this level. If the QS can do anything it should be resolute about the unacceptable nature of "per minute" visits. • The timing of care. For someone with Parkinson's and Lewy Body dementia good quality care would be provided at the time the individual requires it. This can be absolutely vital in the case of medication which in Parkinson's is finely tuned and must be given on time. But it also relates to areas of homecare: such as the undignified way in which people are put to bed according to the times chosen by the provider rather than the individual. A key issue is the variability of someone with DLB or PDD on a day-to-day basis. The fluctuation that is part of the condition	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.

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					means that there might be extreme difference in what help is required, so the care provided needs to be flexible to respond appropriately. Flexibility involves both the range of skills available to help and the amount of time – sometimes more, sometimes less. This is possibly the most specialist aspect of LBD care – responding to ever changing needs • Continuity of care. The high turnover of staff means that people feel they do not know who may be coming through their door from one visit to the next. It is vital that good quality care is measured by a person experiencing continuity and being able to form trusted relationships with professionals. • The QS should particularly emphasise competencies around communicating with people with dementia.	
152	036	Chartered Society of Physiotherapy	3.3.1	c	Can some reference be made to enablement as well as providing care.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard incorporates enablement, personalisation and shared decision making.
153	003	Bournemouth University	3.3.1	d	A gap at the moment appears to be sign-posting of services available to people with dementia and their carers. Work is required to ensure that people have access to information about how to then access services across providers.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard considers appropriate access to information.
154	013	Hampshire County Council Adult Services Department	3.3.1	d	Coordination of care between health and social care needs to make it clear that this covers all health and social care in it's widest sense, not just local authority provision and elements of health care.	Thank you for your comment. The Topic Expert Group agrees with ensuring the quality standard considers coordination and integration of health and social care.
155	014	Royal College of Speech and Language Therapists	3.3.1	d	<u>Training of staff</u> Most persons with severe dementia will have complex and severe communicative problems showing signs of aphasia dyspraxia and social communication disorders. There is strong evidence that speech and language therapists can teach relatives and care staff particular methods of facilitating communication	Thank you for your comment. The Topic Expert Group have identified that training needs of staff and carers is of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated

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					with those with dementia (including those with severe dementia). This is reported to improve mood and reduce behavioural disorders.	measures.
156	015	Tunstall Healthcare	3.3.1	d	People with dementia need access to a range of health and social care services and telecare can greatly assist in the integration of these services. Ensuring closer co-ordination between health and social care should a major aim for the standard. **Case Study** The Croydon telecare services response team works with the emergency response centre to develop an appropriate response for when a dementia user has an incident. If the incident is serious the emergency services can be involved, if it is less serious then a managed response through social services can be arranged. This co-ordination leads to the more efficient delivery of care, as a result of earlier interventions and more appropriate, better responses for users. In order that the standard delivers this it will be important that it is aligned with other existing quality measures including the existing NHS dementia quality standard.	Thank you for your comment. The Topic Expert Group will consider will consider assistive technologies and telecare when developing the quality statements and associated measures.
157	016	Sue Ryder	3.3.1	d	In regards to built environments and the effect they have on people with dementia. The term built is too general and needs further clarification. There needs to be greater understanding of the importance that adaptations to certain environments have on people with dementia. The impact that physical environments have on people with dementia is a preferred subheading.	Thank you for your comment. The Topic Expert Group will consider the impact of physical environments when developing the quality statements and associated measures.
158	017	National Skills Academy for Social Care.	3.3.1	d	(d) On organisation of services, commissioning also plays a part in terms of commissioning for integrated services going forward, and looking at wider forms of integration, including housing, leisure and wider community links. Alongside independent and specialist advocacy organisations and formal mental capacity advocate services we would also wish to see independent information and advice services.	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
159	018	Action on hearing loss	3.3.1	d	Organisation of services We strongly welcome inclusion of coordination between health and social care in this scope. We would also suggest inclusion in this scope of 'coordination between different areas within social care', such as sensory and older people's team, to ensure that people with dementia are able to benefit from an integrated approach to their care.	Thank you for your comment. The Topic Expert Group will consider co-ordination of services when developing the quality statements and associated measures.
160	021	Alzheimer's	3.3.1	d	The Society welcomes the inclusion of the transition between settings in	Thank you for your comment. The

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		Society			the first bullet point as it is often at these handover points that problems occur. We suggest adding "and/ or funding frameworks" after "transition between settings".	Topic Expert Group will consider your comment when developing the quality statements and associated measures.
161	021	Alzheimer's Society	3.3.1	d	The inclusion of de-stigmatisation is supported and we suggest using the umbrella term "dementia friendly".	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
162	021	Alzheimer's Society	3.3.1	d	We welcome the inclusion of the effect of "built environments". We suggest a specific mention of accessible and appropriate housing	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
163	021	Alzheimer's Society	3.3.1	d	We suggest adding a final bullet "access to an effective complaints procedure. Learning from complaints is used to improve services".	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
164	022	Royal college of nursing	3.3.1	d	The importance of the GP's support and understanding for family, carers and care home/service	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The quality standard will build upon minimum standards and consider current practice, including variations in care, to provide aspirational but achievable markers of high quality care.
165	029	Foundation Trust Network	3.3.1	d	Will the standard address the use of end of life care pathways (e.g. Liverpool Care Pathway; communication between acute trusts and GPs	Thank you for your comment. The Topic Expert Group will consider

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					for patients to be entered on the End of Life register) for older patients with dementia?	end of life care specific to people living with dementia when developing the quality statements and associated measures.
166	029	Foundation Trust Network	3.3.1	d	With reference with Section 3.2d (Settings) – will the standard address the influence of the built environment on patients with dementia at a trust-wide level e.g. reflecting the positive effects of dementia friendly cubicles in A&E, rather than focussing specifically on specialist elderly care wards?	Thank you for your comment. The Topic Expert Group will consider the impact of the physical environment when developing the quality statements and associated measures.
167	029	Foundation Trust Network	3.3.1	d	Under "training needs of workforce" it would be useful to have more clarity on what is intended here e.g. will training centre on lower level (recognising confusion) or higher level dementia-awareness training; will there be patient involvement in staff training e.g. patients giving their perspective on care and services?	Thank you for your comment. The Topic Expert Group have identified that training needs of staff is of importance. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
168	031	Bradford Dementia Group	3.3.1	d	We suggest you add Collaboratively safeguarding people with dementia	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
169	031	Bradford Dementia Group	3.3.1	d	Collaborate with people with dementia in positive risk taking including balancing safety and liberty	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
170	032	Dementia UK	3.3.1	d	"De-stigmatisation" needs to include people with dementia (regardless of setting and including people in the categories listed under 3.1.1 d) having equal access to services and community resources. Eg people with dementia in prison being able to access therapies, care home residents not having to fight for NHS services that others can use as a matter of course. Opportunities for involvement in service planning, improvement and research need to be extended to carers of people with dementia too	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures.
171	034	Parkinson's UK	3.3.1	d	Organisation of care does not include within scope, strategic	Thank you for your comment. The

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		and the Lewy Body Society (LBS)			commissioning and procurement issues. A good practice QS must address these issues as they can be the root cause of unacceptable variation and poor quality. There are currently no obligations on social care commissioners to abide by national standards: localism now means local authorities "self assessing" their performance, using the ASCOF framework as a baseline measure. In addition, no overarching national body is holding local commissioners to account, regarding the quality of services they are commissioning. For example, commissioners will procure packages of 15 minutes of care or put contracts out for tender that give unrealistic prices for care thus leading to low pay and high turnover in the workforce, which leads to poor care and lack of continuity. Therefore, the QS should include a standard by which commissioners are required to procure services effectively. Organisation of services should note the danger of loss to follow-up care of patients with dementia as they move from living in the community to living in an institution. The QS should emphasis 'right care in the right place', so that, for examples, people with Parkinson's Disease and dementia are able to continue to see their Parkinson's specialist team while also getting expert support for their dementia. (Salford hospital has done some innovative work on its clinic arrangements in this respect).	Topic Expert Group will consider your comment when developing the quality statements and associated measures.
173	006	Carers Trust (formally The Princess Royal Trust for Carers)	3.3.1	e	The separate section on unpaid carers needs to reflect all previous sections b, c and d. Carers are not separate from these areas. Carers support needs crucially run in parallel and are significantly affected by the lack of inclusion in diagnosis, care delivery and service delivery.	The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
174	015	Tunstall Healthcare	3.3.1	e	The inclusion of statements within the final standard relating to the quality of support for carers are essential for the standard to be effective. Standard 7 of the National Service Framework for Older People focuses on the mental health needs of older people and those who care for them. Carers for those with dementia suffer immense and almost constant emotional and physical strain, and respite from their role is made difficult by the adverse effect it can have on the person they are caring for. Often this strain is at the point of becoming unbearable before they will seek	Thank you for your comment. The Topic Expert Group will consider your comment when developing the quality statements and associated measures. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of

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					support, and carers have reached the stage where they feel residential care is the only solution. Employing supportive technologies and services earlier in this process can mean people with dementia can remain at home for longer, but also that carers receive the support they need before they reach breaking point. Services like telecare can allow a carer to have a good night's sleep, safe in the knowledge that should their loved one leave the house, cause the bath to overflow or even leave their bed for a prolonged period of time, they will be alerted quickly and appropriately. It can enable them to manage difficult situations in an effective and reasonable way. Such services can also make spending a short time away from the house a possibility for the carer, which can make an enormous difference to the quality of everyday life. Tunstall telecare sensors can all link to a personal pager used by the carer, which vibrate in the event of a sensor being activated and display a message telling the carer where in the home a problem may be occurring. **Case Study** Sara lives in Croydon and cares for her 76 year old mother, Alice, who has severe dementia. Due to her inability to turn on the lights, Alice had fallen several times whilst going to the bathroom in the middle of the night. This was affecting Sara's sleep as she was so worried about her mother falling over. When Sara was out Alice repeatedly left the gas cooker on unlit, whilst trying to make a cup of tea. Sara was concerned that a serious gas leak may start as a result. A gas detector has been fitted above the cooker to ensure that if Alice were to leave the gas on, an alert would be sent to the Croydon Careline and the appropriate action would be taken. An automatic light system was installed so that if Alice were to wake up in the night and get out of bed, the lights would come on automatically. This means that Sara can relax in her own home, knowing she doesn't need to get up every time Alice does. Sara is thrilled with the telecare solutions: "Since the equipment has been installed I have started to go out again, and I know Mum will be ok. The equipment really gives me peace of mind."	the draft quality standard.

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175	016	Sue Ryder	3.3.1	e	Agree	Thank you for your comment.
176	021	Alzheimer's Society	3.3.1	e	• The Society suggests that "assessment of carers needs" is added as a first bullet point. This is essential to reflect the action highlighted in the PM challenge document that carers have the right to be assessed and their needs met. • The unpaid carers section must also recognise that quality of life, and the need to engage and be involved in the community, is also vital for carers.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
177	022	Royal college of nursing	3.3.1	e	Need to add: Recognising needs of carers and understanding impact of caring	Thank you for your comment. The Topic Expert Group will consider carers further when developing the quality statements and associated measures.
178	032	Dementia UK	3.3.1	e	The list of suggestions under "Support for unpaid carers" is also surprisingly short, given the importance of the area. Rather than placing the focus on managing differences in the views of people with dementia and their unpaid carers, should it not be about balancing the needs and listening to both perspectives? Specific suggestions might include: - Support and information in responding to the changing needs of the person with dementia – as provided by Admiral Nurses - Facilitation of self-help/peer support - Recognition of their other roles in life - Support to remain in employment	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
179	034	Parkinson's UK and the Lewy Body Society (LBS)	3.3.1	e	This section should have emphasis on: • Training for carers; • Respite breaks (this must be explicit). A trend at present is not to offer night time respite as this is too expensive, and the carer is put under pressure to agree to the person going into residential care; • Treating carers as expert partners in care.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
180	036	Chartered Society of Physiotherapy	3.3.1	e	Include the changing physical and mental health of unpaid carers	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft

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						quality standard.
182	020	British Association for Counselling & Psychotherapy	3.3.1	E,f	In relation to point e and f where support for carers is mentioned, BACP would suggest the inclusion of emotional support for carers. The University of Manchester has completed a systematic review looking at psychological interventions for carers of people with dementia. The review written by Elvish et al is due to be published in the summer.	Thank you for your comment. The Topic Expert Group agrees that the inclusion of carers needs to be further examined and will be addressed by publication of the draft quality standard.
183	003	Bournemouth University	3.3.1	f	Professionals and paid carers also require support and training to help them support the family members of a person with dementia during end of life care. Carers may also require support after a person with dementia has died to prevent for example depression, isolation and a general inability to cope with the strains of caring and the bereavement.	Thank you for your comment. The Topic Expert Group will consider end of life care specific to people with dementia when developing the quality statements and associated measures.
184	004	British pain society	3.3.1	f	F) we would like to see something in this section which acknowledges the need for effective pain control at the end of life and something about the preferred place of death.	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
185	011	NHS Sheffield	3.3.1	f	EOLC the role of social care to initiate or participate in discussions with the patient and carer around advanced care planning for EOLC and choice/consideration of place of care and place of death starting at/shortly after diagnosis of dementia (rather than waiting till last year of life).	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
186	012	Wigan Council	3.3.1	f	In addition we suggest that standards relating to staff/care givers are aware of advance care planning and preferred place of care.	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
187	016	Sue Ryder	3.3.1	f	Advanced care planning, with regular assessment and review for those with dementia needs to be added to end of life care.	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated

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						measures.
188	035	Care Quality Commission	3.3.1	f	End of life care: there could be more emphasis in this section on ensuring that the wishes and preferences of the individual person are listened to and adhered to as far as possible, to support and affect equality of opportunity	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
189	036	Chartered Society of Physiotherapy	3.3.1	f	Advanced care planning for end of life	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
190	036	Chartered Society of Physiotherapy	3.3.1	f	Access to palliative care services	Thank you for your comment. The Topic Expert Group will consider your comment on end of life care when developing the quality statements and associated measures.
191	002	Kent and Medway partnership trust	3.3.2		The scope is extremely broad. My only comment is it excludes medical interventions delivered by NHS staff for people admitted to hospital, but not those delivered by NHS staff for people who are in the community, I wondered how this is to be addressed?	Thank you for your comment. This section excludes activities that would be covered by other guidance products. It has been amended in the scope for clarity.
192	022	Royal college of nursing	3.3.2		It is not clear why medical interventions delivered by NHS staff are being excluded?	Thank you for your comment. This section excludes activities that would be covered by other guidance products. It has been amended in the scope for clarity.
193	009	British association of social workers	3.3.2	a	Areas and activities that will not be considered a) Medical interventions delivered by NHS staff for people admitted to hospital. It is recognised that this work cannot cover everything, but the group are asked to consider two things a) what is meant by "medical interventions" – does that include nursing care? b) that significant difficulties can and do take place regarding medical intervention in hospital which impact on the functioning of the person with dementia and	Thank you for your comment. This section excludes activities that would be covered by other guidance products. It has been amended in the scope for clarity.

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					their carers both in hospital and in the community needs to be acknowledged	
194	024	Dementia care matters	3.3.2	a	The exclusion of medical interventions delivered by NHS staff for people admitted to hospital needs to be reconsidered. Guidance on designing medical interventions which enable people with dementia to gain optimal benefit from medical treatment is required. The impact of cognitive impairment on compliance with some routine treatment regimens e.g.: Insulin regulated diabetes; pain management; and treatment for osteoporosis fail to take into account a person's capacity to remember the specific instructions and mode of drug administration. This, in turn, increases the risk and the occurrence of hospital admission. Guidance on history taking and prescribing interventions to people with dementia could help to reduce the need for hospital admission and readmission by, e.g.: use of transdermal analgesia and insulin; provision of drug / treatment alternatives to bisphosphonates and cardiac glycosides; considering alternative approaches to anti-coagulation.	Thank you for your comment.. This section excludes activities that would be covered by other guidance products. It has been amended in the scope for clarity.
196	025	Registered Nursing home association	4		"other NICE accredited sources" must include the academic research which is available. For example the many works of Kitwood continue to be highly relevant but frequently not implemented. As a minimum the works of Kitwood, Stirling, Bradford and Michigan must be incorporated into the standard.	Thank you for your comment. NICE quality standards use only NICE-accredited evidence sources. Organisations are encouraged to apply for accreditation (see www.evidence.nhs.uk)
197	008	Nutricia UK	4.1		NICE CG 32 Nutrition Support in Adults 2006 needs to be referenced	Thank you for your comment. NICE CG32 is not being used as a primary development source. However, in deliberating a statement on nutrition support, the group will be guided to consider CG32 where appropriate.
198	008	Nutricia UK	4.1		APPG on Dementia evidence summary for the 2011 inquiry 'How to save money in dementia care and deliver better outcomes for people with dementia' needs to be referenced and key sections incorporated – note section 2.1.5 within this evidence summary	Thank you for your comment. Your comment has been shared with the NICE technical team for consideration.
199	008	Nutricia UK	4.1		Add reference to the Care Quality Commission's report *Dignity and Nutrition for Older People* sets out good examples of NHS providers treating patients with dignity and respect	Thank you for your comment. Your comment has been shared with the NICE technical team for consideration.

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200	008	Nutricia UK	4.1		Add reference of NHS Operating Framework because of the references to dementia care for example section 4.19 on dementia services	Thank you for your comment. The quality standard will appropriately highlight links the NHS operating framework.
201	009	British association of social workers	4.1		The wide range of relevant documents is welcomed.	Thank you.
202	021	Alzheimer's Society	4.1		The Society would add to key development sources the Equality and Human Rights Commission (2011) publication *Information for care services providers* EHRC, London	Thank you for your comment. Your comment has been shared with the NICE technical team for consideration.
203	025	Registered Nursing home association	4.1		The standard must not be used as another implementation plan for the MCA.MCA is legislation and hence must be embedded just as Food Hygiene or Health and Social Care Act 2008 must be embedded. All legislation is a hygiene factor for these standards.	Thank you for your comment. Your comment will be considered when developing the quality statements and associated measures