

## Dementia (update)

### Consultation on draft scope Stakeholder comments table

8<sup>th</sup> July – 5<sup>th</sup> August 2015

Stakeholder	Page	Section / Line	Comments	Developer's response
Action on Hearing Loss	General	General	<p>Action on Hearing Loss welcomes the opportunity to submit comments on the proposed updates to the NICE guideline scope for "Dementia: supporting people with dementia and their carers in health and social care."</p> <p>Action on Hearing Loss (formerly RNID) is the main charity for people with hearing loss across the UK. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality.</p> <p>Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf. We are happy for the details of this response to be made public.</p> <p>Please do contact us if you require further information or evidence.</p>	Thank you for your comment. We appreciate the time taken to provide detailed feedback.
Action on Hearing Loss	General	General	<p>Action on Hearing Loss welcomes that the guidance will focus on varying groups of people affected by and working with dementia, especially those who are affected and have other</p>	Thank you for your comment. We have highlighted people with sensory impairment and people with communication difficulties among the groups requiring special consideration within this guideline

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			<p>comorbidities that may affect the treatment and management of their condition.</p> <p>More than ten million people in the UK have hearing loss, about 1 in 6 of the population. The prevalence of hearing loss increases with age. Over 71.1% over 70 year olds have some form of hearing loss, and given that most people with dementia are over 70, most people with dementia will also have hearing loss (1). Strong evidence shows that hearing aids and other support have a big impact on quality of life and improve communication, but there is an urgent need to increase the numbers of people who get help - only one third of people who could benefit from hearing aids currently have them (2).</p> <p>Hearing loss and dementia are likely to occur together because they are both linked to ageing, but there is also now strong evidence that having hearing loss increases the risk of going on to develop dementia - mild hearing loss doubles the risk of developing dementia, with moderate hearing loss leading to three times the risk and severe hearing loss five times the risk (3). Evidence</p>	<p>and will therefore search for appropriate evidence pertaining to this group when looking at issues of diagnosis and management of dementia. The draft review questions now include the assessment of needs for people living with dementia which will incorporate issues relating to sensory impairment including hearing loss.</p>

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			<p>suggests that proper diagnosis and management of hearing loss, including provision of hearing aids, reduce the risk and impact of dementia (4).</p> <p>Communication difficulties caused by unaddressed hearing loss and / or dementia can lead to a lack of diagnosis, misdiagnosis and/or mismanagement of either or both conditions. The diagnosis and management of both hearing loss and dementia need to take into account the association between the two conditions and the likelihood that they will occur together. We recommend that hearing loss be included in the scope and guideline as a clear risk factor and area to be covered. The rest of our response provides more detail on what this means for individual areas that will be covered by the updated NICE guideline on Dementia.</p> <p>(1) Action on Hearing Loss. (2011). Hearing Matters. <a href="http://www.actiononhearingloss.org.uk/hearingmatters">www.actiononhearingloss.org.uk/hearingmatters</a></p> <p>(2) Action on Hearing Loss. (2011). Hearing Matters. <a href="http://www.actiononhearingloss.org.uk/hearingmatters">www.actiononhearingloss.org.uk/hearingmatters</a></p>	

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			<p>(3) Lin FR, Thorpe R, Gordon-Salant S, Ferrucci L. (2011) Hearing loss prevalence and risk factors among older adults in the United States. <i>J Gerontol A Biol Sci Med Sci</i> 66(5):582-90; Lin, F.R. et al. (2013), Hearing Loss and Cognitive Decline in Older Adults. <i>Internal Medicine</i> 173(4): 293-299, <a href="http://archinte.jamanetwork.com/article.aspx?articleid=1558452">http://archinte.jamanetwork.com/article.aspx?articleid=1558452</a>; Gurgel RK, Ward PD, Schwartz S, Norton MC, Foster NL, Tschanz JT. Relationship of hearing loss and dementia: a prospective, population-based study. <i>Otol Neurotol</i> 2014 Jun;35(5):775-81; Albers et al. (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease: <i>Alzheimers and Dementia Journal</i> 11(1): 70–98.</p> <p>(4) Deal JA, Sharrett AR, Albert MS, Coresh J, Mosley TH, Knopman D, Wruck LM and Lin FR, Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. <i>American Journal of Epidemiology</i>, 2015, 181 (9), 680-690; Dawes P, Emsley R, Cruickshanks KJ, Moore DR, Fortnum H, Edmondson-Jones M, McCormack A,</p>	

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			<p>Munro KJ, Hearing loss and cognition: the role of hearing aids, social isolation and depression. PLoS One. 2015, 10(3):e0119616. doi: 10.1371/journal.pone.0119616; Action on Hearing Loss, <i>Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions</i>, 2013. London: Action on Hearing Loss. Available at: <a href="http://www.actiononhearingloss.org.uk/joiningup">www.actiononhearingloss.org.uk/joiningup</a></p> <p>(5) Bauer K. et al., A claims data-based comparison of comorbidity in individuals with and without dementia. BMC Geriatrics, 2014. 14(10); Behrman S. et al., Considering the senses in the diagnosis and management of dementia. Maturitas, 2014.</p>	
Action on Hearing Loss	2	21 -23	<p>There is clear evidence that hearing loss co-occurs with, is associated with, and leads to issues with the treatment and management of dementia. Hearing loss should therefore be given special consideration by the guideline committee alongside other comorbidities. We recommend that sight loss and hearing loss be included as a separate bullet in this list.</p>	<p>Thank you for your comment. We have highlighted people with sensory impairment among the groups requiring special consideration within this guideline and will therefore search for appropriate evidence pertaining to this group. We will consider both the needs of people with hearing loss and people with sight loss discretely.</p>
Action on Hearing Loss	5	4	<p>The impact of hearing loss on the costs of diagnosing and managing dementia should be</p>	<p>Thank you for your comment. The <a href="#">NICE guidelines manual</a> sets out the reference case to be used</p>

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			<p>included in the economic evidence and economic analyses. Proper management of hearing loss improves communication with health professionals (for example in diagnosing and managing dementia), quality of life and health outcomes, as well as reducing the risk of depression, falls and other conditions, so it makes a big difference to the overall health and social care costs for people with dementia. It is estimated that at least £28 million per year could be saved in England by properly managing hearing loss in people with dementia, and thus delaying their admission to residential care. This is calculated by offsetting the cost of community-based provision for people with severe dementia against the cost of residential care, which would be avoided (6). More generally, given the low levels of diagnosis and management of hearing loss, it is estimated that communication difficulties caused by unaddressed hearing loss cost the NHS £76 million in extra GP visits and £60 million in increased use of social care (7).</p> <p>(6) Action on Hearing Loss (2013) Joining Up <a href="http://www.actiononhearingloss.org.uk/joiningup">www.actiononhearingloss.org.uk/joiningup</a></p>	<p>when undertaking economic analyses. NICE reference case to be used for questions in this guideline will be agreed with the guideline committee and NICE quality assurance staff and will guide which costs and benefits will be considered. If appropriate, economic analyses may estimate the cost effectiveness of an intervention a given subgroup. We recognise sensory impairment as an important issue and people with sensory impairment including hearing loss have now been highlighted as a group requiring special consideration within the guideline.</p>

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			(7) The Ear Foundation, 2014. The Real Cost of Adult Hearing Loss: Reducing its impact by increasing access to the latest hearing technologies. Nottingham: The Ear Foundation.	
Action on Hearing Loss	5	27	<p>We support the inclusion of recognising symptoms of co-existing conditions that may mask or mimic dementia. Hearing loss should be included here, as it is a risk factor for dementia and is very likely to co-occur alongside dementia. There is good evidence that when people are being diagnosed, hearing loss is often confused with dementia.</p> <p>Not only is hearing loss often undiagnosed, but hearing loss may be misdiagnosed as dementia or make the symptoms of dementia appear worse, or dementia may be undiagnosed because of hearing loss or deafness (8). We hear many examples of misdiagnosis of hearing loss as dementia, often due to tests used to diagnose dementia not taking into account hearing loss – for example we have been told that one test gives a positive diagnosis of dementia if the person asks the question to be repeated, something which will be very common if the person has hearing loss, whether the hearing loss is diagnosed or undiagnosed.</p>	<p>Thank you for your comment. We have amended the scope to ensure people with hearing loss are captured. We recognise sensory impairment as an important issue and people with sensory impairment including hearing loss have now been highlighted as a group requiring special consideration within the guideline. We will take this into account when looking at evidence and developing recommendations based on the diagnosis and management of dementia.</p>

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			<p>Where both hearing loss and dementia are present, their management can also be complicated. For example, where unaddressed hearing loss causes communication problems in people with dementia, this can lead to behavioural and psychological problems which could have been avoided by better diagnosis and management. Both hearing loss and dementia need to be addressed early (9) and when they are diagnosed and treated they should take into account each other's challenges. Specialist diagnostic tools as well as improved management (such as through well-maintained hearing aids and support) are needed (10).</p> <p>At the moment, hearing loss and dementia are usually addressed separately. There should therefore be an approach to hearing assessment, systematically taken, that allows for the high levels of co-occurrence of hearing loss and dementia and takes into account the challenges around this. Similarly, it is essential that services address the under diagnosis of dementia in the presence of hearing loss. People with hearing loss should be able to access specialist services that diagnose</p>	

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			<p>and help people with hearing loss to manage their dementia as effectively as possible.</p> <p>(8) Bauer K. et al., A claims data-based comparison of comorbidity in individuals with and without dementia. BMC Geriatrics, 2014. 14(10); Behrman S. et al., Considering the senses in the diagnosis and management of dementia. Maturitas, 2014; Boxtel van, M P J et al., "Mild hearing impairment can reduce verbal memory performance in a healthy adult population" Journal of Clinical and Experimental Neuropsychology 2000, 22(1): 147-154; Burkhalter C L et al., "Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviors" Journal of American Academic Audiology 2009, 20(9): 529-38</p> <p>(9) <a href="http://www.alz.co.uk/info/diagnosis">http://www.alz.co.uk/info/diagnosis</a></p> <p>(10) Action on Hearing Loss (2013) Joining Up <a href="http://www.actiononhearingloss.org.uk/joiningup">www.actiononhearingloss.org.uk/joiningup</a></p>	
Action on Hearing Loss	6	1	See comment 5 above – assessments for dementia must take into account hearing loss, whether	Thank you for your comment. We recognise that sensory impairment is an important issue. Our

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			diagnosed or undiagnosed, which many people who develop dementia will have.	draft review questions include the assessments for suspected dementia and we will take into account people with hearing loss when considering this review question.
Action on Hearing Loss	6	7	<p>Hearing loss is a risk factor for dementia, and so ensuring more people are diagnosed with hearing loss and get hearing aids and other support is likely to prevent them developing dementia (11). Those diagnosing and managing dementia should recognise hearing loss and refer a person for hearing tests, and ensure that the care they provide takes into account their hearing loss.</p> <p>(11) Deal JA, Sharrett AR, Albert MS, Coresh J, Mosley TH, Knopman D, Wruck LM and Lin FR, Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. American Journal of Epidemiology, 2015, 181 (9), 680-690; Dawes P, Emsley R, Cruickshanks KJ, Moore DR, Fortnum H, Edmondson-Jones M, McCormack A, Munro KJ, Hearing loss and cognition: the role of hearing aids, social isolation and depression. PLoS One. 2015, 10(3):e0119616. doi: 10.1371/journal.pone.0119616; Action on Hearing</p>	Thank you for your comment. We will ensure the needs of people with sensory impairment including hearing loss are emphasised when looking at the areas of diagnosis and management of dementia.

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			Loss, Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions, 2013. London: Action on Hearing Loss. Available at: <a href="http://www.actiononhearingloss.org.uk/joiningup">www.actiononhearingloss.org.uk/joiningup</a>	
Action on Hearing Loss	6	12	See comment 5 above – assessments for dementia must take into account hearing loss, whether diagnosed or undiagnosed, which many people who develop dementia will have.	Thank you for your comment. We will give special consideration to the needs of people with hearing loss when looking at the evidence pertaining to dementia assessments.
Action on Hearing Loss	6	18-28	Unaddressed hearing loss can result in communication difficulties and reduced functioning in people with dementia, and it can have a major impact on the effectiveness of management of dementia. It is therefore crucial that it is diagnosed properly and managed properly, but also that all health and social care services are accessible for people with hearing loss. In our recent research, more than a quarter (28%) of people with hearing loss did not understand their diagnosis after visiting their GP, rising to two fifths (41%) of profoundly deaf British Sign Language users, and one in seven respondents had missed an appointment because they did not hear their name being called in the waiting room (12).	<p>Thank you for your comment. We will consider the needs of people with sensory impairment and their communication difficulties throughout the guideline.</p> <p>We will be considering assistive technologies when looking at the evidence for interventions to maximise the health and wellbeing of people living with dementia and we have updated the scope to make this explicit as follows:</p> <p>“What interventions (for example cognitive stimulation therapies, pharmacological</p>

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			<p>Under equalities legislation and the new mandatory Accessible Information Standard (13), NHS and adult social care services must identify, record and meet the information and communication needs of people with hearing loss, sight loss and learning disabilities. These needs should be recorded on people's medical records and staff should be alerted so that they can meet them, and they should also be shared with other services when patients are referred.</p> <p>For example, people with hearing loss may need staff to face them so that they can lipread, they may need the use of a hearing loop or personal listener, and they may need to be contacted by email, textphone or SMS rather than by phone. For people who use British Sign Language (BSL) as a first language, English is often a second language and access to written English can be challenging. Any written information should therefore be produced in accessible, plain English, accompanied by a visual representation of the key messages. BSL users require registered BSL interpreters in medical appointments.</p>	<p>interventions, assistive technologies or music therapy) are effective, when compared with placebo or usual care, in maximising the health and wellbeing of people living with dementia who experience changes in cognitive function?"</p> <p>In addition, we will also consider other interventions to assist people with hearing loss or communication difficulties, which are not listed within the scope and this may include the use of subtitles or BSL videos.</p>

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			<p>Further to these steps:</p> <ul style="list-style-type: none"> <li>- All reception and other frontline staff should be trained in deaf awareness and communication tips so that they can recognise hearing loss and communicate effectively with people with hearing loss.</li> <li>- Assistive technologies (e.g. loop systems) should be provided, along with a range of methods for contacting the service (including email, textphone and SMS)</li> <li>- Videos with BSL translation and subtitles should be used to convey key health information.</li> </ul> <p>(12) Ringham, L (2013), Access All Areas, London: Action on Hearing Loss, Available at: <a href="http://www.actiononhearingloss.org.uk/accessallareas">www.actiononhearingloss.org.uk/accessallareas</a></p> <p>(13)<a href="http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/">http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/</a></p>	
Action on Hearing Loss	7	3 4 8 9 13	Action on Hearing Loss welcomes the inclusion of non-pharmacological interventions for managing the effects of dementia, such as cognitive, behavioural, emotional and functional features.	Thank you for your comment. We will consider the needs of people with sensory impairment throughout the guideline. We will be considering various non pharmacological interventions to maximise the health and well-being of people living

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		14 18 19	<p>Hearing aids are a non-pharmacological intervention and the only viable treatment option for people with hearing loss (14). The evidence is clear that hearing aids improve communication, health and quality of life for people with hearing loss.</p> <p>Research has shown wearing hearing aids could also help prevent cognitive decline and dementia, given the strong evidence of a link between all levels of hearing loss and cognitive decline and dementia, as well as with the progression of dementia (15). There is also evidence that hearing aids may reduce the risk of developing dementia (16).</p> <p>(14) Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. Journal of American Academy of Audiology 18: 169</p> <p>(15) Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology and Neurotology 35(5): 775-</p>	with dementia and this may include the use of hearing aids.

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			<p>81; Lin et al (2011) Hearing loss and incident dementia. Archives of Neurology 68(2): 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. Internal Medicine 173(4): 293-299; Uhlmann et al (1989) Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. Journal of the American Medical Association 261: 1916-1919</p> <p>(16) Deal JA, Sharrett AR, Albert MS, Coresh J, Mosley TH, Knopman D, Wruck LM and Lin FR, Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. American Journal of Epidemiology, 2015, 181 (9), 680-690; Dawes P, Emsley R, Cruickshanks KJ, Moore DR, Fortnum H, Edmondson-Jones M, McCormack A, Munro KJ, Hearing loss and cognition: the role of hearing aids, social isolation and depression. PLoS One. 2015, 10(3):e0119616. doi: 10.1371/journal.pone.0119616; Action on Hearing Loss, Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions, 2013. London: Action on Hearing Loss. Available at:</p>	

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Action on Hearing Loss	7	20	<p><a href="http://www.actiononhearingloss.org.uk/joiningup">www.actiononhearingloss.org.uk/joiningup</a>.</p> <p>New evidence suggests that as well as being linked to the development of dementia, hearing loss may accelerate its progression (17).</p> <p>(17) Lin, F.R., et al., Hearing Loss and Incident Dementia. Arch Neurol, 2011. 68(2): p. 214-220; Lin, F.R. et al., Hearing Loss and Cognitive Decline in Older Adults. Internal Medicine, 2013. 173(4): 293-299, <a href="http://archinte.jamanetwork.com/article.aspx?articleid=1558452">http://archinte.jamanetwork.com/article.aspx?articleid=1558452</a>;</p>	Thank you for your comment. Our draft review questions now include reference to slowing the progression of dementia. We will take into account people with hearing loss when considering the evidence for this question.
Age UK	General	General	Age UK welcomes the opportunity to comment on the draft scope of the forthcoming update of the NICE Clinical Guideline on dementia (CG42). Dementia is one of the most important challenges facing our ageing society, where a growing number of older people live with the condition. Updating the NICE guideline offers a welcome opportunity to reflect changes and developments in the sector, but also to clarify the pathway for those who receive a diagnosis of dementia and their families.	Thank you for your comment
Age UK	General	General	Age UK particularly supports the stronger emphasis within the draft scope on assessing and managing co-morbidities in people with dementia, as studies	Thank you for your comment.

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			have shown that around 95% of people with dementia live with at least one other health condition (Barnett K et al, <i>The Lancet</i> , 2012). This is particularly important as evidence suggests that people with dementia do not have the same access to treatment and monitoring for conditions such as visual impairment and diabetes as those with similar comorbidities but without dementia (Bunn F et al, <i>BMC Medicine</i> , 2014). The high rate of comorbidity – with the average of 3-4 comorbidities accompanying dementia (Poblador-Plou B et al, <i>BMC Psychiatry</i> , 2014) – also emphasises the need to provide person-centred, integrated care services which are suited to catering for a wide range of individual needs within a local population, and we welcome the renewed focus on integrated care within the scope of the guideline.	
Age UK	6	17	While we understand that elements of what constitute good post-diagnosis support may be scattered throughout different sections of the guideline (e.g. advice on emotional support or managing functional features), we are concerned the draft scope may miss out on an opportunity to clarify the pathway following diagnosis of dementia, and set a benchmark for what good post-diagnosis	Thank you for your comment. Our intention is that the guideline will consider issues of support post diagnosis. A number of areas of the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia The guideline committee will take into

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			<p>support should look like. At the moment, access to help and advice on what happens after a diagnosis and the support available through the journey remains patchy throughout the country, and appropriate support is too often lacking (All-Party Parliamentary Group on Dementia, <i>Building on the National Dementia Strategy: Change, progress and priorities</i>, 2014). For example, a recent survey by the Dementia Action Alliance found that 89% of people with dementia felt they did not have enough information to get what they need following diagnosis (Dementia Action Alliance, <i>Annual report 2014/2015</i>, 2014).</p> <p>Comprehensive advice and support after diagnosis is, however, important in order to equip individuals and their families with the tools, connections, information and plans they need to live with dementia as well as possible, and prepare for the future, when they are ready to do so. Unlike Scotland, there are still no minimum requirements of post-diagnosis support in England – although we understand that NHS England is currently looking at this issue (NHS England, <i>Business Plan 2015/16</i>, 2015) – and it is unclear whether</p>	<p>consideration the inclusion of issues of post diagnosis support when looking at the evidence for this section.</p>

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			<p>responsibility for support should sit with the NHS or social care, or both. We also know that a number of GPs still do not diagnose dementia in people because they feel that 'nothing can be done to support them' (Department of Health, <i>Dementia – A state of the nation report on dementia care and support in England</i>, 2013). Tackling inadequate provision of post-diagnosis support as well as raising awareness among GPs of what services are available locally therefore seems essential to encouraging timely diagnosis and support for people with dementia.</p> <p>This is why Age UK believes that there should be a national minimum standard of good-quality post-diagnosis support for people with dementia and their carers. Specifically, ensuring that the new version of the NICE guideline covers a set of minimum requirements for high-quality support following diagnosis would be helpful in clarifying and spreading good practice in this field, building on recommendations from existing relevant NICE quality standards (QS1 and QS30). This should include recommendations around the type of information, advice and support that should be</p>	

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			<p>provided to people with dementia and their families following diagnosis, and the ways in which these should be delivered (e.g. timings, level of detail, presentation, etc), recognising the current role of the voluntary sector in providing such support. We would therefore recommend that a key issue be added to section 1.5 on 'key issues and questions', below line 17 on page 6, as follows: 'Provision of good-quality post-diagnosis support'. Questions to explore may include:</p> <ul style="list-style-type: none"> <li>- What type of information, advice and support should be provided to individuals and their families following diagnosis?</li> <li>- How should post-diagnosis support be provided in practice, e.g. who should be responsible for it and in which manner should this be provided?</li> </ul>	
Alzheimer's Society	4	1.3	<p>Under the 'Integrated health and social care' section there must be a focus on, and therefore research into, the admission and discharge process from hospital. The Alzheimer's Society report "Counting the Cost" found people with dementia stay in hospital far longer than other people admitted for the same reason, partly as a result of lack of coordination of care in the community and</p>	<p>Thank you for your comment. We have amended the scope and have now included a review question to consider the needs of people living with dementia at different stages of the disease and in different settings.</p>

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			also within hospitals themselves.  Alzheimer's Society advocate for an assessment, carried out by several health and social care professionals and involving the person with dementia and their carer, of people with dementia prior to discharge. This may involve a home visit to ensure the person is returning to a safe and manageable environment. This assessment may suggest that the person with dementia would benefit from adaptations or the use of assistive technology.	
Alzheimer's Society	4	1.3	The phrasing 'co-morbidities' does not match up with the later reference to 'Multi-morbidities' (Q10, pg6) so we would suggest using the same phrase throughout the guideline to avoid confusion.	Thank you for your comment. We have amended the scope.
Alzheimer's Society	4	1.3	Inpatient dementia services should not be stood down. There would be benefit to including the need for activities such as exercise and therapeutic groups to be included in inpatient treatment as they can play a great part in treatment and recovery. It would also be useful to state that carers and relatives should be encouraged to come onto the wards to help and support patients in practical ways. This could mean talking about memories or	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.

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			helping at meal times.	
Alzheimer's Society	5	1.4	Whilst responding to this consultation Alzheimer's Society engaged with our supporters who raised the issue of the economic aspects section not touching on the effect on quality of life. Alzheimer's Society feel that the outcomes should not be solely concerned with economic or purely health benefits but should incorporate quality of life for people with dementia.	Thank you for your comment. Quality of life is included in the scope as an outcome. As per the <a href="#">NICE guidelines manual</a> , quality of life will usually be considered as the direct health effect in economic analyses.
Alzheimer's Society	5	1.5 Point3	It is worth noting that the Prime Minister's Dementia 2020 Challenge recognises the need for the health and social care sector to be trained in dementia as one of the visions is: <i>'All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.'</i>	Thank you for your comment. The guideline committee may choose to consider this intervention when looking at the evidence for this section of the guideline, if they think this is appropriate.

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			Alzheimer's Society would suggest NICE look at the Focus Intervention Training and Support (FITS) programme whilst researching models of training for health and social care staff. It is especially relevant to Sec 1.5 Q 14 as the FITS programme led to a 40% reduction in the prescription of anti-psychotic drugs.	
Alzheimer's Society	6	1.5 Point7	<p>Alzheimer's Society knows that increasing the amount of cognitive and physical activities people carry out can help to prevent dementia.</p> <p>There is growing evidence that more focused intervention on people aged between 50-65 years old to set goals to reduce risks is effective and fairly low cost.</p> <p>A recent trial carried out by Dr Linda Clare called "Age Well" involved 75 people, who were given access to a <u>community resource centre</u> offering physical and mentally-stimulating activities including gentle exercise classes, dancing, computing, art, local history and reading groups.</p>	Thank you for providing this reference.

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			<p>Over a one-year period, the team found that those volunteers who showed the greatest increases in physical and cognitive activity were those who set goals at the start of the study and had mentoring every two months to monitor their progress. Volunteers in this group reported improvements in wellbeing, as well as diet and weight compared to those participants who weren't given as much support.</p> <p>There also needs to be recognition of the link between depression and dementia as there is growing evidence to highlight depression in early life increases the risk of dementia. (Dr Steve Iliffe has done numerous studies to this effect).</p>	
Alzheimer's Society	6	1.5 Point8	<p>Alzheimer's Society recognises that some memory clinics are not part of the Memory Services National Accreditation Programme (MSNAP) which outlines good practice in memory service delivery. The standards cover:</p> <ul style="list-style-type: none"> <li>• Management systems for the service</li> <li>• Resources available to support assessment and diagnosis</li> <li>• Assessment and diagnosis</li> </ul>	Thank you for your comment.

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			<ul style="list-style-type: none"> <li>• Pharmacological interventions</li> <li>• Signposting to ongoing care management and follow up</li> <li>• Psychosocial interventions</li> </ul> <p>As many people are diagnosed with dementia at a Memory Clinic it is important to recognise the accreditation.</p>	
Alzheimer's Society	6	1.5 Point8	There needs to be guidance on how people with dementia and their carers are involved with the diagnosis process. In addition it would be beneficial to consider how health and social care workers should communicate the diagnosis to people with dementia and their carers. It therefore would be useful to add a question such as 'How is a diagnosis communicated to a person with dementia and their carer?'	Thank you for your comment. Our intention is that the guideline will consider issues of support for people living with dementia, their family and carers at each stage during and post diagnosis. Many areas covered in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia The guideline committee will take into consideration the issues of information and support when looking at the evidence for this section.
Alzheimer's Society	6	1.5 Point11	Alzheimer's Society has engaged with supporters about this scope who stated there was an issue with the language of this question as ' <i>people with dementia should be able to experience 'risk' as they are first and foremost people who should not</i>	Thank you for your comment. We have now amended this question in the scope.

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			<i>be babied</i> '.	
Alzheimer's Society	6 -7	1.5  Point12	In relation to this question Alzheimer's Society would recommend NICE look at the SMART trial carried out by Linda Clare which showed there was significant improvement through Cognitive Rehabilitation interventions which had been personalised in order to help answer this question. <a href="http://www.uclouvain.be/cps/ucl/doc/ir-irss/images/Clare_et_al_2010_ajgp.pdf">http://www.uclouvain.be/cps/ucl/doc/ir-irss/images/Clare_et_al_2010_ajgp.pdf</a>	Thank you for your comment. The guideline committee will take into consideration cognitive rehabilitation interventions when looking at the evidence for this section.
Alzheimer's Society	7	1.5  Point14	Alzheimer's Society has engaged with supporters about this scope and were given feedback that if anti-psychotic drugs are prescribed for use in the home both the person with dementia and their carer need to know how to use them. Support for the carer using anti-psychotics should be in place before their use is considered. We would ask you to bear this in mind whilst you are researching this area.	Thank you for your comment. The guideline committee will take into consideration these issues when looking at the evidence.
Alzheimer's Society	7	1.5  Point18	Alzheimer's Society welcomes the inclusion of a section on Integrated health and social care. Dementia is a complex condition combining features of chronic neurological disease, mental illness, physical frailty and communication problems. Because of this complexity and the fact people with dementia often move between care	Thank you for your comment. We have highlighted people with specific housing needs including the provision of an environment which is sensitive to cognitive impairment as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this group

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			settings, they often receive formal care from a range of health and social care services. Effective integration is therefore essential if formal care services are to meet the needs of people with dementia.	
Alzheimer's Society	9	General	The " <i>NICE guidance in development that is closely related to this guideline</i> " section should include NICE's guidelines on Home Care.	Thank you for your comment. We have now amended the scope to include this.
Alzheimer's Society	12	3.2	Alzheimer's Society would welcome clarity on whether you can use acetylcholinesterase in conjunction with memantine as these guidelines do not make that clear.	Thank you for your comment. The guideline committee will take into consideration these combinations of pharmacological interventions outside of the TA217 recommendations.
Alzheimer's Society	General	General	The importance of social interaction and engagement must be emphasised and recognised in any research which is carried out. There needs to be recognition that people's needs evolve and develop over time and the support provided must adapt whether this be in an acute or community setting.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline and the needs of people living with dementia and their carers will be taken into consideration at every opportunity.
Alzheimer's Society	General	General	Alzheimer's Society believes that all hospitals should be a dementia friendly environment. This is in line with the Prime Minister's vision for 'All hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting' in his Dementia 2020 strategy. The	Thank you for your comment... We have included a review question to consider inpatient services "How should people living with dementia in inpatient services be cared for?" which will take account of dementia friendly environments within

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			<p>suggested research questions do not explore the importance of a dementia friendly environment e.g. dementia friendly colours, signage and flooring. This would also incorporate the need for carers of people with dementia to be allowed to visit out of hours, with the potential to stay over, as is advocated in John's Campaign which is supported by Alzheimer's Society.</p> <p>We would suggest that the benefits of dementia friendly environments and the benefits of enabling carers to come and go as they please, as is the case for parents of children staying in hospital, ought to be researched in the development of this guideline.</p>	hospital settings.
Alzheimer's Society	General	General	The awareness of assistive technology is currently very low and access to it across the country is variable. Alzheimer's Society advocates for the inclusion of assistive technology in care packages and service providers having to ensure their staff are trained in assistive technology (how to access them and how to use them). The technology should be able to enhance wellbeing whilst keeping people safe and healthy.	Thank you for your comment. The guideline committee will be considering assistive technologies when looking at the evidence for non-pharmacological interventions and we have now updated the scope to make this explicit as follows "What interventions (for example cognitive stimulation therapies, pharmacological interventions, assistive technologies or music therapy) are effective, when compared with placebo or usual care, in maximising the health

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			Therefore we recommend that research is carried out by NICE, or that NICE draw on previous research, to show the effects of assistive technology in ensuring people with dementia maintain their independence and stay safe. With this evidence the inclusion of assistive technology in care packages can be supported.	and wellbeing of people living with dementia who experience changes in cognitive function?"
Association for Dance Movement Psychotherapy UK	9	5	<p>We note that the draft scope has implications for the updating of the following guidance: Dementia: supporting people with dementia and their carers in health and social care (2006) NICE guideline CG42 Having consulted this guideline, we note the following section:</p> <p>1.7.1.2 For people with all types and severities of dementia who have comorbid agitation, consideration should be given to providing access to interventions tailored to the person's preferences, skills and abilities.</p> <p>Dance is one of the possible interventions mentioned. We wish to draw to the panel's attention the fact that there is a Cochrane Systematic Review underway (Karkou &amp; Meekums) of Dance</p>	Thank you for your comment and for providing these references. The guideline committee will take into consideration the inclusion of dance therapy when looking at the evidence for non-pharmacological interventions for people living with dementia.

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			<p>Movement Therapy for Dementia. This is a specific treatment, requiring specialist training. Early indications two included papers, as follows:</p> <p>Hokkanen L, Rantala L, Remes AM, Harkonen B, Viramo P, Winblad I. (2008). Dance and movement therapeutic methods in management of dementia: a randomized, controlled study <i>Journal of the American Geriatrics Society</i>, 56 (4), pp. 771-772.</p> <p>Hyang-Hee Hwang &amp; Yun-Jeong Choi (2010). The effects of the Dance Therapy Program through rhythmic exercise on cognitive memory performance of the elderly with dementia. <i>Proceedings of the 21<sup>st</sup> Pan-Asian Congress of Sports and Physical Education</i>, Nanchang, China, April 23-25 2010, pp. 12-17.</p> <p>We would be happy to supply further details of these papers, if requested. Early indications are that there may be positive effects from Dance Movement Therapy on cognitive function.</p>	
Association of British Neurologists ( <i>endorsed by Royal College of</i>	2	General	The exclusion of MCI from the scope is problematic, particularly because the boundary between MCI and dementia varies widely between	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with

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Physicians)			centres and specialities. Ever increasing understanding and use of biomarkers, such as structural and functional imaging, amyloid PET and CSF examination, is making a positive diagnosis of the underlying disease (eg Alzheimer's disease, frontotemporal dementia, dementia with Lewy Bodies) more realistic. By the time that this guideline is published there will a higher proportion of individuals with MCI who are diagnosed with 'early Alzheimer's', for example, and in whom the long-term prognosis is much clearer. Perhaps the scope could be adjusted to include those individuals with MCI who are highly likely to have a specific pathological process (on the basis of CSF examination/amyloid imaging).	MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Association of British Neurologists ( <i>endorsed by Royal College of Physicians</i> )	2	General	Parkinson's disease dementia will be excluded from the new clinical guidelines as it will presumably be covered in the pending Parkinson's disease CG. However, can we be reassured that the revised dementia CG will include advice on diagnosis and management of dementia with Lewy Bodies?	Thank you for your comment. We intend to consider all forms of dementia within this guideline however we may cross refer to the guideline update for Parkinson's disease for recommendations associated to the pharmacological management of Parkinson's disease dementia. We will be covering the recognition, diagnosis and assessment of people with dementia with Lewy Bodies.
Association of British	2	General	Although the scope states that it will cover people	Thank you for your comment. We have now

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Neurologists ( <i>endorsed by Royal College of Physicians</i> )			of all ages with dementia, do individuals with young-onset dementia need specific consideration (as per people with HIV and other co-morbidities)?	highlighted people with early-onset dementia (between ages of 40 and 64) as a group requiring special consideration within this guideline and will search for appropriate evidence pertaining to this group. However, due to the different pathway and presentation of juvenile onset dementia, this group will not be covered by the guideline.
Association of British Neurologists ( <i>endorsed by Royal College of Physicians</i> )	3	23	Instead of referring to 'identifying dementia subtypes', this should be described as 'identifying the underlying cause' or 'underlying disease process'. Dementia with Lewy Bodies is not a different 'subtype' of dementia from Alzheimer's disease. It is a completely different disease. Use of the term 'subtype' diminishes the importance of making a correct disease diagnosis.	Thank you for your comment. We will consider this description when exploring the evidence for this review and when writing the guideline.
Association of British Neurologists ( <i>endorsed by Royal College of Physicians</i> )	6	3	Section 1.5 paragraph 6, asks "What are the indications for referral for specialist diagnostic assessment?" NICE might consider what is meant by "specialist assessment" and whether it is appropriate for all patients with suspected dementia to be referred to a generic memory clinic. In particular, NICE might wish to comment on which patients should be considered for referral to regional specialist centres, such as cognitive neurology services. This advice will help	Thank you for your comment. We have now included a review question to capture these issues.

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			commissioners and service providers develop pathways that are centred around the needs of individual patients rather than assuming that all patients have the same diagnostic requirements and can be handled in one service. A starting point for this discussion might be the Memory Services National Accreditation Programme (MSNAP) Standards, which state "There are also specific forms of dementia, particularly those occurring in younger adult populations, where the dominant presenting problems are not in memory (they may be in behaviour, language or vision for example). These disorders include Creutzfeldt-Jakob disease, Huntington's disease, frontotemporal dementias, posterior cerebral atrophy, or unusual presentations of Lewy body dementia. These require referral direct to a neurological or appropriate specialist service. This will vary according to availability but may be the local memory services provided that they include appropriate expertise from neurology and neuropsychology."	
Association of British Neurologists ( <i>endorsed by Royal College of</i>	6	6	With respect to prevention, there should be guidance regarding Multivitamins, Exercise and 'Brain-training' applications.	Thank you for your comment. We have modified this section of the scope to reflect slowing the progression of dementia. The guideline committee

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Physicians)				will take into consideration these interventions when looking at the evidence for this section.
Association of British Neurologists ( <i>endorsed by Royal College of Physicians</i> )	6	16	Section 1.5 paragraph 9, asks "What is the diagnostic accuracy of imaging to differentiate between dementia subtypes?" We recommend that NICE does not focus exclusively on imaging. The key to diagnosing different forms of dementia is clinical assessment of the patient. If performed by someone with sufficient expertise, the diagnosis can be determined clinically in the vast majority of cases. Indeed, there is a risk that over-reliance on imaging might result in mis-diagnosis e.g. over-diagnosis of vascular dementia on the basis of small vessel disease on brain imaging, or under-diagnosis of behavioural variant FTD where frontal atrophy isn't demonstrated. There are also non-imaging based techniques such as CSF biomarkers which although not routinely available (and conversely perhaps over-used in some quarters) might have a role. We would therefore encourage NICE to broaden this question to "what is the diagnostic accuracy of clinical assessment, imaging and other investigations to differentiate between different underlying causes of dementia".	Thank you for your comment. A review question considering these issues has been included in the scope. The guideline committee will take into consideration the inclusion of these diagnostic biomarkers when looking at the evidence.
Association of British	7	3	Non-pharmacological therapies that should be	Thank you for your comment. The guideline

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Neurologists ( <i>endorsed by Royal College of Physicians</i> )			evaluated should include novel stimulation systems that are now licensed in Europe (eg the Neuronix system which is now being marketed in the UK)	committee will consider the evidence for the non-pharmacological interventions and this may include novel or existing stimulation systems.
Association of British Neurologists ( <i>endorsed by Royal College of Physicians</i> )	General	General	We would encourage NICE to consider producing recommendation/guidance about whether patients should still have regular contact with specialist services after diagnosis.	Thank you for your comment. This area will be covered in the review question on needs assessment for people with dementia.
British and Irish Orthoptic Society	4	15	It is pleasing to see that co-morbidities are included, to add further clarity visual impairment should be changed to read – 'co morbidities that may require treating differently because of the presence of dementia such as reduced visual acuity, ocular motility defects as well as visual perception deficits.'	Thank you for your comment. We have inserted examples of co-morbidities only within this section. We have, however, highlighted people with sensory impairments as a group requiring special consideration and will search for appropriate evidence during development of the guideline.
British and Irish Orthoptic Society	6	General	Point 10 – add 'how should co-sensory deficits be assessed and managed?'	Thank you for your comment. We have now amended this question within the scope. We have highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
British and Irish Orthoptic Society	8	General	Multi-morbidities such as visual impairment needs adding in to section 1.6.	Thank you for your comment. We have now updated the scope to incorporate this.
British and Irish Orthoptic Society	General	General	Attention to environment should be included and how the environment can be arranged to cater for the needs of dementia patients and their families	Thank you for your comment. We will search for evidence pertaining to dementia friendly living environments within the area of the guideline that

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			and carers.	looks at interventions to maximise the health and wellbeing of people living with dementia. We have also highlighted "people with specific housing and supported living needs, including the need for a living environment adapted for people with cognitive impairment" as a group requiring special consideration.
British Association for Music Therapy	General	General	As a stakeholder we are commenting generally upon the consultation and first make general points, but secondly list some research and RCT published trials evidence that may not be included in documentation so far. We welcome the new guidelines and dementia is a priority area for music therapy and BAMT. We have recently had an MP sponsored event in Portcullis House, supported also by Alzheimer's Disease Society, MHA Nottingham University and Anglia Ruskin University. Evidence was put to this Round Table and to the Parliamentary House of Lords debate chaired by Lord Berkley. This included music therapy and music and the brain evidence. Music therapy has a unique role to play for older people and the evidence for health and social care and well- particularly for those with dementia include key areas mentioned in the scope document such	Thank you for your comment and for supplying these references. The guideline committee will be considering music therapy when looking at the evidence for the non-pharmacological interventions.

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			<p>as choice, working with families and carers for example. General information about music therapy as follows should be known to readers but in case not, here is a summary. Music therapists are professional musicians with a high level of skill as therapists and musicians. They are registered with the HCPC. Music therapy, as defined by the World Federation of Music Therapy is an intervention where a trained music therapist uses music and elements of it, to enhance quality of life, bring about change, and to improve social, 'emotional, intellectual communicative, intellectual and spiritual wellbeing'. Work is carried out in medical, community educational and social settings. Music therapy can involve interactive musical processes or receptive listening techniques, according to the needs of the participant. In groups it leads to social connectedness and higher levels of engagement (Odell-Miller, H. (1995) 'Approaches to music therapy in psychiatry with specialist emphasis upon a research project with the elderly mentally ill' In T..Wigram., B. Saperston and R. West. (Eds). <i>The art and science of music therapy: a handbook Switzerland</i>: Harwood Academic. Also Aldrige, D. (2000). Music therapy in dementia care London:</p>	

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			<p>Jessica Kingsley.</p> <p>Music therapy became an established profession during the middle to latter part of the 20th century. In some countries music therapy is a legally registered profession, for example in the UK, similar to medicine nursing and other allied health fields. Although smaller in size, and more specialised than, for example sister professions, physiotherapy and psychotherapy, the music therapy profession has established rigorous training standards, a developing research and evidence base in some key areas. The practice varies across countries, and cultures, but leading music therapy associations, institutes and governments collaborate so that there is increasing parity and knowledge exchange.</p> <p><b>How does music therapy work?</b></p> <p>Music therapy is the use of music, whether live improvised and interactive, or receptive listening, in order to help towards desired change psychologically, socially, physically, or for larger communities, culturally engaging in change on a larger scale. Most commonly it is helpful on a non-verbal level for people who have communication</p>	

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			<p>problems, such as older people with cognitive decline following dementia or acquired brain injury, children and adults with autism, and children and adults with delayed or no spoken language with learning difficulties. Music therapy is also increasingly practised in community settings where processes and outcomes focus upon well-being, such as through singing, instrumental playing and recovery work.</p> <p><b>The UK</b> Music therapists in the UK are registered with the Health and Care Professions Council HCPC.</p> <p>There are over 800 in the UK working in the public and private sector fully qualified and a further 80 in training at any one time, on MA courses approved by the HCPC. Universities are at the cutting edge of research in this area and have thriving PhD programmes. Dementia is a priority, so several studies are planned or have been completed in this area. There are several opportunities in universities and these are linked with the international field and research is carried out across countries in multi-centred studies.</p>	

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British Association for Music Therapy	8	1.6	<p>We would make the case that music therapy contributes to health social care and quality of life improved outcomes for people with dementia. Qualified professional music therapists receive referrals at all stages of dementia pathways in care homes and NHS and statutory sector services. Choice is offered and music therapists specifically target those in the final stages of dementia. Those who cannot normally access programmes which require skill such as singing for the brain can be helped by music therapy. Evidence shows a reduction in levels of agitation significant to the treatment group in an RCT trial.</p> <p>Ridder, H. M. O., Stige, B., Qvale, L. G., &amp; Gold, C. (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial. <i>Aging &amp; Mental Health</i>, 17(6), 667-678. doi: 10.1080/13607863.2013.790926</p> <p>No prior musical experience or skill is needed and there are some research studies not included in the consultation which show significant evidence from RCT trials. The programme research for singing, reported in the well-known Coulton study did not</p>	Thank you for providing these references. The guideline committee will take into consideration the inclusion of music therapy when looking at the evidence for the non-pharmacological interventions for people living with dementia.

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			<p>seem to extend to individuals who are not able to sing or independently access the programme due to age related/physical/mental health conditions. Community singing might not be one size fits all. However, music therapy offered on a 1:1 or group basis for people with dementia should be considered in order to cater for individuals with reduced faculties and those who find engaging in group activities difficult. Music therapists are trained to adapt and tailor make interventions when cognitive decline and words are not available. Evidence in the Ridder study shows singing and other live interventions are used, and a music therapist can draw upon any musical intervention that someone needs including but not only singing.</p> <p><b>Summary of Ridder et al. (2013)</b> Objectives: Agitation in nursing home residents with dementia leads to increase in psychotropic medication, decrease in quality of life, and to patient distress and caregiver burden. Music therapy has previously been found effective in treatment of agitation in dementia care but studies have been methodologically insufficient. The aim of this study was to examine the effect of individual</p>	

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			<p>music therapy on agitation in persons with moderate/severe dementia living in nursing homes, and to explore its effect on psychotropic medication and quality of life.</p> <p><b>Method:</b> In a crossover trial, 42 participants with dementia were randomized to a sequence of six weeks of individual music therapy and six weeks of standard care. Outcome measures included agitation, quality of life and medication.</p> <p><b>Results:</b> Agitation disruptiveness increased during standard care and decreased during music therapy. The difference at !6.77 (95% CI (confidence interval): !12.71, !0.83) was significant (p ¼ 0.027), with a medium effect size (0.50). The prescription of psychotropic medication increased significantly more often during standard care than during music therapy (p ¼ 0.02).</p> <p><b>Conclusion:</b> This study shows that six weeks of music therapy reduces agitation disruptiveness and prevents medication increases in people with dementia. The positive trends in relation to agitation frequency and quality of life call for further</p>	

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			research with a larger sample.	
British Association for Music Therapy	8	6.1  Point10	<p><b>Patient family members and carers satisfaction and experience.</b> Music therapists respond to the inclusion agenda and include people at all stages of dementia and their carers and significant others when relevant. In addition to evidence mentioned above, a most recent study points to the benefits of music therapy as demonstrated in MHA, which is a group of over 70 residential care homes which increased posts for fully qualified music therapists from 1 post in 2006 to 13 music therapists in 2015 in the organisation. A testimony of the impact and efficacy which can be seen on its website. In addition the study accepted for publication summarised below is a small RCT trial showing significant results in areas of reduction of behavioural problems.</p> <p><b>Summary of Hsu et al (2015)</b></p> <p>Hsu, M., Flowerdew R., Parker M., Fachner J., Odell-Miller H. (2015) Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a randomised controlled feasibility study. <i>BMC Geriatrics</i> 15:84</p>	Thank you for providing these references. We will be considering music therapy within the section considering Interventions to maximise the health and wellbeing of people living with dementia. We have included this within the scope for clarity. We have not been explicit in the different types or formats of music therapy or any other therapy so as not to inadvertently exclude any particular format (individual, group, conjoint etc).

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			<p>doi:10.1186/s12877-015-0082-4</p> <p>Published: 18 July 2015</p> <p>This study reports initial feasibility and outcomes from a five month music therapy programme including weekly individual active music therapy for people with dementia and weekly post-therapy video presentations for their carers in care homes.</p> <p><b>Methods</b> 17 care home residents and 10 care staff were randomised to the music therapy intervention group or standard care control group. The cluster randomised, controlled trial included baseline, 3-month, 5-month and post-intervention 7-month measures of residents' symptoms and well-being. Carer-resident interactions were also assessed.</p> <p>Feasibility was based on carers' feedback through semi-structured interviews, programme evaluations and track records of the study.</p> <p><b>Results</b> The music therapy programme appeared to be a</p>	

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			<p>practicable and acceptable intervention for care home residents and staff in managing dementia symptoms. Recruitment and retention data indicated feasibility but also challenges. Preliminary outcomes indicated differences in symptoms (13.42, 95%CI: [4.78 to 22.07; p=0.006]) and in levels of wellbeing (-0.74, 95%CI: [-1.15 to -0.33; p=0.003]) between the two groups, indicating that residents receiving music therapy improved. Staff in the intervention group reported enhanced caregiving techniques as a result of the programme.</p> <p><b>Conclusion</b> The data supports the value of developing a music 52 therapy programme involving weekly active individual music therapy sessions and music therapist-carer communication. The intervention is feasible with modifications in a more rigorous evaluation of a larger population in a multi centred trial in the planning stages with partners including Anglia Ruskin University, Nottingham University and others.</p>	
British Association for Music Therapy	General	General	BAMT would like to draw the committee's attention to the following latest up- date on music and brain	Thank you for your comment and for supplying these references. The guideline committee will be

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			<p>research. Music and brain research. To support all the music therapy therapeutic and clinical evidence, the most recent relevant music and brain research is summarised here which points to the importance of music therapy which includes all aspects of music engagement for older people and not only singing. Regarding older people with depression and anxiety, recent RCT findings from Guetin et al. (2009) and Sarkamo et al. (2013) offers promising evidence for the relief of these common symptoms of dementia. Recent research indicates that music therapy is able to reduce symptoms of depression and anxiety (Erkkila et al., 2011; Fachner et al., 2013), with the findings of the abovementioned trials showing consistency with dementia clients.</p> <p>A common observation with dementia clients is that certain songs seem to reactivate memory and cognitive function, especially those songs with strong emotional connections (Cuddy, 2005). Research on music and emotion shows involvement of the nucleus accumbens and amygdala as well as orbito-frontal activation, which triggers dopamine release supporting attention and</p>	<p>considering music therapy when looking at the evidence for the non-pharmacological interventions.</p>

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			<p>memory (Levitin, 2006; Salimpoor et al., 2011; Koelsch, 2012). Regarding the use of singing, and in particular, familiar songs, MRI evidence from semantic dementia indicates that the right temporal pole is correlated with remembrance of songs and the grade of deterioration. This indicates a definite neuroanatomical correlate between deterioration and the degree of musical knowledge (Hailstone et al., 2009; Hsieh et al., 2011/2). Another RCT on singing with Clients with frontotemporal dementia benefit from group singing (Johnson, 2011) and choir singing induces neurotransmitter-balance and a good ratio of release and re-uptake, possibly indicating symptom prevention (Kreutz 2013). Making music trains audio-motor coupling and assists channel agitation with clients with dementia (indicated in a level 2b RCT, see Ridder et al., 2013) and helps to maintain healthy levels of motor function (Altenmueller, 2014).</p> <p>Raglio et al. (2015) investigated music therapy interaction by contrasting two independently rated excerpts of session material recorded in a therapy session prior to fMRI scanning. Participants listened to the two contrasts representing high and</p>	

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			<p>low interaction patterns from the sessions and differences in frontal, temporal and occipital areas of the brain were described.</p> <p><i>Brain Imaging and Behavior</i>, 1-5. doi: 10.1007/s11682-015-9380-x</p> <p>Ridder, H. M. O., Stige, B., Qvale, L. G., &amp; Gold, C. (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial. <i>Aging &amp; Mental Health</i>, 17(6), 667-678. doi: 10.1080/13607863.2013.790926</p> <p>Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., &amp; Rantanen, P. (2014). Cognitive, Emotional, and Social Benefits of Regular Musical Activities in Early Dementia: Randomized Controlled Study. <i>The Gerontologist</i>, 54(4), 634-650. doi: 10.1093/geront/gnt100</p> <p>Salimpoor, V. N., Benovoy, M., Larcher, K., Dagher, A., &amp; Zatorre, R. J. (2011). Anatomically distinct dopamine release during anticipation and experience of peak emotion to music. <i>Nat Neurosci</i>, 14, 257-262. doi: 10.1038/nn.2726</p>	
British Association for Music Therapy	5	1.5 Point2	Supporting people with dementia to exercise choice is related to the approach and help from carers and professionals including family members. Music	Thank you for your comment. We have amended this section within the scope. The role of non-pharmacological interventions in improving the

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			therapists and others of course, are trained to provide dementia patients and their carers with choice and to work at a pace and in environments where this is possible. For this to be part of guidelines relatives and carers need to know they can have access to therapies and activities which do not require complex cognitive powers but which focus upon positive non-verbal interaction which is usually possible even in the last stages of dementia. There should be choice and access for people to access arts based activities and arts therapies, and especially where there is evidence of efficacy as presented above in the research studies which provide just a few examples. Music therapy is also useful for people who do not have English as their first language supporting the NICE scope which emphasises equality of access. In fact music can bridge the communication gap across cultures.	health and wellbeing of people living with dementia will be included in the final guideline.
British Association for Music Therapy	5	1.5 Point4	In answer to the question about training and development and which models of training and health and social care staff have positive outcomes for people with dementia, BAMT would stress that providing all who work with people with dementia specific training as the dementia awareness	Thank you for your comment. The guideline committee will consider all training programmes for which appropriate evidence is available.

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			programmes in the UK do, is essential. However missing from some of these programmes currently is an emphasis upon how to communicate through sensory, art-based media, and music and other arts therapies could be integral to such training. Current research (Hsu etc al 2015) shows early indication that training carers to use music in their daily communication with people with dementia improves quality of life for both sufferers and their carers.	
British Association for Music Therapy	6	1.5 Point6	Indications for specific referral for diagnostic specific procedures in relation to dementia are strong but others will provide evidence for this. However BAMT would endorse this as a key factor and that this assessment should include AHP in-put such as from arts therapists who are trained to assess capacity for communication and non-verbal comprehension meaning and interaction. Assessment research is key to BAMT agenda and in the future further studies in this area are proposed.	Thank you for your comment. The guideline committee will take into consideration these issues when looking at the evidence for this section. .
British Association for Music Therapy	6	1.5 Point10	Multi-morbidity and comorbidity are key areas for music therapists and BAMT would endorse joined up management for this population who have specific psychiatric medical and psychosocial needs. Music therapists can work across all these	Thank you for your comment.

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			areas as the existing research shows, and also there are new studies proposed to assess and devise manuals which will enable carers to use adjusted interactive techniques in music therapy alongside generic ways of treating and interacting, and so music therapists could assist in immediate deterioration as listed in this question section, as they are trained to work with the most complex medical and physiological and psychiatric implications of the disease in terms of helping in the moment with agitation, mood regulation and social relating, including enabling families and carers to understand and work across comorbidity.	
British Association for Music Therapy	7	1.5 Point12	Non-pharmacological interventions are crucial in this field as to date there are no effective cures for the disease and it is increasing (WHO 2014) so that providing psychological and psychosocial interventions is key. In the above sections (General) there is evidence to show that music therapy is effective as a non-pharmacological intervention not only at the moment when it is delivered by the skilled music therapist, but through the 'spin off' when carers adapt methods used by music therapists and also when carers are involved in family interventions which enable well-being and	Thank you for your comment. The guideline committee will take into consideration the inclusion of these interventions when looking at the evidence for this section.

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			improve carers situations and help maintain safe environments.	
British Association for Music Therapy	7	1.5 Point14	See above for BAMT information on recent research which shows music therapy can effectively reduce agitation (Ridder et al 2013) and Behavioural /Psychological Symptoms (Hsu 2015) significantly through rigorous RCT trials and feasibility study.	Thank you for providing these references.
British Association for Music Therapy	7	1.5 Point16	See above for how carers needs can be addressed through joining in music therapy and also through transferring of skills where non-verbal and adjusted ways of interacting are taught to professionals.	Thank you for your comment.
British Association for Music Therapy	7	1.5 Point17	Music is a social activity and BAMT would support the notion that social interventions for carers are met by some singing for the brain programmes but also by music therapy programmes which integrate families and carers (see above for the research and reference points to this important area).	Thank you for your comment. The guideline committee will take into consideration the inclusion of music therapy when looking at the evidence for this section.
British Psychological Society	2	24 -26	<i>'Groups that will not be covered – People with MCI who are not suspected of having dementia.'</i>  The Society believes that this has the potential to cause a great deal of confusion unless it is clarified. Above it was stated that the guideline will cover people 'with dementia or suspected dementia'.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.

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			<p>Research tells us that, while people considered to fit the category of MCI are at increased risk of developing dementia, only a proportion will progress to dementia, while some will remain the same and some will improve, and there is no way of predicting which individual with MCI will fall into which category. However, in practice, the MCI classification is often used where early signs of dementia are strongly suspected but the person does not (yet) meet diagnostic criteria for dementia. It is not clear what 'people with mild cognitive impairment that are not suspected of having dementia' refers to.</p> <p>It would make sense to exclude people with cognitive impairment arising from other reasons from the dementia guideline. Alternatively, perhaps the intention is to exclude a focus on preventive, risk-reduction and self-management approaches for people who meet criteria for mild cognitive impairment. If so then this needs to be made explicit, and the statement about including people with 'dementia or suspected dementia' needs to be modified; for example, 'people who meet diagnostic criteria for dementia', would be more appropriate. It</p>	

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			is really essential to clarify this issue and a sensible and pragmatic solution would be to rule out cognitive impairment that clearly arises from causes not associated with dementia, but to include people meeting criteria for MCI.	
British Psychological Society	2	3	<i>'All settings in which NHS-funded health and social care is received'</i> . The statement is vague. The Society believes that it would be preferable to indicate that the guideline will cover, for example, care delivered in the home, in community settings, in NHS primary, secondary and tertiary care facilities, both in- and out-patient, in day care provision and in residential and nursing homes.	Thank you for your comment. We can confirm that the guideline will be relevant to people living with dementia, their families and carers across all settings, however, the section of the scope entitled who the guideline is for identifies specific groups within these settings.
British Psychological Society	2	6	<i>'Guideline recommendations will normally fall within licensed indications'</i> – this refers only to pharmacological treatment whereas much of the focus of the guidelines will be on psychosocial aspects of care. It should be made explicit in this statement (e.g. <i>'guideline recommendations for pharmaceutical prescribing will normally fall within licensed indications...'</i> )	Thank you for your comment. We have amended the scope to reflect this.
British Psychological Society	4	18	<i>'Areas that will not be covered – pharmacological management of Parkinson's Disease Dementia.'</i> This raises the question of what definitions of dementia are being applied in this guideline as,	Thank you for your comment. We will consider all forms of dementia within this guideline however we may cross refer to the guideline update for Parkinson's disease for recommendations

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			while the most common forms of dementia are Alzheimer's, vascular and mixed dementia, there are also rarer forms of dementia and a number of neurodegenerative conditions that can result in dementia. There needs to be a clear statement about what is covered in the guideline such as other aspects of PDD and rarer forms of dementia or conditions where dementia can arise in the later stages.	associated to the pharmacological management of Parkinson's disease dementia. We will define the full range of dementias covered within the final guideline.
British Psychological Society	4	20	'Areas from the published guideline that will not be updated.' This refers only to the section on end-of-life care and we believe that it would be helpful to know the rationale for not updating this section. This raises concerns about other sections. For example, under 'areas from the published guideline that will be updated' the first area listed is 'principles of care' and here three sub-topics are given. The original guideline, under 'principles of care', contains a number of other sub-topics as well as these three, such as 'diversity, equality and language', 'impact of dementia on personal relationships', 'risk of abuse and neglect', 'management and co-ordination of care', etc. This implies that these other sub-topics will be removed This would seem to be unfortunate as there are a	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care. Although we do not have review questions that directly address these issues the sections of the guideline relating to diversity, equality and language, impact of dementia on personal relationships, risk of abuse and neglect, management and co-ordination of care will be updated within the areas of the scope assessing patient needs, interventions for people living with dementia and risk management and support for

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			number of very important points covered in these sub-topics. Perhaps the intention is simply not to update these sub-topics, but if so it would be helpful to make this clear.	people living with dementia.
British Psychological Society	4	23	<i>'Areas from the published guideline that will be removed.'</i> The rationale for removing reference to inpatient services needs to be given. Quality of NHS inpatient services for people with dementia is a major concern and people with dementia are vulnerable to abuse and neglect in these contexts, which is unacceptable.	Thank you for your comment. A review question considering inpatient services will now be included in the guideline update.
British Psychological Society	4	25	<i>'Areas from the published guideline that will be removed.'</i> Removing reference to people with learning disabilities raises concern, especially given that NHS England expects that people with learning disabilities should be able to access mainstream services wherever possible and that these services should work together with specialist learning disability services. It seems questionable to include dementia in a general mental health guideline for people with learning disabilities, where dementia will be at best only a subsidiary topic that does not fit well, and exclude people with learning disabilities from consideration in the dementia guideline. This is particularly so given the attempt to be inclusive at	Thank you for your comment. We have taken this into consideration and people with learning disabilities will now be included within the guideline update.

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			the start, which refers to 'people with different levels of educational attainment' – one might have assumed that this would cover people with intellectual disabilities and it is disappointing to see that this is not the case.	
British Psychological Society	5	13	'Key issues and questions.' It is very striking that the issue of how to provide high-quality person-centred care across all stages of dementia is markedly absent from this list, yet it is one of the greatest challenges that dementia poses, and one of the greatest concerns for people living with dementia and for carers of people with dementia. For example, improving standards of care in care contexts such as, but not limited to, residential and nursing homes, and making care more person-centred and less institutional, should be a central theme. It is good to see that integrated health and social care is on the list, but the issues are much greater than that.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline and we will search for appropriate evidence pertaining to this.
British Psychological Society	5	13	'Key issues and questions.' It is good that the list does identify the importance of choice and autonomy, but there are wider societal issues about rights of people with dementia and citizenship of people with dementia that should be acknowledged. They are surely one of the last	Thank you for your comment. We intend to consider social care and health related issues within the guideline update. We have taken this into consideration and amended the language and structure of the scope so that social issues are more prominently addressed.

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			groups within our society that it is considered acceptable to institutionalise and to house in settings where poor-quality care is common.	
British Psychological Society	6	6	'7. Preventing dementia.' The Society believes that it would be more appropriate to talk about risk reduction. This would seem to be a more realistic focus at present given the current state of knowledge. Also, as there is a NICE guideline forthcoming on mid-life approaches to prevention, should the issues of (a) primary prevention and risk reduction in later life and (b) secondary prevention for those at high risk not be separated out into a different guideline rather than attempting to encompass everything into this one. These are extensive topics in their own right.	Thank you for your comment. We have now modified this section of the scope to reflect slowing the progression of dementia.
British Psychological Society	6	32	'Key issues and questions' points 12 – 15. We believe that these raise a number of issues. It is heartening to see that cognitive, emotional, behavioural and functional aspects are referred to as 'features' rather than 'symptoms'. However, the emphasis on 'managing' each of these domains in isolation belies the interrelated nature of the features listed. To give one simple example, changes in cognitive ability may lead to emotional distress, loss of confidence and difficulty coping	Thank you for your comment. We have now amended this section of the scope to address the health and wellbeing of people living with dementia. Our intention is that person centred care is incorporated throughout the guideline and we have highlighted environmental needs as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this group.

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			<p>with daily activities, resulting in behavioural changes and impacting on family relationships with resulting increased distress for family members, all of which may be mitigated by good support and a well-designed environment or worsened by lack of support and a poorly-adapted environment.</p> <p>Therefore, it is important to view the person with dementia holistically and in context. Rather than trying to 'manage' individual features, there is a need to understand and acknowledge that these things are complex and that each individual is different. A better starting point is an individual formulation made within a biopsychosocial framework, which makes it possible to identify specific needs and appropriate avenues for support or intervention, and then draw on evidence-based strategies and approaches to try to ameliorate the situation. The value of this guideline would be in identifying which kinds of approaches and strategies offer best evidence and hence can be confidently applied by clinicians in this kind of context. 'Managing' seems to imply a limited goal of suppressing difficulties, whereas a more appropriate aim would be to enable the person to function at the optimal level that is possible given</p>	

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			the nature of the dementia. This is the fundamental principle of rehabilitation or re-ablement, which provides a valuable framework for thinking about care of people with neurodegenerative conditions.	
British Psychological Society	6	32	<i>'Key issues and questions' points 12 – 15.</i> Given concerns about medication use and polypharmacy in people with dementia, we have concerns that the first approach considered for 'managing' each type of feature is pharmacological. Surely this should be a last resort rather than the first approach taken. Guidance on anti-psychotic prescription for behavioural 'features' is quite clear that this should be avoided wherever possible.	Thank you for your comment. We have now amended this section of the scope to address the health and wellbeing of people with dementia more prominently.
British Psychological Society	6	32	<i>'Key issues and questions' points 12 – 15.</i> 'Non-pharmacological interventions' is not a meaningful category. Firstly, it is never helpful to define something merely in terms of what it is not. Secondly, this umbrella term covers a very wide range of approaches with different underpinning theories and principles, different methods, different levels of intervention and different types of outcome. This diversity should be fully acknowledged. Thirdly, it is important to recognise that these interventions are not something that can be broadly 'prescribed' for all people with dementia.	Thank you for your comment. We have taken this into consideration and amended this section of the scope.

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			<p>Instead they offer a range of options that could be drawn upon depending on the needs and preferences of the person and/or carer. Just as when a drug is prescribed the reaction to it will differ depending on the person's physiology, so that it may be effective for one person but not for the next, the response to 'non-pharmacological' interventions will differ depending on what the person brings to the situation – attitudes, beliefs, personal characteristics, past experience, preferences and so on. It is completely inappropriate to say that everyone should receive a specific 'non-pharmacological' intervention. Furthermore, for any given feature causing concern, for example a particular behaviour, the reasons why this has arisen may be completely different to the reasons underlying the development of the same behaviour in another person with dementia. Therefore interventions cannot be simply matched to specific behaviours. As noted above, the selection of suitable 'non-pharmacological' intervention approaches should be based on an understanding of individual needs and preferences, and where appropriate on considered hypotheses about the reasons why particular needs or</p>	

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			difficulties are being expressed at any given time. This is of course also consistent with an emphasis on choice and control for the person with dementia.	
British Psychological Society	8	5	'Main outcomes.' The main outcomes listed are largely individual, but we believe that quality of care should be the most important outcome when considering NHS provision. This is important across the board but especially in relation to people with severe dementia who are no longer communicating verbally, and in relation to institutional settings.	Thank you for your comment. We have now amended this section of the scope.
British Psychological Society	General	General	The Society believes that it is important to ensure that there is sufficient flexibility allowed for the guideline update committee to be able to address issues that emerge from literature searches.	Thank you for your comment. The guideline committee's two main roles are to address issues that emerge from literature searches and to draft recommendations.
British Society of Audiology	General	General	The British Society of Audiology (BSA) is supportive of the update to the NICE guidelines, in particular the inclusion of detail on co-morbidities. BSA welcomes a review of the links between dementia and hearing impairment, inclusion of hearing assessment in differential diagnosis, and addressing hearing impairment in people living with dementia.	Thank you for your comment. We have highlighted people with sensory impairment as a group requiring special consideration within this guideline and will therefore search for appropriate evidence pertaining to this group, where appropriate.
British Society of Audiology	2	12	To extend "People of all ages with dementia or suspected dementia" to "People of all ages living with dementia or suspected dementia or at higher	Thank you for your comment. We have now highlighted people with sensory impairments as a group requiring special consideration and we will

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			<p>risk of dementia.”</p> <p>Those groups at higher risk of dementia, such as those with sensory impairments and other risk factors, are included in the scope through sections such as “Preventing dementia” and “Risk factors and early identification”. There is a key health message for those groups that is not included in the original NICE guideline. Evidence of benefits of early use of sensory aids such as glasses and hearing aids may then be reviewed for this group within the update, in addition to those suspected or living with dementia likely to be at later stages of the condition.</p>	<p>search for appropriate evidence pertaining to this group. However the guideline will only cover people in whom dementia is suspected or diagnosed.</p>
British Society of Audiology	2	15 -17	<p>To extend “(including people who do not speak English as a first language)” to “(including people who do not speak English as a first language, and those that use sign language, e.g. British Sign Language)”</p> <p>Those that use British Sign Language as their first language are a specific minority cultural group within the larger population of those with hearing impairment. Known as either the Deaf Community or culturally Deaf people, they both have a specific</p>	<p>Thank you for your comment. We have now highlighted people with sensory impairment (which includes people who use sign language) as a group requiring special consideration and this will also cover the questions on assessments and diagnostic tests.</p>

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			need in terms of diagnosis and the impact on communication ability, but also have an increased risk of dementia. Lin et al (2011) found those with severe-profound hearing loss were at a 5 times greater risk of dementia. The original NICE guidance included information and interpreters, but this is not sufficient for diagnostic testing. There has been work to develop a suitable BSL diagnostic test by Deafness Cognition and Language (DCAL) Research Centre, but at present there are very few places in the UK that offer this.	
British Society of Audiology	2	21 -22	It is not clear why there is an example of HIV and no others at this point, whereas in other sections there are other examples given.  To aid clarity and consistency.	Thank you for your comment. HIV had been included only as an example of a comorbidity or condition that may require special consideration because it is known that HIV status has implications for the treatment and care of people living with dementia. However to ensure clarity we have amended this section of the scope and removed the example of HIV.
British Society of Audiology	2	23	A further bullet to be added to "Groups that will be covered": "– people with sensory impairment (visual impairment, hearing impairment)"  Hearing impairment was minimally considered in	Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration.

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			the original NICE guidelines, only mentioned with a list of other disabilities in terms of specific needs in care and assessment, despite research since early 1990s showing an association between dementia and hearing impairment. Further evidence has supported this link, and research groups are now seeking to understand the underlying pathology. Hearing impairment affects a significant number of those living with dementia: 71% of the general population over 70 have a significant hearing impairment (Action on Hearing Loss, 2011) and the prevalence will be greater in those with dementia (e.g. Lin et al, 2011).	
British Society of Audiology	3	22	To be added specifics of “(including differential diagnosis of impairments and conditions that may mask, mimic and exacerbate dementia)”  Current NICE guidelines are not specific in “physical examination and other appropriate investigations” and have been open to interpretation, with differential assessments such as hearing impairment being substituted by self-report or clinician judgement (both known to be a poor indicator): e.g. RCPsych audit includes only “consideration” of sensory impairment.	Thank you for your comment. We have amended this section of the scope to reflect we will now be considering the differential diagnoses of dementia (medical, psychiatric or sensory conditions) that may mask, mimic or exacerbate dementia.

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			See comment 12 regarding wording.	
British Society of Audiology	3	24	To be added "such as non-visual, non-verbal and British Sign Language tools for those with sensory impairments"  Those with sensory impairment are at particular risk of mis-diagnosis due to reliance on both verbal and visual communication in diagnostic tests. Diagnostic tools have been developed for specific groups, including BSL users; however, these are not commonly available in practice and there is further consideration needed of those with hearing impairment, a significant proportion of those likely to be completing the tests.	Thank you for your comment. We have highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
British Society of Audiology	3	28	Outdated terminology, suggest instead "Strategies to support people living with dementia" and similarly use "living with dementia" as preferred language throughout.  To update terminology.	Thank you for your comment. We have amended this section of the scope so it more prominently addresses the health and wellbeing of people living with dementia.
British Society of Audiology	3 4	28 2	Section 5 to include two further bullets: "- environmental features - sensory features including communication ability"	Thank you for your comment. We have now highlighted people with sensory impairment and communication difficulties alongside people with specific housing and living needs as groups

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			<p>Given that many people with dementia live in residential care, the whole communication environment must be taken into account. There are many barriers to communication in residential homes, such as poor acoustics and background noise (Pryce, 2012). Guidelines to improve services for people with dementia should consider that many of them will have hearing loss and the 'hearing-friendliness' of the environment they are in needs consideration, as do the communication abilities of the people that care for them.</p> <p>Managing dementia to include sensory, particularly communication features in presence or absence of hearing impairment. There is evidence regarding effect of hearing impairment and management of this with hearing devices, awareness by carers and communication tactics. Given prevalence of hearing impairment and its effect, this should be within the pathway rather than as aside (both prevalence of both sensorineural hearing loss and processing disorder that require different approaches).</p>	<p>requiring special consideration. This includes the provision of an environment which is sensitive to cognitive impairment. We will search for appropriate evidence pertaining to these groups and issues.</p>
British Society of Audiology	4	3 -5	Section 6 to include further bullets: " – environment and social context	Thank you for your comment. The guideline committee will consider these areas when looking

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			<p>- health and social needs of carers - information on access to services"</p> <p>Emphasis is placed on significant deterioration in those with dementia; however, significant change may also occur due to changes in health or other needs of carers, especially informal family care. Carers with medical or sensory needs are at particular risk of</p>	<p>at the evidence pertaining to the needs of family members and carers. We have highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.</p>
British Society of Audiology	4	6	Section 7 to include further detail to clarify	Thank you for your comment. We have now added in two sub sections relating to experiences of people living with dementia and their informal carers and arrangement of care within this section of the scope.
British Society of Audiology	4	9	<p>"may mask" to be extended to "may mask, mimic or exacerbate"</p> <p>Conditions such as hearing impairment that present risk of mis-diagnosis of either dementia or the other condition (mimic), or of consideration of only one in the presence of both (mask), or have an affect on the symptoms of the other (exacerbate) are better described by these three possibilities. One NHS Trust uses the phrase "4d's - dementia, delirium, depression and deafness".</p>	<p>Thank you for your comment. We have amended the scope as suggested.</p> <p>We now recognise sensory impairment as an important issues and that people with sensory impairment including hearing loss are highlighted as needing special consideration</p>

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British Society of Audiology	4	9 -10	<p>“Medical conditions ... (for example delirium or depression)” to be extended to “Medical, sensory and psychiatric conditions ... (for example delirium, depression or sensory impairment)”</p> <p>Hearing impairment is under-diagnosed in those with dementia, and there is a risk of mis-diagnosis of dementia in those with hearing impairment. Symptoms of hearing impairment extend across all the symptoms of dementia, not just communication ability, with either masking presence of the other, but also presence of hearing loss may exacerbate symptoms of dementia. Hearing aids are known to reduce the exacerbating effect. The original guidelines mentioned only medical and psychiatric features, in which sensory impairment does not naturally fit.</p>	Thank you for your comment. We have inserted examples of co-morbidities within this section. We have, however, highlighted people with sensory impairments as a group requiring special consideration and will search for appropriate evidence during development of the guideline.
British Society of Audiology	4	11 -12	<p>“(for example diabetes mellitus or cardiovascular disease)” to be extended to “(for example diabetes mellitus, cardiovascular disease and sensory impairment)”</p> <p>Hearing loss is known to not only mask diagnosis, but also those with hearing loss face a greater progression of dementia. There is some recent</p>	Thank you for your comment. We have inserted these as examples only and the list is not exhaustive. We have, however, highlighted people with sensory impairments as a group requiring special consideration and will search for appropriate evidence during development of the guideline.

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			evidence to suggest that hearing aid use may reduce this rate (Deal et al, 2015); however, further studies are underway to provide generalizable evidence.	
British Society of Audiology	4	15 -17	<p>“may require treating differently because of the presence of dementia” to instead read “may require a different approach and/or specific consideration (higher priority) because of the presence of dementia”</p> <p>Certain co-morbidities requiring greater/more urgent consideration on dementia assessment and in-patient pathways, than for other groups, such as assessment and management of hearing impairment early in an in-patient stay rather than on discharge. This will also prompt other services such as Audiology to consider those with dementia within their own pathways.</p>	Thank you for your comment. We have inserted examples of co-morbidities only within this section. We have, however, highlighted people with sensory impairments as a group requiring special consideration and will search for appropriate evidence during development of the guideline.
British Society of Audiology	4	17	<p>Section 1 to include further bullet point “- Social context”</p> <p>To ensure consistency with other points</p>	<p>Thank you for your comment We have amended the section of the scope and have referred directly to social context.</p> <p>The text now reads ‘Recommendations in areas that are not being updated may be edited to ensure that they meet current editorial standards,</p>

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				and reflect the current policy, and practice and social context'.
British Society of Audiology	4	24	May be more appropriate to include inpatient considerations within sections for "training", "diagnosis", multimorbidity and sudden deterioration" and "risk management of independence" rather than a section of its own, ensuring that it is clear that the guidance applies to both pathways in memory services and to in-patient pathways. This would indicate a need for its consideration, but in a different integrated form.	Thank you for your comment. We will consider the inpatient needs of people living with dementia throughout the guideline and consider the integrated needs of people in inpatient hospital settings when looking at issues of diagnosis, assessment, support and appropriate interventions for this group.
British Society of Audiology	5	4 -12	Whilst encouraged that the review will include carrying out economic analyses, would suggest that perspective should not only "include direct health effects" but also to be added "and whole system costs, such as social care and community considerations". Social care costs are not only implicated in questions regarding a "focus on social care", particularly when the aim is for an integrated health and social care system.	Thank you for your comment. Health and social care service use and costs are listed as outcomes in the scope. In <a href="#">the NICE guidelines manual</a> , the reference case outlines which costs will be considered.
British Society of Audiology	5	19 -23	Communication and affect of sensory impairment to be included at this point also.  In addition to assessment of hearing in terms of differential diagnosis, research in the US	Thank you for your comment. We have highlighted people with sensory impairment as a group requiring special consideration. We will search for appropriate evidence pertaining to this during

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Stakeholder	Page	Section / Line	Comments	Developer's response
			encourages the use of simple hearing devices in diagnostic assessments.	development of the guideline.
British Society of Audiology	5	24 -26	To add "including incidence, awareness, support and suitable environments for those with co-morbidities such as hearing impairment" to clarify that this extends to more than the original guidance on "pacing of communication non-verbal communication and use of language..."  See comment 9	Thank you for your comment. We have now modified this question within the scope. We have highlighted people with sensory impairment as a group requiring special consideration and will search for appropriate evidence.
British Society of Audiology	5	27 -31	Sentence is unclear, as there is overlap between "symptoms", differential diagnosis" and "co-existing conditions that mask or mimic". Suggest may be better to pose a series of questions such as: "- What are the signs and symptoms of dementia? - What are the signs and symptoms that also present in medical, psychiatric or sensory conditions that mask, mimic or exacerbate dementia? - What are the risk factors for dementia?"  To ensure clarity.	Thank you for your comment. We have now modified this question within the scope and we have now included reference to conditions that may mask, mimic or exacerbate dementia.
British Society of Audiology	6	6 -10	Positioning of the section "Preventing dementia" between "6 Referral criteria" and "8 Diagnosing	Thank you for your comment. Our focus is on secondary issues of prevention, rather than

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			dementia” separates two closely related sections, key as aspects of differential diagnosis should be considered at the point of referral. Suggest moving to earlier, possible to be the first in this section.  To ensure clarity.	primary prevention. We have modified this section of the scope to reflect slowing the progression of dementia and this now addresses the issues of progression once dementia has been diagnosed. We think this is correctly placed within the scope.
British Society of Audiology	6	14 -15	“(medical or psychiatric conditions that may mask dementia)” to be extended to “(medical, sensory or psychiatric conditions that may mask, mimic or exacerbate dementia)”  Despite consideration of sensory loss being included on the RCPsych audit of memory services, it is not current practice to include hearing assessments in differential diagnosis; however, there is evidence that self- or carer-report underestimates incidence and that simple modified hearing assessment is reliable in the majority of those with dementia, in addition to risk of mis-diagnosis in the presence of hearing loss or significant impact from an undiagnosed co-morbidity.  See comment 12 re “mask, mimic or exacerbate”.	Thank you for your comment. We have amended the scope. We now have sections to consider the differential diagnoses of dementia (medical, psychiatric or sensory conditions) that may mask, mimic or exacerbate dementia.
British Society of Audiology	6	19	Clarify difference between “multimorbidity” and co-	Thank you for your comment. We have now

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			morbidity, used interchangeably throughout.  To ensure clarity.	amended the sections of the scope to provide more clarity.
British Society of Audiology	6	19	Why does this section only include “sudden deterioration in function”? Could the section title be changed to reflect this, i.e. “Multi-morbidities and sudden deterioration in function” Co-morbidities then should be strengthened in sections 4 and 8, including managing intercurrent illness and co-morbidities  To ensure clarity.	Thank you for your comment. We have now amended these sections of the scope.
British Society of Audiology	6	19	Similar to above, a third co-morbidity to be added: “- How should sensory co-morbidities be managed in people living with dementia who have a sudden deterioration in functioning?”  To ensure consistency with above comments.	Thank you for your comment. We have now amended these questions within the scope. We have highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
British Society of Audiology	7	20	To add 2 further sections “Managing sensory and communication features” and “Managing environmental features”  To ensure consistency with above comments.	Thank you for your comment. We have highlighted people with sensory impairment and environmental issues of people living with dementia as areas requiring special consideration. We will therefore search for appropriate evidence pertaining to this

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				group.
British Society of Audiology	7	28	Later states that experience in adult NHS services covered by guidance CG138; however,	Thank you for your comment
British Society of Audiology	8	8 -10	“(including memory loss, language changes, behavioural or mood changes, and problems with cognitive reasoning)” to be changed to “(including memory loss, perceptual and communication changes, behavioural or mood changes, and problems with cognitive reasoning)”  Ability to communicate is wider than purely language, including perception and understanding of information/cues heard and seen.	Thank you for your comment. We have amended the scope to reflect these changes.
British Society of Audiology	8	13	To include wider quality of life than just those related to health and social care.	Thank you for your comment
British Society of Audiology	11	Diagram	Additional separate section at top of diagram: “Person at increased risk of dementia -> Preventing dementia”  To ensure consistency with other additions.	Thank you for your comment. The pathways diagram has been amended.
British Society of Audiology	11	Diagram	“Diagnosis and assessment, including: <ul style="list-style-type: none"> <li>• Signs and symptoms of dementia</li> <li>• Comorbidities that may mask dementia” </li></ul> to be expanded to: “Diagnosis and assessment, including:	Thank you for your comment. The pathways diagram has been amended.

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			<ul style="list-style-type: none"> <li>• Signs and symptoms of dementia</li> <li>• Comorbidities that may mask, mimic or exacerbate the progression of dementia”</li> </ul> <p>To ensure consistency with other additions.</p>	
British Society of Audiology	11	Diagram	<p>“Management, including:</p> <ul style="list-style-type: none"> <li>• Comorbidities that may mask progression of dementia</li> <li>• Cognitive, emotional, behavioural and functional features”</li> </ul> <p>to be expanded to: “Management, including:</p> <ul style="list-style-type: none"> <li>• Comorbidities that may mask, mimic or exacerbate the progression of dementia</li> <li>• Cognitive, emotional, behavioural, functional, sensory and environmental features”</li> </ul> <p>To ensure consistency with other additions.</p>	Thank you for your comment. The pathways diagram has been amended.
British Society of Audiology	12	General	<p>“Key facts and figures” Paragraph to be added regarding co-morbidities including sensory impairment.</p> <p>Details regarding hearing impairment (other stakeholders may provide information regarding</p>	Thank you for your comment. We have amended the scope to include reference to sensory impairment. We have also included two sections within the scope that consider intercurrent illness and multi-morbidities in people living with dementia. These sections will consider medical

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			visual impairment and other co-morbidities) such as: "The NICE guideline on dementia included minimal mention of co-morbidities of dementia, such as sensory impairment (hearing and vision). A report by Action on Hearing Loss (2014) shows how large cost savings and improvements to quality of life for those with dementia and hearing loss could be achieved from better provision of integrated services, at least £28 million in England for a particular scenario, and the need for recognition of hearing loss in assessing, diagnosing and supporting people with dementia."	conditions that may mask, mimic or exacerbate a diagnosis of dementia. We will review evidence regarding sensory impairments when considering these review questions.
British Society of Audiology	General	General	Key group missing from committee is Clinical Scientist (Audiology).  Expert to report on co-morbidity, masking/exacerbation and risk factor of hearing impairment.	Thank you for your comment. We are seeking representation for a Speech and language therapist to join the committee to help with the issues raised in your own and other comments.
Care & Repair England	1	0	Who the guideline is for: Add that the guideline is for health, <b>housing</b> and social care staff Add in integrated health, social care and <b>housing</b> settings Add, in the last para, housing associations and	Thank you for your comment. It is intended that this guideline would be appropriate for people who work in housing associations. This has been highlighted in the section entitled "Who the guideline is for?"

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Care & Repair England	General	General	<p>private and <b>voluntary</b> organisations</p> <p>The Care Act 2014 defines well-being to include the suitability of living accommodation.</p> <p>It expects local councils to ensure the integration of care and support including housing. There is recognition that the suitability of living accommodation is a core component to enable people to live independently.</p> <p>As a result we ask that the guideline includes housing as an important consideration in the provision of health and social care for people with dementia and their carers.</p> <p>We make the following general points on the importance of considering housing alongside health and care</p> <ul style="list-style-type: none"> <li>• Many of the chronic health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes. This factor should be considered in the provision of health and</li> </ul>	<p>Thank you for your comment. We have added people with specific housing needs to the groups that will have special consideration in this guideline.</p>

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			<p>social care interventions to support wellbeing</p> <ul style="list-style-type: none"> <li>• Whilst we would not expect social care and health practitioners to deal with housing issues per se we would argue that housing needs to be considered in any social care and health assessment and that staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed in so far as they impact on a persons' wellbeing.</li> <li>• There is an expectation in the Care Act that housing factors are a part of an integrated assessment.</li> </ul>	
Care & Repair England	General	General	<p>The guidance does not cover in any detail what happens after diagnosis and feels too focused on a health perspective and not on the social care issues for supporting people with dementia. This means that there are no issues and questions focused on assessing the needs of people with dementia for services and support following diagnosis nor any consideration of the types of services that support people with dementia. This is picked up later in comments about the key issues</p>	<p>Thank you for your comment. We have now added questions on the assessment of needs of people with dementia. We have also amended the scope so that social care issues are more prominently addressed.</p>

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			and questions	
Care & Repair England	3	1.3	It would be helpful to explain what 'licensed indications' means and explain this first paragraph as it seems to sit poorly as the introduction to the areas covered since it is focused on one issue about medicines and patients?	Thank you for your comment. Licensing indications refer to medication considerations. We have amended this section of the scope to provide more clarity.
Care & Repair England	3	1.3 Point5	Managing dementia: Would it be better to call this section managing and supporting dementia? Managing dementia does not sound very person centred in this context.	Thank you for your comment. We have amended this section of the scope to address the interventions that promote the health and wellbeing of people living with dementia.
Care & Repair England	4	1.3 Point5	Add a new section <ul style="list-style-type: none"> <li>Support for the person with dementia to include assessment of needs, interventions and advice and information</li> </ul>	Thank you for your comment. The guideline committee will consider advice and information when looking at the sections addressing the assessment of needs and interventions to promote the health and wellbeing of people living with dementia.
Care & Repair England	4	1.3 Point6	We would like to add advice and information as a sub section	Thank you for your comment. The guideline committee will consider advice and information when looking at the sections addressing the assessment of needs and interventions to promote the health and wellbeing of people living with dementia.
Care & Repair England	4	1.3	Add integrated health, social care <b>and housing</b>	Thank you for your comment. We have not added housing to this heading but have highlighted the

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		Point7		housing needs of people living with dementia as an area requiring special consideration and we will search for appropriate evidence.
Care & Repair England	5	1.5 Point3	Add training and development of health, social care <b>and housing</b> staff <ul style="list-style-type: none"> <li>amend question to say what models of training for health, social care <b>and housing</b> staff</li> </ul>	Thank you for your comment. Although we will not cover training for housing staff directly, we will consider people working in health and social care who have involvement with people living with dementia and this may include staff involved in housing provision or support.
Care & Repair England	6	1.5 Point5	Define what is suspected dementia? Is this a useful term?	Thank you for your comment. This question is intended to explore the assessments carried out to recognise dementia when a person presents with signs or symptoms which indicate a possible diagnosis of dementia.
Care & Repair England	6	1.5 Point8	Add a section on post diagnosis <ul style="list-style-type: none"> <li>what support and services are available after diagnosis?</li> <li>assessing the needs for support and services including housing interventions</li> <li>advice, information and advocacy to access support and services</li> </ul>	Thank you for your comment. Our intention is that the guideline will consider issues of support for people living with dementia, their family and carers post diagnosis. Many areas covered in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia. The guideline committee will take into consideration the issues of information and support when looking at the evidence for this section.

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Care & Repair England	7	1.5 Point15	Refer to the above point. There is this section on assessing the needs of carers but no section on assessing the needs of people with dementia. The guidance needs to cover both	Thank you for your comment. We have now amended this section of the scope to address the health and wellbeing of people living with dementia.
Care & Repair England	7	1.5 Point18	Add integrated health, social care <b>and housing</b> and also amend what experiences do health, social care <b>and housing</b> staff have?	Thank you for your comment. We have highlighted the housing needs of people with dementia as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this group.
Care & Repair England	8	1.5 Point18	Add – how can a person's home environment help to optimise independence and choice for people with dementia and their carers	Thank you for your comment. We have highlighted environmental issues as an area requiring special consideration.
Care & Repair England	8	1.6	Amend 3 to health, social care and <b>housing</b> related quality of life	Thank you for your comment. We have highlighted housing needs as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this area.
Care & Repair England	8	1.6	Add <ul style="list-style-type: none"> <li>Wellbeing of person with dementia</li> <li>Independent living</li> </ul>	Thank you for your comment. These outcomes have been incorporated into this section of the scope.
Care Council for Wales	2	12	The focus group does not include people's route into assessment and diagnosis. To an extent, and for specific groups of people, this is considered amongst the 'special consideration' section that sits below. It would be useful to include people who have not yet been identified in this category so that	Thank you for your comment. We intend to address the issues of assessment and diagnosis for all people with suspected dementia within the guideline update. The guideline committee will also consider the areas we have highlighted for special consideration when looking at the evidence

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			the broader issues that prevent seeking diagnosis can be considered alongside the effects of this on outcomes for people with dementia and carers.	associated with these review questions.
Care Council for Wales	5	17	The wording of this is unclear: doing nothing is a choice which could also be seen as an action. It might be better to consider whether it is ever appropriate to intervene when someone with dementia cannot give consent or has refused consent.	Thank you for your comment. We have amended this section within the scope.
Care Council for Wales	5	20	The question asks how people can be given choice in decisions about their care. Including a greater degree of involvement of the person with dementia would fit better with recent legislation. Involvement and control also need to be considered as well as choice.  Carers are also likely to be involved in choices about care, but they are not included here. Including carers would give greater clarity in these situations.	Thank you for your comment. The guideline committee may consider carers involvement when looking at the evidence for this question, if they think this is appropriate.
Care Council for Wales	5	25	The complexity of the workforce means that the models of training are likely to be different depending on the roles, autonomy, level of involvement etc of workers. It also needs to consider including people who work in services	Thank you for your comment. We will search for a broad range of issues when considering the review question about training and development of health and social care staff. The guideline committee may further sub-analyse interventions within this way

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			where there is a high likelihood of coming into contact with people who have dementia, whether diagnosed or not, but who do not work specifically in dementia services.	when looking at the evidence for this question.
Care Council for Wales	6	2	The question asks about the diagnostic accuracy of initial assessments. An additional question about the impact of language, in particular people undergoing assessment in their second language, could help to address some of the issues highlighted by the Equality Impact Assessment. If the Guideline is adopted in Wales, this would also help to address issues around Welsh Language.	Thank you for your comment. We have highlighted people with language and communication difficulties as a group requiring special consideration. This will include people who undergo assessment in their second language. We will search for appropriate evidence pertaining to these groups.
Care Council for Wales	6	11	As noted above (comment 1), this section could be broadened to consider people's journey to the point where a diagnosis of dementia is suspected. This could potentially support increased diagnosis rates.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline.
Care Council for Wales	7	3 8 13 18 23 25	When considering the needs of people with dementia, the term 'non-pharmacological support' is used. For carers, social care and psychological interventions are listed. The types of intervention for both appear to be broad and similar, but the language used creates a clear dichotomy defined around pharmacological interventions for people with dementia. The difference in language used could limit the scope of the guidelines and focus	Thank you for your comment. We have taken this into consideration and we have now amended the language and structure of the scope to more prominently address the health and wellbeing of people living with dementia.

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			care and support for people with dementia around pharmacy.	
Care Council for Wales	7	20	The question about medical conditions effecting the progression of dementia could equally be applied to medical conditions that affect cognitive, emotional, behavioural and functional features of dementia.	Thank you for your comment we have now amended this section of the guideline.
Care Council for Wales	7	22	<p>The question asks about how carers needs could be assessed. As above, an additional question about the impact of language, in particular people undergoing assessment in their second language, could help to address some of the issues highlighted by the Equality Impact Assessment. If the Guideline is adopted in Wales, this would also help to address issues around Welsh Language.</p> <p>The provision and timing of information for carers and people with dementia could be included as an additional consideration. This has been identified to us as a key issue for carers.</p>	Thank you for your comment. We have highlighted people with language and communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this group. The timing of information for carers will be addressed within the guideline. This will be considered when looking at the evidence relating to the interventions 12Interventions to maximise the health and wellbeing of people living with dementia and the assessment of needs.
Care Council for Wales	7	23	The section titled 'social interventions for carers' would have a better fit with recent legislation if it were broadened to 'support for carers'.	Thank you for your comment. Our intention is that carer support will be considered within this section of the guideline.
Care Council for Wales	8	1	The question asks how care can be arranged to optimise independence of carers and people living with dementia. Promoting health, well-being,	Thank you for your comment. The guideline committee will take into consideration the inclusion of these issues when looking at the evidence.

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			satisfaction and positive outcomes for people would capture more precisely the main outcomes listed later in the document.	
Care Council for Wales	11	Diagram	The 'risk factors and prevention' section is listed on the pathway following the person having, or suspected of having, dementia. action on prevention needs to come some time before this. It would be useful to consider how people can be supported or encouraged to get to the first stage where dementia is identified as a possibility.	Thank you for your comment. The pathways diagram has been amended.
Carers Trust	2	10	The draft does not state inclusion of people with LD and dementia. This is a growing concern which needs a targeted approach, carers of adult children who then develop a dementia, find getting appropriate support difficult. should be people with all levels of educational attainment, people who are very clever can often hide the symptoms or manage them well so go miss diagnosed this can be particularly difficult for carers who often without a diagnosis are left to manage alone.	Thank you for your comment. People with learning disabilities will now be included within the guideline update.
Carers Trust	2	23	Maybe consider something about monitoring and studying people with MCI, if they are not covered in the guide lines they may be ignored at a time when they can be taking steps to help manage their everyday life and prevent a deterioration.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be

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				covering people with MCI if they do not have dementia.
Carers Trust	4	3	Under assessment of carers needs could it specify training for example in communication dealing with behaviours, moving and positioning. Training carers will help them keep themselves and the person they care for well. Prevent a crisis	Thank you for your comment. The guideline committee will consider training needs as part of the assessment of needs of carers
Carers Trust	4	7	Because most people with dementia live in the community and are supported by family, much more emphasis should be put on social support.	Thank you for your comment.
Carers Trust	4	21	Palliative care wonder if this should be updated in light of the new evidence coming out in this area.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
Carers Trust	4	22	Acute in patient services should remain nearly three quarters of those in general hospital have a dementia.	Thank you for your comment. A review question considering inpatient services will now be included in the guideline update and this will include acute settings.
Carers Trust	4	23	LD should not be treated separately, carers really struggle to get the right support for older people with LD who develop a dementia. Think it further	Thank you for your comment. We have taken this into consideration and people with learning disabilities will now be included within the guideline

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			stigmatises people to remove them from the general NICE guidelines, there is a worry people with LD will not be offered the same level of service if they are not included here	update.
Carers Trust	7	General	Maybe a sub title what social / housing/ family interventions could be included it sounds very medical when a lot of dementia support is social	Thank you for your comment. Our intention is that these issues will be included. We have amended this section of the scope to address the health and wellbeing of people living with dementia.
Carers Trust	7	16 17	How should the health of carers be assessed what health interventions for carers are effective flu vaccination health checks etc. carers of people with dementia have poor health outcomes themselves. What would reduce this	Thank you for your comment. The guideline committee will take into consideration the inclusion of these issues when looking at the evidence for this section.
Carers Trust	8	General	Bullett point 9: Can we add health to wellbeing	Thank you for your comment. We have now updated the scope to reflect this change.
Collaboration for Leadership in Applied Health Research and Care	1	0	Who the guideline is for : For clarity it would be helpful to list the settings the guideline covers for people with dementia and their carers and the public – both community and healthcare settings.	Thank you for your comment we have amended the scope so it reflects all settings including the community and healthcare.
Collaboration for Leadership in Applied Health Research and Care	2	0	Equality considerations: The equality impact assessment could also include reference to specific issues relating to equality in residential/nursing care for people with dementia for all minority and cultural groups e.g. dietary	Thank you for your comment. These are issues we have identified for special consideration within the guideline and the guideline committee will review appropriate evidence pertaining to these issues. In line with NICE's policy on equality a full equality

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			issues, cultural issues, equal treatment of partners etc.	impact assessment has been carried out during the scoping period and will be monitored throughout development of the guideline and drafting of recommendations
Collaboration for Leadership in Applied Health Research and Care	2	1.1	The guideline states people with dementia and their carers are the focus but further on it also states that prevention of dementia and risk factors are included which would be aimed at people currently without dementia.	Thank you for your comment. We have included people with suspected dementia for these questions.
Collaboration for Leadership in Applied Health Research and Care	3	1.2	Settings – it would be helpful to specify examples of settings as the roles and remits of NHS and social care have changed or overlap.	Thank you for your comment. We have amended this section of the scope to cover all settings.
Collaboration for Leadership in Applied Health Research and Care	5	1.5 Point4	What are the risk factors for dementia? – This is potentially very broad - It would be helpful to specify types of risk factors to be considered e.g. lifestyle, vascular or related health conditions, psychological e.g. depression, environmental, genetic etc.	Thank you for your comment. The guideline committee will consider a broad range of risk factors when considering the evidence for this review question and it is likely that this will be sub-analysed by categories of risk factors, for example lifestyle or genetic risk factors .
Collaboration for Leadership in Applied Health Research and Care	6	7	Preventing dementia – prevention <i>or delay</i> of the onset of dementia? Prevention of dementia may need to be considered at different stages of the lifecourse. The level of available evidence varies accordingly and would influence the nature and strength of recommendations.	Thank you for your comment. We have now modified this section of the scope.

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			Some consideration could be given here to preventing dementia in people with a family history or genetic risk factors for dementia. The recent Dementia Priority Setting Partnership:- ( <a href="http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1427">http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1427</a> ) involved people with dementia, their carers and health and social care professionals in identifying and prioritising research questions for dementia. In relation to prevention of dementia a recurring theme was not just how to prevent dementia but how to prevent dementia in people with a family history or genetic risk factors for dementia.	
Collaboration for Leadership in Applied Health Research and Care	8	1	Effect of integrated health and social care – also quality of life an important outcome? The questions could be phrased differently to inform the guideline. Telling us how people “experience” integrated care doesn’t tell us how effective or cost effective integrated care is for people with dementia and their carers; nor does it tell us what the “active” ingredients are/or what aspect(s) of integrated care proved more effective for people at different stages of the disease process – this is critical especially if the guideline is to make recommendations across health and social	Thank you for your comment. We have now amended this section of the scope to address the health and wellbeing of people living with dementia.

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			care settings. The evidence review should probably focus on those aspects, too.	
Collaboration for Leadership in Applied Health Research and Care	5	1.5	Key issues and questions – managing some of these issues applies across a range of care settings – including home care, residential care, nursing care, ambulance, hospital/acute care and different approaches may be needed for different settings or for transfers between different settings.	Thank you for your comment. Our intention is to consider the full range of care settings appropriate for people living with dementia and we will search for evidence pertaining to all settings when considering each review question. Where appropriate, sub-group analysis may be undertaken by setting.
Collaboration for Leadership in Applied Health Research and Care	General	General	The Dementia Priority Setting Partnership involved all stakeholders in dementia in identifying a list of questions relating to prevention, diagnosis, treatment and care of dementia that are relevant to this guideline. <a href="http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1427">http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1427</a>	Thank you for highlighting this document.
Collaboration for Leadership in Applied Health Research and Care	General	General	The document states that the guidelines is for people living in all settings and my only comment is that as the majority of residents in care homes have dementia, they should be highlighted as a care setting of particular interest to NICE. I would suggest that residents living with dementia and their paid and family carers should be considered as a discrete group in the guidelines particularly in the area of integrated care.	Thank you for your comment. We have added people with specific housing needs to the groups that will be given special consideration in this guideline alongside those with sensory impairment and other groups.

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			We know that NHS provision to care homes is variable, reactive and often inequitable, it would be a very important contribution if NICE consultation could particular attention to what residents with dementia in care homes should receive as support from different NHS services and how effectiveness and quality of care in this area can be measured.	
Collaboration for Leadership in Applied Health Research and Care	5	1.5	On page 5 section 1.5 there is a bullet point about supporting people with dementia to exercise choice. I know the scope addresses issues around the management of comorbidities but I wondered if it needed to include something specific around self management of long term conditions - with self-management being conceptualised as something that involves family carers as well as patients.	Thank you for your comment. Our intention is that the guideline will address the management of co-morbidities and inter-current illnesses within the context of people living with dementia. We anticipate that exercising choice about self-management of multi-morbidity will be included.
College of Mental health Pharmacy & Royal Pharmaceutical Society (joint response)	General	General	We are writing to you to express our concerns at the apparent omission of pharmacist members ( <a href="http://www.nice.org.uk/Media/Default/Get-involved/Join-a-committee/Member-dementia-update-gc/Member-dementia-update-job-desc.pdf">http://www.nice.org.uk/Media/Default/Get-involved/Join-a-committee/Member-dementia-update-gc/Member-dementia-update-job-desc.pdf</a> ) on the group developing guidelines on Dementia, supporting people with dementia and their carers in health and social care. Overall, the committee contains the representatives of the main	Thank you for your comment. We have not included a pharmacist within the guideline committee. However, if the committee believe that there is a need to seek expert opinion in relation to co-morbidities, then they may choose to appoint a topic expert to inform decision making.

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			<p>professions involved in the care of people with dementia including GPs, Psychiatrists, OTs, psychologists, Social Workers, CPNs, Neurologists, commissioners and geriatricians, but yet no pharmacist. This is a particular concern because medication management in dementia is a key element of the scope of the guideline, and more importantly optimal medication management is a vital part of safe and effective dementia care. The key questions in the scoping document include pharmacological interventions for managing cognitive, emotional, behavioural and functional features of dementia. Managing multi-morbidity is a significant part of the scope of the guideline and one of the main outcomes is assessing the evidence for polypharmacy.</p> <p>To conclude we would be grateful if you would include a pharmacist on your group, or alternatively explain your rationale for the current exclusion.</p>	
College of Occupational Therapists	General	General	<p>The scope follows the structure of the original guideline which takes a 'medical' approach. The sections on managing cognitive features, managing behaviours features etc. all start with pharmacological interventions, whereas in practice most services would aim to provide non</p>	<p>Thank you for your comment. We have taken this into consideration and amended the scope to put greater emphasis on psychosocial and support interventions.</p>

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			pharmacological interventions in the first instance and progress to pharmacology as a secondary intervention. The College would suggest that a change in the order of content would be useful.	
College of Occupational Therapists	General	General	<p>The original guideline mentions maintaining activity of daily living skills briefly but this is not included in this scoping document. There is also no section on 'managing occupational features' or on occupational interventions. Restricting the occupational therapy role to activities of daily living and environmental adaptations misses the opportunity to include the richness of occupational therapy that exists in practice – particularly occupation centred practice. The College would strongly advocate that this diversity included in the scope, particularly given the current national drivers in maintaining independence for as long as possible and the evidence that supports the fact that by maintaining occupations and independence people can often remain healthier for longer (College of Occupational Therapists (2011) Occupational Therapy Evidence Fact Sheets, Occupational therapists help those with dementia and their carers.</p> <p><a href="http://www.cot.co.uk/sites/default/files/commissioni">http://www.cot.co.uk/sites/default/files/commissioni</a></p>	<p>Thank you for your comment. The guideline committee will consider occupational therapies when looking at the evidence for non-pharmacological interventions. We have also amended the scope to include both physical functioning and activities of daily living and the guideline committee will be able to consider these outcomes if appropriate evidence if available.</p>

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			<a href="http://ng_ot/public/ot-dementia-fact-sheet.pdf">ng_ot/public/ot-dementia-fact-sheet.pdf</a> accessed 05.08.2015	
College of Occupational Therapists	General	General	The College would suggest that it would be useful to include a section on family interventions, working collaboratively with the family and service user.	Thank you for your comment. The role of family therapy will be covered in the review questions on interventions to maximise health and wellbeing as well as the questions on support for people with dementia and their carers
College of Occupational Therapists	General	General	The current guidelines have a substantial content on person centre care and approaches. However the only key messages that have permeated into practice are those related to medication use and support for cognitive stimulation therapy. To increase the impact of the other areas of the guideline it would be useful to consider how they are understood in practice and to change the structure and language to emphasis other areas of practice and intervention.	Thank you for your comment. We have amended the language and structure of the scope to emphasise that we intend to consider both pharmacological and non-pharmacological interventions within the guideline update.
College of Occupational Therapists	2	14	The College would suggest that vulnerable social situations and carer's comorbidities should be included as special circumstances. Many practitioners are faced with this kind of complexity when caring for people with dementia. It would be useful for this focus to be present from an early point in the development of the new guidelines.	Thank you for your comment. We have now highlighted people at risk of social exclusion and isolation as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
College of Occupational	4	24	In-patient dementia units are not to be included.	Thank you for your comment. This has been taken

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Therapists			This is an area of practice where improvement is required and it would therefore seem imprudent to omit it. Although its inclusion would substantially increase the length of the guideline the College would consider that this would be useful to include, unless a separate guideline on this area is being considered.	into consideration and a review question considering inpatient mental health and psychiatric services will now be included in the guideline update.
College of Occupational Therapists	4	21	The College believes that the Palliative Care section would benefit from revision. There is scope to draw more explicit links between this section and that on advanced decision making. There should be an emphasis about the quality of these discussions and the role that a range of professionals can play in supporting end of life care along with maintaining the quality of life as dementia progresses. These are not currently included but would strengthen the guideline and should incorporate occupational therapy.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
College of Occupational Therapists	6 7	General	The language and points stated are overly medical and reductionist. The College would suggest that this section could be re titled 'Supporting people with dementia'.	Thank you for your comment. We have taken this into consideration and amended this section of the scope to more prominently address the health and wellbeing of people with dementia.
College of Optometrists	2	11	Add a bullet for people with visual impairment (VI) and / or sensory loss please. All of the groups listed in the current version would experience additional	Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration and we will

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			difficulties if member so from these groups were also living with visual or sensory impairment. Adding a discreet bullet to cover all individuals living with visual or sensory impairments would highlight the specific issues faced by this group when also living with dementia. People with dementia are more likely that their age-matcher peers to be living with visual impairment and / or other sensory impairment.	search for appropriate evidence pertaining to this group.
College of Optometrists	3	20	<p>Consider re-ordering the numbered points so that:</p> <ul style="list-style-type: none"> <li>- point 3 is before point 1.</li> <li>- points 2 and 4 could also become the new 2 and 3 with the current point 1 becoming 4 and the rest following on from there. i.e. the new order would be:</li> </ul> <ol style="list-style-type: none"> <li>1. Preventing Dementia</li> <li>2. Risk Factors and Early detection</li> <li>3. Diagnosing and assessing dementia</li> <li>4. Principles of care for people [living] with dementia</li> <li>5. Managing dementia (though we would suggest re-titling this section to: 'Supporting people living with dementia to manage' or similar')</li> <li>6. Support for family members and carers of people</li> </ol>	Thank you for your comment. We have amended the scope to provide more clarity.

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			[living] (suggest adding 'living' here) with dementia. 7. Integrated health and social care  This would be more logical as dealing with prevention would come before the other points relating to care, detection and so on.	
College of Optometrists	4	12	Suggest including 'visual impairment' and / or sensory impairment in the examples of co-morbidities that may affect the progression of dementia. Correcting vision impairments has been shown to slow the progression of Alzheimer's in at least one recent study in the US. Also suggest adding VI to the conditions that may mask or mimic a diagnosis of dementia.	Thank you for your comment. We have inserted these as examples only and the list is not exhaustive. We have, however, highlighted people with sensory impairments as a group requiring special consideration and will search for appropriate evidence during development of the guideline.
College of Optometrists	8	10	Suggest including 'problems with vision' - PCA in particular is often first identified via primary care optometry services, in many cases prior to a diagnosis of PCA / dementia.	Thank you for your comment. We have amended the scope to include reference to this
College of Optometrists	11	3.1	Suggest adding a bullet for 'changes in vision / problems with vision' - some sub-forms of dementia (e.g. PCA) in particular have early changes to vision as an early symptom, but all forms of dementia will ultimately produce neurological changes to vision as the disease progresses. Emerging findings from PrOVIDe (NIHR funded)	Thank you for your comment we have amended the scope to reflect this.

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			suggest that the prevalence of visual impairment from all causes is higher in the dementia population than in age matched non-dementia populations.	
College of Optometrists	General	General	Panel structure: We would like to see an optometrist on the panel. While we recognise that panel size must be managed, an optometrist could offer valuable insights to how vision and visual impairment may impact on daily living, risk of falls, mental health etc.	Thank you for your comment. Although optometry is not represented in the guideline committee, if the committee believe that there is a need to seek expert opinion in this area, they may decide to appoint a topic expert to inform decision making.
Compassion in Dying	5	20	The draft scope identifies as a key question how it can be ensured that people with dementia can exercise choice in decisions about their care. We welcome the inclusion of this question and the acknowledgement that it is important for people with dementia to be involved in decisions about their care and to exercise choice in relation to these decisions.  We feel it is important that within this question the issue of fluctuating capacity is clearly addressed.  Health and social care professionals need to be aware that a person with dementia's capacity can fluctuate depending on the time and the decision	Thank you for your comment. The guideline committee may consider issues of fluctuating capacity when looking at the evidence for this question, if they think this is appropriate.

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			that needs to be made. This could mean choosing particular times and settings where it is best to support the person with dementia to understand and engage in decisions about their care.	
Compassion in Dying	5	22	<p>The draft scope identifies as a key question how it can be ensured that people with dementia are able to make use of advance-decision making and advance care plans. We welcome the inclusion of this question as planning ahead for future care and treatment is important with conditions such as dementia, which results in a loss of capacity.</p> <p>In order to do this effectively, we feel it is important to ensure that the different tools for planning (Advance Decisions to Refuse Treatment, Advance Statements and Lasting Powers of Attorney as well as the umbrella term 'Advance Care Planning' which is an approach commonly used for people in the last 12 months of life) are identified and encouraged. There can sometimes be confusion about these tools, and people (patients and healthcare professionals) do not always recognise the differences between them.</p> <p>These different tools have different purposes and</p>	Thank you for your comment. We are seeking to recruit a consultant in palliative care to advise the guideline committee on these issues. The guideline committee may take into consideration tools and methods for use in advanced decision making and the timing of these in relation to end of life care and indeed at earlier stages of dementia.

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			<p>benefits and people with dementia should be able to understand and be able to choose the tool that is right for them. Some people for example may not feel comfortable or ready to make specific refusals of medical treatment but do feel strongly about where they would like to be cared for and the type of care they would like to receive. For some people therefore, an Advance Statement can be the most effective way of expressing a person's key concerns and wishes. Exploring this in the consultation would be invaluable.</p> <p>Compassion in Dying runs an Information Line, providing information and support to people who want to plan ahead for their future treatment and care. Respondents to follow-up monitoring reported that 8% of doctors had not heard of Advance Decisions, and of the people who reported a negative reaction to their Advance Decision, 49% said this was from a doctor or other healthcare professional. Evaluation from our My Life, My Decision project, which provides face-to-face support to older people to plan ahead also reflects this, with variance in healthcare professionals' understanding of the tools under the Mental</p>	

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			Capacity Act.  In order to ensure that people with dementia can make use of all of the tools for planning ahead, healthcare professionals need to be aware of them and able to initiate conversations about them early on, especially after diagnosis. Addressing these issues early means that people can take their time in deciding what they would or would not want to happen should they lose capacity in the future, and also ensures that they do not lose capacity before they have been able to express their wishes.	
Cumbria Partnership NHSFT	4	25	It is proposed that assessing and managing dementia for people who have learning disabilities will be removed from the guideline. This seems inappropriate as these clients are often seen within mainstream dementia services so should be included in the generic NICE guidelines for dementia.	Thank you for your comment. We have taken this into consideration and people with learning disabilities will now be included within the guideline update.
Department of Health	General	General	<b>Messaging</b> – The very fact that you can <b>live well</b> with dementia needs to be better reflected throughout the guidance. Whilst not suggesting advocating a particular treatment, therapy or environment– the guidance does need to reflect the wealth of complementary therapies available for	Thank you for your comment. We intend to consider person centred care and both social care and health related issues within the guideline update. We have amended the scope so that well-being and care related issues are more prominently addressed.

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			<p>people with dementia, from music, arts, drama, CST, reminiscence, other non-pharmacological interventions currently available and housing (some with ever growing and roust evidence bases). A change to the overall tone to reflect a more positive approach would be in line with the groundswell movement on dementia care and support in recent years, a vast improvement of awareness of dementia with over 1 million dementia friends, and the contribution of the work all parts of society are involved in locally to create dementia friendly communities.</p> <p><b>Meaningful care</b> - The Prime Minister's Challenge on Dementia 2020 (PM Challenge 2020) published 22 February 2015 – stated that by 2020: 'Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published NICE standards.' The revision to the dementia guideline presents a timely opportunity to ensure 'meaningful care' is suitably defined and in a way that can be measured, with the Secretary of State for Health's intention for the information to be made publicly</p>	

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			<p>available. Specific characteristics of meaningful care as outlined in PM Challenge 2020 include, for example:</p> <ul style="list-style-type: none"> <li>• Receiving information on what post diagnosis services are available locally and how these can be accessed, through for example an annual information prescription.</li> <li>• Access to relevant advice and support to help and advise on what happens after a diagnosis, and support available through the journey.</li> <li>• Carers of people with dementia being made aware of, and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.</li> </ul> <p><b>Education and training</b> - there seem to be missing messages about highlighting the importance and value of education and training on dementia, what training should cover and the level of training which</p>	<p>Training and development for health and social care staff is covered within the scope and will be addressed by the guideline committee.</p> <p>The guideline committee will consider assistive technologies when looking at the evidence for the non-pharmacological interventions.</p>

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			<p>is appropriate for different staff groups, as well as the point highlighted about models of training which have positive outcomes for people with dementia.</p> <p><b>Assistive Technology</b> - it's important to emphasise that any updates to the dementia guidelines either specifically on independent living or generally on other sources of support highlight technology and/or assistive technology, for example, the following sections could include such lines; P3 – (5): managing dementia; P4 – (6): support for family members and carers of people with dementia; P5 – (2): supporting people with dementia to exercise choice; P6 – (11): Risk management and how it can support people with dementia to avoid harm and stay independent; P8 – (1.6 – 5): choice and control for people with dementia.</p>	
Department of Health	1	17	Should this not read: 'Commissioners, providers and regulators of dementia services'.	Thank you for your comment. We have amended the scope to reflect this change.
Department of Health	1	22	Sub bullet re 'the community' – does this cover primary care settings?	Thank you for your comment. It is intended that this guideline would be appropriate for people who work in primary care settings as part of the NHS.
Department of Health	1	24	What is meant by 'group care'?	Thank you for your comment. We have now removed this from the scope.

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Department of Health	1	27	Should this final bullet not be integrated with other "settings" that health and social care staff will work in as listed at line 12.	Thank you for your comment. We intended to highlight this as a separate bullet in order to give greater clarity on the type of settings in which support may be provided.
Department of Health	2	General	We would want to make sure that social exclusion picks up rural v urban issues.	Thank you for your comment. We have highlighted people at risk of social exclusion and isolation as a group requiring special consideration within this guideline and will search for appropriate evidence associated with rural and urban issues
Department of Health	2	14	The section of the guideline that sets out that special consideration will be given should include those with sensory loss and British sign language and gender.	Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
Department of Health	2	23	Example of those who are at risk of social exclusion could include substance users, those in prison and/or homeless.	Thank you for your comment. We intend to consider all groups at risk of social exclusion / isolation and it is expected that this will include substance users, people in prison and homeless people.
Department of Health	2	25	How exactly will it be defined that someone either has mild cognitive impairment Vs dementia. Does mild cognitive impairment need its own guideline?	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have

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				dementia.
Department of Health	3	3	People with dementia are patients of health services, users of social care, often both at the same time. Moreover, they are citizens. Consequently, is the guidance really just about 'All settings in which NHS-funded health and social care is received' as where will guidance for self-funders be covered?	Thank you for your comment we have amended the scope so it reflects all settings.
Department of Health	3	11	Within the entire ' <i>Areas from the published guideline that will be updated</i> ' we suggest keeping in mind the guidelines should not simply be around managing the condition, but living well with dementia (see comment 1 messaging).	Thank you for your comment. We have amended this section of the scope so it more prominently addresses the health and wellbeing of people living with dementia.
Department of Health	3	20	Suggesting amending this to include 'Prevention and <b>risk reduction</b> ' – Public Health England are focused on risk reduction and prevention of dementia, key pieces of work include the Blackfriars Consensus and development underway of a 'brain age tool'.	Thank you for your comment. This section of the guideline is intended to address the area of minimising the progression of dementia. We have now amended the relevant section of the scope to reflect this more clearly.
Department of Health	3	27	We suggest splitting this area into two separate areas: one is supporting people to avoid harm, the other is supporting people to stay independent in their own homes.	Thank you for your comment. We have clarified this within the scope to cover how should individual risks (for people living with dementia, their family members, carers, and health and social care staff) be assessed? This will be including risk management and how it can support people living

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				with dementia to avoid harm and maintain independence.
Department of Health	3	General	Where is 1.5 Promoting and maintaining independence of people with dementia now covered within the revised scope. If missing it needs to be reinserted as per comments above about line 27.	Thank you for your comment. We have included a draft review question to address the issues of promoting and maintaining independence of people with dementia within the guideline update.
Department of Health	3	29 30	Why are we calling these 'features'	Thank you for your comment. We have amended this section of the scope. This section now considers interventions to promote the health and wellbeing of people living with dementia, who experience changes in cognitive functioning and interventions to promote the health and wellbeing of people living with dementia, who experience changes in non-cognitive symptoms of dementia, including changes in: Behaviour, physical functioning and activities of daily living; Mood and mental health; and physical symptoms such as incontinence and pain.
Department of Health	3	28	Should 'environment' be included in the managing dementia section i.e. health and care settings, wider communities, loneliness etc...	Thank you for your comment. We have highlighted environmental needs as an area requiring special consideration and the guideline committee will consider these issues when looking at the evidence for this area.

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Department of Health	4	1 2	As above	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.
Department of Health	4	3 4 5	This should be about supporting carers more generally, not just assessment of need (which should to make reference to the new Care Act 2014 duties in respect of carers) but also services (specifically Post diagnosis and meaningful care), support, advice, respite. The scope should also include: <ul style="list-style-type: none"> <li>• Social action solutions - such as peer support and befriending services can also provide practical and emotional support to people with dementia and their carers.</li> <li>• Carers of people with dementia being made aware of, and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.</li> </ul>	Thank you for your comment. The guideline committee may consider these interventions when looking at the evidence on interventions and on assessments of needs.
Department of Health	4	6	The guidelines will need to recognise that integrated health and care services is a journey localities are currently working on meaning there	Thank you for your comment. The committee will be mindful of this.

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			will be different approaches and maturities for this across the country.	
Department of Health	4	15	Other examples of a Co-morbidities that may require treating differently because of the presence of dementia could include nutrition, hydration, urinary tract .	Thank you for your comment. The comorbidities we have listed are not an exhaustive list and the committee will look at others
Department of Health	4	22	What is the rationale for not including: 'Palliative care, pain relief and care at the end of life for people with dementia' in the scope of the revision? This is an important part of the guidance and if not included here reference or links to the updated guidelines on Liverpool pathway should be included.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
Department of Health	4	25	Why will "Inpatient dementia services" be removed. Is this not remiss due to updated Mental Health Act and links to Deprivation of Liberty considerations.	Thank you for your comment. This has been taken into consideration inpatient services will now be included in the guideline update.
Department of Health	4	General	There are a number of important areas missing from the scope:  <b>Post diagnosis support</b> – there has been a significant focus in recent years on improving diagnosis rates with NHS England moving ever	Thank you for your comment. We intend to consider social care and health related issues within the guideline update.  Many areas covered in the scope, particularly around reducing the risk of progression of

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			<p>closer to achieving their ambition in the mandate that two thirds of people with dementia receive a diagnosis. With so many more people getting a diagnosis than ever before, it is imperative that there are adequate care and support services available for them and their families. We too often hear about people feeling 'unsupported' and in a 'back hole'. The period immediately following a diagnosis is a critical time for people with dementia and their families, with access to information, advice and support being key at this often worry and difficult time. This can be via tailored information on what post diagnosis services are available locally, or access to support, help and advice on what happens after a diagnosis and throughout the journey. This can be via a care coordinator, dementia adviser, support worker or similar service. This period is so significant and can make a huge difference to the experience of a person with dementia, their family and carer, We feel it warrants consideration within the scope in its own right.</p> <p><b>Personalisation</b> - Post diagnosis support services need to also be tailored to diverse needs. People's</p>	<p>dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia. It is intended that this will incorporate person-centred care taking account of individual needs and post diagnosis support.</p> <p>We will consider support for independent living in our review questions addressing risk management and how it can support people living with dementia to avoid harm and maintain independence and the interventions to maximise the health and wellbeing of people living with dementia.</p> <p>The guideline committee will take into consideration social action solutions, sources of support and dementia friendly environments when looking at the evidence for the review questions that consider interventions to maximise the health and wellbeing of people living with dementia. We have now modified our section addressing support for carers to include information and advice for carers.</p> <p>The scope provides an opportunity to link to</p>

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			experience of living with dementia or caring is significantly determined by characteristics such as ethnicity, age and comorbidities. More people are receiving a diagnosis, often at the earlier progression of the disease with a greater proportion of people with young onset dementia than ever before. This needs to be acknowledged, and services tailored to this cohort of people. There is also evidence that shows that BAME communities in particular have lower rates of access to these services. There needs to reference to building the support around the needs of the individual with dementia, their family and carer. There is already evidence to suggest that mental health groups and BAME tend to fare less well from personalisation (on the social care side) and the guidance may wish to refer to best practice guidance from Think Local, Act Personal on barriers to older people accessing personal budgets. There should be more choice, control and flexibility in the way they receive care and support regardless of the setting in which they receive it. The guidance should also distinguish between personalised care on the health and social care side, and how this can be used as a lever for integration (ie a joint budget	related NICE guidance. Although we do not have a guideline on housing currently in development, we have now provided reference to the NICE guideline on home care.

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			<p>pooling funds from health and care).</p> <p><b>Support for Independent Living</b> - there needs to be greater emphasis on the need to support people to live in their own homes as appropriate for as long as they chose and is deemed suitable. This is which is a large and complex work area with the aim of keeping people in their own environments for longer, better care and support in the community, avoiding costly crisis care and keeping people out of hospital and expensive residential care settings. This remit also covers technology, adaptations, housing, social action solutions and has a wider link to dementia friendly communities.</p> <p><b>Social action solutions</b> - such as peer support and befriending services can also provide practical and emotional support to people with dementia and their carers. The impact of these interventions is being robustly tested so that evidence on the most effective interventions can be disseminated.</p> <p><b>Housing</b> - Is there a NICE guide on housing? If so this should link to the dementia guideline.</p>	

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			<p><b>Dementia Friendly Communities</b> - It would be useful to weave the DFCs message into the guideline, which could be linked to the living well message which also appears to be missing.</p> <p><b>Sources of support</b> - Not sure if it is appropriate for this type of guideline, but another key issue/question which could be considered is signposting to other sources of support outside the health and social care system (voluntary sector organisations, dementia cafés, Alzheimer's Society services, Singing for the Brain, etc.)</p> <p><b>Support for carers</b> – this not only needs to cover assessment of needs and the new responsibility for carers as per the duties in the Care Act, but it also needs to cover direct care and support, information, advice, signposting and access to carer networks.</p>	
Department of Health	5	16	Advanced decision making – Does this not also relate to 'end of life / palliative care' which will not be updated? If you are considering questions or further work in this area, it will need to be reflected in the section on palliative care.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry

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				forward the previous recommendations relating to palliative care.
Department of Health	5	17	Is the same not true of a person without dementia?	Thank you for your comment. We have amended this section within the scope.
Department of Health	5	19	People with dementia can exercise choice by the management of an effective care and support plan. There are many incentives in place in the system, for example: Dementia CQUIN Dementia Direct Enhanced Service QOF payments for an annual review of care plans for people with dementia	Thank you for your comment. The guideline committee may choose to consider these interventions when looking at the evidence for this section of the guideline if they think this is appropriate.
Department of Health	5	22	As per comment 13- advanced decision making and advanced care plans links to end of life and will therefore need reflecting in the guidance.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
Department of Health	5	26 30	<i>Should 'risk factors' be listed as under a heading 'prevention' and not 'recognition'?</i>	Thank you for your comment. Our intention is that this section explores issues of recognising dementia rather than prevention.
Department of Health	6	1	Would it be appropriate to include a list of the type of information a GP referral letter should contain as	Thank you for your comment. . The guideline committee will take into consideration the points

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			a minimum. There is great variability in the quality of information and the range of preliminary diagnostic tests undertaken in primary care. Whilst it would not be clinically appropriate to carry out the same tests on every patient, anecdotal evidence from memory assessment services state that the amount of time spent obtaining further patient information or enquiring about specific diagnostic assessments has a significant impact on the day to day running of the service.	you have raised when reviewing the evidence for this section.
Department of Health	6	27 28	As per comment 6B above, I would suggest splitting 'avoiding harm' and 'staying independent'. As per comment 12 – support for independent living needs greater emphasis.	Thank you for your comment. The guideline committee will take into consideration the appropriateness of reviewing these issues separately when looking at the available evidence for this section.
Department of Health	7	5 10 15	Is there another word that can be used to replace 'features'? Maybe 'managing emotional <b>changes</b> '	Thank you for your comment. We have taken your comments into consideration and we have amended the wording in the scope.
Department of Health	7	20	Should this be termed 'Comorbidities'	Thank you for your comment we have now amended this section of the guideline.
Department of Health	7	23	As per comments 9B above - this should be about supporting carers more generally, not just about social care interventions.	Thank you for your comment. The guideline committee will take into consideration the inclusion of issues relating to carer support when looking at the evidence for this section.

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Department of Health	8	1	In response to the question asked, the reply is: Around the individual and their family, irrespective of the care provider or the location of services.	Thank you for your comment.
Department of Health	8	5	A missing outcome from the list is evidence focusing on: <ul style="list-style-type: none"> <li>- Effectiveness of CST interventions</li> <li>- Prevention and risk reduction</li> <li>- Effectiveness of care planning</li> <li>- Evidence of the importance of immediate post diagnosis period</li> <li>- Evidence of the effectiveness of a care coordinator /dementia adviser / support worker</li> </ul>	Thank you for your comment. The evidence associated with these outcomes may be considered by the guideline committee when looking at the evidence for the relevant review questions. The list of outcomes provided is not exhaustive and the guideline committee may choose to add to it or to be more specific in which measures are used to report on these outcomes.
Department of Health	11	Diagram	Care pathway box 5 – needs to include in 'management' – a reference to social interventions and non-pharmacological interventions.	Thank you for your comment. The pathways diagram has been amended.
Department of Health	11	1	Context needs significant strengthening to include more positive messages and direct reference to 'meaningful care' and the fact that a large number of people for many years can 'living well' with dementia.	Thank you for your comment. We have amended this section of the scope.
Department of Health	12	24	Current practice – needs to make reference to the non-pharmacological interventions, for example CST and reminiscence therapy.	Thank you for your comment. We have amended the scope to include reference to non-pharmacological interventions
Department of Health	13	13	Needs to include reference to the two latest	Thank you for your comment. We have now

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			Department of Health dementia policy documents: <ul style="list-style-type: none"> <li>- Prime Minister's Challenge on Dementia 2020 (published February 2015)</li> <li>- Prime Minister's Challenge on Dementia (published May 2012)</li> </ul>	amended the scope to include these policies.
Department of Health	13	13	Needs to refer to the Care Act guidance in addition to the primary legislation	Thank you for your comment. We have amended the scope to include this.
Foundations	General	General	Foundations very much welcomes the effort by NICE of revisiting the Guideline on Dementia in the light of the implementation of the Care Act 2014 and the new evidence accrued since 2009.	Thank you for your comment
Foundations	3	1.3 Point3	Training and Development for and of health and Social Care staff should include training and development of Housing related support staff in accommodation based services and the community.	Thank you for your comment. We will not be covering the training and development of housing staff directly However, If housing staff are involved in the health and social care of people living with dementia, they will be included here.
Foundations	3	1.3 Point4	Options for and consideration of Risk management should include the contribution housing and design of the home environment can make to prolonging independence by making changes early enough to enable patients to accommodate those changes before that ability is impaired by cognitive deterioration.	Thank you for your comment. We have highlighted the housing and living needs including the provision of environments which are sensitive to cognitive impairment as an area requiring special consideration. We will search for appropriate evidence pertaining to this issue.
Foundations	4	1.3	Interventions should include a consideration of potential impact adaptations, assistive technology	Thank you for your comment. The guideline committee will consider impact adaptations,

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		Point6	and home design within the place patients call home can have in delaying the need for more extensive care and intensive care packages.	assistive technology and home design when looking at the sections addressing the assessment of needs and interventions to promote the health and wellbeing of people living with dementia. We have now added the need for extensive care as an outcome we will consider when reviewing the evidence.
Foundations	4	1.3 Point7	Please include a reference to housing as an essential within the integrated health and care economy.	Thank you for your comment. We have not added housing to this heading have highlighted the housing needs of people living with dementia as an area requiring special consideration and we will search for appropriate evidence.
Housing Learning and Improvement Network	1	0	Last bullet: Why is the scope limited to services contracted by the NHS and ASC? It excludes those procured privately	Thank you for your comment. We have taken this into account and have amended the scope to incorporate all settings.
Housing Learning and Improvement Network	3	1.2	Wording either ambiguous or scope excessively limited to only NHS-funded services. Suggest re-word to "All settings in which social care or NHS-funded health services are received"	Thank you for your comment. We have amended this section of the scope to cover all settings.
Housing Learning and Improvement Network	7	17	The term "social care" can often be interpreted in quite a narrow way to exclude, for example, housing-related interventions, assistive technology. Excluding the word "care" would broaden the options, fitting better into the aspiration of the Care	Thank you for your comment. We have amended the scope and taken out the word 'care' so that we can consider a broader evidence base.

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Housing Learning and Improvement Network	7	18	Would you consider broadening the scope here to including the housing sector? The sector can often contribute very favourably to an integrated pathway if included.	Thank you for your comment. We have highlighted the housing needs of people living with dementia as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this group.
Housing Learning and Improvement Network	3	1.3	Why only health and social care staff? Why not housing professionals who provide services to people with dementia?	Thank you for your comment. This section of the scope has been removed.
Housing Learning and Improvement Network	General	General	While you obviously need to set limits on the scope of these guidelines, firstly the wording at present as indicated above is unclear, but secondly it risks excluding interventions and a workforce that can (and do) contribute significantly to supporting people with dementia and their carers. While I can see the logic of limiting the workforce aspects to health and social care, given NICE's remit, it doesn't really make sense to me to limit the interventions to health and social care.	Thank you for your comment. We have not listed specific non-pharmacological interventions to be covered in the scope and we will rely on the guideline committee to advise on which interventions are used in England and to help prioritise these for review.
HQT Diagnostics	General	General	GP to test for Fatty Acids and re-test after 3 months  Major improvements in Dementia have been seen within 3 months of supplementing levels of Omega-3 Fatty Acids to achieve: <ul style="list-style-type: none"> <li>• <b>Omega-3 Index &gt;8%</b></li> </ul>	Thank you for your comment. The scope outlines that we will be covering assessment for people with suspected dementia and we have not, at this stage, excluded looking at any test or assessment strategy. We have also included a question on strategies to

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			<ul style="list-style-type: none"> <li><b>Omega-6/3 Ratio &lt;3:1</b></li> </ul> <p>The <b>Omega-3 Index</b> is designed to provide a more reliable indicator of the level of specific Fatty Acids than any other method. This can be achieved by eating more oily fish or taking Fish Oil supplements</p> <p>The <b>Omega-6/3 Ratio</b> shows the level of Omega-6 compared to Omega-3 and is a good indicator of Inflammation. This can be improved by increasing Omega-3 and eating less Sunflower oil (64% Omega-6), less Corn oil (52%) and less Soybean oil (51%)</p> <p>The HQT Diagnostics Fatty Acid Test shows an average of all Fatty Acids eaten over the previous 60-90 days</p> <p><b>Sources:</b>  <a href="http://www.expertomega3.com/omega-3-study.asp?id=56">http://www.expertomega3.com/omega-3-study.asp?id=56</a>  <a href="http://www.ncbi.nlm.nih.gov/pubmed/25446949">http://www.ncbi.nlm.nih.gov/pubmed/25446949</a>  <a href="http://omega3care.com/wp-">http://omega3care.com/wp-</a></p>	<p>minimise the progression of dementia.</p>

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			<p><a href="http://content/uploads/2013/11/Omega-3LiteratureListJuly2013.pdf">content/uploads/2013/11/Omega-3LiteratureListJuly2013.pdf</a> ( 61 references on Dementia )</p> <p><a href="http://omegamatrix.eu/wasistomega3index.html?lang=EN">http://omegamatrix.eu/wasistomega3index.html?lang=EN</a></p> <p><a href="http://www.hqt-diagnostics.com">www.hqt-diagnostics.com</a></p>	
HQT Diagnostics	General	General	<p>Patients who may have Cognitive Impairment to do the online test at <a href="http://www.foodforthebrain.org">www.foodforthebrain.org</a></p> <p>This test has already been done by 220,000 people. Those who fail receive a letter for their GP suggesting that they test for Homocysteine.</p> <p>The correlation of Homocysteine with Dementia was established by the OPTIMA project at Oxford University.</p> <p>More information: <a href="http://www.foodforthebrain.org/alzheimers-prevention.aspx">http://www.foodforthebrain.org/alzheimers-prevention.aspx</a></p>	Thank you for your comment. The scope outlines that we will be covering assessment for people with suspected dementia and we have not, at this stage, excluded looking at any test or assessment strategy.
HQT Diagnostics	General	General	GP to test for Homocysteine and re-test after 3 months	Thank you for your comment. The scope outlines that we will be covering assessment for people

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			<p>If Homocysteine is high, treatment is suggested to reduce the level to &lt; 9 micromol/L. This can include a cocktail of B-Vitamins, including Vitamin B6, Vitamin B9 Folic acid and Vitamin B12.</p> <p><b><i>This has been shown to reduce the rate of atrophy in the brain and slow the progression of Dementia</i></b></p> <p>More information:  <a href="http://ajcn.nutrition.org/content/102/1/7">http://ajcn.nutrition.org/content/102/1/7</a>  <a href="http://greenvits.eu/collections/vitamin-b">http://greenvits.eu/collections/vitamin-b</a></p>	<p>with suspected dementia and we have not, at this stage, excluded looking at any test or assessment strategy.</p> <p>We have also included a question on strategies to minimise the progression of dementia.</p>
HQT Diagnostics	General	General	<p>GP to test for Vitamin D and re-test after 3 months</p> <p>Major improvements in Dementia have been seen within 3 months of supplementing levels of Vitamin D so that 25(OH)D is between 100-150 nmol/L</p> <p><b>Sources:</b>  <a href="http://www.vitamindwiki.com/Alzheimers-Cognition+-+Overview">http://www.vitamindwiki.com/Alzheimers-Cognition+-+Overview</a></p>	<p>Thank you for your comment. The scope outlines that we will be covering assessment for people with suspected dementia and we have not, at this stage, excluded looking at any test or assessment strategy</p> <p>We have also included a question on strategies to minimise the progression of dementia.</p>
Lilly	2	24	<p><i>Groups that will not be covered: People with mild cognitive impairment who are not suspected of</i></p>	<p>Thank you for your comment. We will be including people with mild cognitive impairment if they are</p>

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			<p><i>having dementia.</i></p> <p>We feel that all people with mild cognitive impairment should be included within the scope seeing that the initial assessment for suspected dementia is a key issue this guideline aims to address. It is proposed that the diagnostic accuracy of initial assessments be reviewed as part of this guideline, and excluding people with mild cognitive impairment who are not suspected of having dementia from the scope makes an assumption that initial assessments for suspected dementia are of sufficient accuracy to reliably categorise patients.</p> <p>Patients in the early stages of dementia will present with mild cognitive impairment. Definitive tests to determine which of these patients will go on to develop dementia is not widely used or available in the NHS at this stage. As a result, some patients with dementia, mistakenly categorised as not suspected of having dementia, will progress to more advanced stages without intervention when the opportunity to intervene and significantly slow the progression of the illness is no longer available. Therefore, careful consideration of mild cognitive</p>	<p>suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.</p>

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			<p>impairment is vital when focussing on the prevention/delay of dementia.</p> <p>In addition, new randomised controlled trial findings recently published in the Lancet<sup>1</sup> suggest that multi-domain intervention strategies (including lifestyle advice) could improve or maintain cognitive functioning in at-risk elderly people from the general population. We consider this evidence relevant to this topic area, and suggest it should be reviewed in the development of this guideline for the benefit of all patients with mild cognitive impairment.</p> <p>Identifying patients in the mild cognitive impairment stage of dementia is in line with the goal of using preventative strategies to delay progression to dementia. Identifying and managing patients with mild cognitive impairment will be of increasing importance within the evolving therapeutic landscape for dementia.</p>	
Lilly	3	28	<p><i>5 Managing dementia</i></p> <p>This guideline should consider the evolving pharmaceutical landscape and the infrastructure</p>	<p>Thank you for your comment. The guideline committee may consider the options for intravenous drugs when looking at the evidence for pharmacological interventions. We will however,</p>

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			support that will be needed for the management of dementia with intravenous (IV) drugs. This guideline should consider future service design and equal access in order to be relevant at the time of publication.	not make recommendations for future service design.
Lilly	5	4	<p><i>Section 1.4 Economic aspects</i></p> <p>Consideration of wider societal costs in review questions focussed on both social care and health outcomes is crucial as national policy moves towards closer integration of health and social care (as seen in new care models piloted at 29 Vanguard sites<sup>2</sup>).</p> <p>The true economic burden of dementia can only be realised if the costs of informal/social care are included. According to Wimo et al (2010)<sup>3</sup> “the costs of informal care and the direct costs of social care contribute similar proportions of total costs, whereas the direct medical costs were much lower.” In the UK context, a report commissioned by the Alzheimer’s Society<sup>4</sup> included the following: <i>The overall economic impact of dementia to society in the UK is £26.3 billion, with an average annual cost of £32,250 per person.</i></p>	Thank you for your comment. Health and social care service use and costs are listed as outcomes in the scope. In <a href="#">the NICE guidelines manual</a> , the reference case outlines which costs will be considered.

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			<ul style="list-style-type: none"> <li>• £4.3 billion spent of healthcare costs (including £85 million on diagnosis)</li> <li>• £10.3 billion is spent on social care (publicly and privately funded).</li> <li>• £11.6 billion is contributed by the work of unpaid carers of people with dementia</li> </ul>	
Lilly	5	24	<p>3 Training and development of health and social care staff</p> <p>In reviewing what models of training for health and social care have positive outcomes for people with dementia, it is important that consideration be given to the following:</p> <ul style="list-style-type: none"> <li>• Who is responsible for different aspects of care and in which setting</li> <li>• Who is responsible for training the staff</li> <li>• Which staff would be trained: e.g. GPs, district nurses, social workers, occupational therapist, care workers, dementia advisers</li> <li>• What level of service and support can a patient and carer expect at the different stages of dementia (including how these services will be appropriately staffed)</li> </ul> <p>We believe that consideration of models of training</p>	Thank you for your comment. We will search for a broad range of issues when considering the review question about training and development of health and social care staff. The guideline committee may consider these interventions when looking at the evidence for this question.

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			beyond the NHS and the UK (e.g. Europe) will significantly increase the evidence base and provide valuable insights.	
Lilly	6	1	<p><i>5 Initial assessments for suspected dementia</i></p> <p>We agree that a review of the diagnostic accuracy of initial assessments is a key issue to consider as part of this guideline.</p> <p>The state of the nation report on dementia care and support in England<sup>5</sup> highlighted the fact that less than 50% of people with dementia receive a diagnosis and that there is much variation in the time people have to wait before being seen by a memory service. The variability of available post-diagnosis support also varies too much across the country.</p> <p>It is important to consider not only the initial assessment, but also the timing of subsequent assessments for suspected dementia.</p> <p>In addition, we also believe a review of the outcomes of national screening programmes would be of value.</p>	<p>Thank you for your comment. We have now amended this question. Our intention is that the guideline committee will consider issues of post diagnosis support for people living with dementia. Many areas covered in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia. It is beyond the remit of the Guideline Committee to review any decisions made by the National Screening Committee.</p>

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Lilly	6	6	<p><i>7 Preventing dementia</i></p> <p>The questions currently listed under this section focuses on modifying and managing cardiovascular risks factors. We suggest that wider consideration of preventative treatments for slowing progression of dementia should also be included under this section (e.g. lifestyle changes, brain exercises, music therapy).</p>	Thank you for your comment. We have now modified this section of the scope to reflect slowing the progression of dementia. The guideline committee will take into consideration these interventions when looking at the evidence for this section.
Lilly	6	11	<p><i>8 Diagnosing Dementia</i></p> <p>Please also consider/include the following under this section:</p> <ul style="list-style-type: none"> <li>• What is the use and added value of more advanced diagnostic tools (e.g. FDG positron emission tomography (PET), Amyloid PET)?</li> <li>• A review of all diagnostic methods currently available, including magnetic resonance imaging (MRI), PET, single photon emission computed tomography (SPECT) imaging, Amyloid Scan and cerebrospinal fluid (CSF) biomarkers.</li> </ul>	Thank you for your comment. The guideline committee will take into consideration a range of diagnostic methods when looking at the evidence for this section.
Lilly	6	15	<p><i>9 Identifying Dementia subtypes</i></p> <p>In this section, please differentiate further into the</p>	Thank you for your comment. The guideline committee will take into consideration the need for differentiation of subtypes of Alzheimer's Disease

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			subtypes of Alzheimer's Disease (e.g. Amyloid Positive sub type or APOE positive subtypes) as the different forms of this condition have different prognoses and future treatments in development.	when reviewing the evidence relating to this section.
Lilly	7	23	<i>17 Social Interventions for carers</i>  It would be useful to know the cost of interventions for informal care.	Thank you for your comment. In <a href="#">the NICE guidelines manual</a> , the reference case details the perspectives taken on costs. It is not usual for the costs of informal care to be considered as these are not borne by the NHS or social care systems.
Lilly	7	28	<i>18 Integrated health and social care</i>  We believe that a review of integrated health and social care pathways in order to identify examples of good practice would be of value in ensuring the best possible outcomes for people with dementia.  Appropriate support following a dementia diagnosis is not currently available to everyone as there is no mandatory minimum provision of support. This could in part be due to the lack of clarity on where the balance of responsibility for providing dementia services lie between the NHS and social care. We believe that clearer guidance on the optimal design and management of integrated health and social care services will benefit dementia patients and	Thank you for your comment. Our intention is that the guideline will consider issues of support post diagnosis. A number of areas in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia. The guideline committee will take into consideration the inclusion of these issues when looking at the evidence...

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			reduce the unacceptable variation in diagnosis and care patients currently experience across the country. <sup>5</sup>	
Lilly	8	8	<p><i>1 Signs and symptoms of dementia</i></p> <p>Please differentiate by Alzheimer's Disease subtype in addition to dementia subtype.</p>	Thank you for your comment. The guideline committee will take into consideration the differentiation of Alzheimer's Disease by sub-type when they analyse the evidence relating to this condition.
Lilly	8	19	<p><i>14 Resource use and cost</i></p> <p>Please include informal/social care costs when considering this outcome. The true economic impact of dementia can only be realised if the costs of informal/social care are included</p>	Thank you for your comment. Health and social care service use and costs are listed as outcomes in the scope. In the <a href="#">NICE guidelines manual</a> , the reference case outlines which costs will be considered. It is not usual for the costs of informal care to be considered as these are not borne by the NHS or social care systems.
Lilly	General	General	<p><b>References</b></p> <ol style="list-style-type: none"> <li>Ngandu, Tiia, et al. "A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial." <i>The Lancet</i> (2015).</li> <li>NHS England. "New care models – vanguard sites."</li> </ol>	Thank you for highlighting these references.

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			<p><a href="http://www.england.nhs.uk/ourwork/futurenhs/5yfv-ch3/new-care-models/">http://www.england.nhs.uk/ourwork/futurenhs/5yfv-ch3/new-care-models/</a> (last accessed 5 August 2015)</p> <p>3. Wimo, Anders, et al. "The worldwide economic impact of dementia 2010." <i>Alzheimer's &amp; Dementia</i> 9.1 (2013): 1-11.</p> <p>4. Alzheimer Society. "Dementia UK: Second edition – Overview." London: King's College London and London School of Economics; September 2014. <a href="http://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition_-_Overview.pdf">http://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition_-_Overview.pdf</a></p> <p>5. Department of Health. "Dementia. A state of the nation report on dementia care and support in England." London: Department of Health; November 2013.</p>	
London Borough of Camden	3	20	The title of this section is preventing dementia. There is no known way to prevent dementia, but there are a number of recommendations to reduce the risk of developing dementia. To avoid confusion it would be preferable if the name of this section was changed to something more accurate, like reducing the risk of developing dementia	Thank you for your comment. This section of the guideline is intended to address the area of minimising the progression of dementia. We have now amended the relevant section of the scope to reflect this more clearly.
London Borough of Camden	6	6 -10	Similar to comment above about preventing dementia being used inappropriately. Would be	Thank you for your comment. We have now modified this section of the scope to reflect slowing

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			clearer to talk about risk reduction instead of prevention.	the progression of dementia.
London Borough of Camden	General	General	One of the key issues for me is how we can enable people to live well with dementia and change the perception that people with dementia can't have a good quality of life. One of the key areas is the terminology used, with terms such as "dementia sufferer" or "Dementia patient" being used, which offers only negative connotations. The draft does not use any of this terminology.	Thank you for your comment. We expect the guideline committee to be mindful of these issues and to draft their recommendations accordingly
London Borough of Camden	General	General	Looks to be a comprehensive document which will be a really useful resource, look forward to reading the final copy.	Thank you for your comment
London Borough of Havering	2	1.1	Groups that will be covered: We think it may be worth mentioning people with learning disabilities (PwLD) as a specific group on your list. Although we believe PwLD will be covered in more details in other guidance documents and one that is currently under development, we would like to suggest the importance of covering some specific subgroups such as for e.g. individuals diagnosed with a Down's syndrome as they are considered at a higher risk of developing dementia.	Thank you for your comment. We have taken on board your comments and people with learning disabilities will now be included within the guideline update.
London Borough of Havering	4	General	Under 6 – the support for family members and carers of people with dementia (PwD) only	Thank you for your comment. We will not be including a specific review question to address the

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			<p>includes: *assessment of needs; and, * interventions</p> <p>We think there is scope to also add any training/support available for them as that's also backed by the evidence.</p> <p>1. Inpatient dementia services; 2. Assessing and managing dementia for people who have learning disabilities</p> <p>We understand that both points will be covered by the guideline on mental health problems and learning disabilities currently in development. However, we don't see why these can't be mentioned briefly in the dementia guidelines document probably with a note to let the audience know where to find a more detailed and thorough discussion on these topics, especially as the other two are under development.</p>	<p>training of carers, however, we do have a review question which considers the models of training for health and social care staff and this may include carers of people living with dementia.</p> <p>We have now amended the scope so that the guideline update includes people with learning disabilities and inpatient dementia services.</p>
London Borough of Havering	5	1.5	<p>This is an important area for consideration and attention. We believe that it will be beneficial to refer to the mental capacity act (MCA), and, distinguish the right time to when a patient diagnosed with dementia had the chance to</p>	<p>Thank you for your comment. The guideline committee may choose to refer to this legislation when looking at the evidence for this section of the guideline, if they think this is appropriate.</p>

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			discuss any advanced decision-making options with a specialised independent MAC adviser. The more people we have diagnosed at an early stage of the condition the more beneficial it will be to empower them with a lasting power of attorney so they can make the right decisions about their care and future choices at the time when they will lose the mental capacity to do so.	
London Borough of Havering	6	1.5 Point7	We think it may be worth adding a focus on certain (i) risk factors such as binge drinking and poor diet as well as physical inactivity as well as (ii) risk groups i.e. people with LD (down syndrome specifically), Diabetes (type I and II), other LTCs - which have not been listed.	Thank you for your comment. The guideline committee will consider a broad range of risk factors when considering the evidence for this review question and it is likely that the evidence will be categorised to cover lifestyle, genetic risk factors etc.
London Borough of Havering	7	1.5 Points 13-15	We would like to mention the benefit of adding carers to all the above subsections. In particular the effectiveness and benefits of teaching family members and carers to manage behavioural change (e.g. CRISP).	Thank you for your comment. The guideline committee will take into consideration the inclusion of these issues when looking at the evidence.
London Fire Brigade	General	General	<b>Q) 1 Ethics, consent and advance decision-making</b> <b>Is it ever appropriate to act when a person with dementia has not been able to give or has withheld consent?</b>	Thank you for your comment. We have now removed this topic and question from the scope.

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			<p>As an emergency service one of our priorities is to protect people. Our frontline staff are sometimes faced with situations where a person or property would be at risk if appropriate action were not carried out with their without consent.</p> <p>Some examples of this are:</p> <ul style="list-style-type: none"> <li>• Immediate response – a person may be in danger of harm</li> <li>• Safeguarding concern/serious outstanding risk – intervention of social care may be necessary</li> <li>• Home fire safety visit – working with partners to ensure preventative measures are carried out</li> </ul>	
London Fire Brigade	General	General	<p><b>11. Risk management and how it can support people with dementia to avoid harm and stay independent</b></p> <p><input type="checkbox"/> <b>How should individual risk (to people with dementia, their family members, carers, and health and social care staff) be assessed and managed?</b></p> <p>As an emergency service we work closely with partners to ensure we do all that we can to support</p>	Thank you for your comment and the examples provided.

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			people with dementia and keep them safe in their home. We do this by carrying out Home Fire Safety Visits and assessing and mitigating risk. One example of this is by making sure there are working smoke alarms in the home. We also have other resources available like fire retardant bedding and nightwear. Familiarisation sessions on dementia are currently being delivered to firefighters across London and as a service this allows us to manage each situation involving a person with dementia in a more effective way and give home fire safety advice to the individual and if necessary to the carer.	
Medway Community Healthcare	3	1.2	The draft scope indicates all settings in which NHS-funded health and social care is received... Does this EXCLUDE then settings wherein care received are PRIVATELY funded ( mostly in care homes ) ?	Thank you for your comment. We have amended this section of the scope to cover all settings.
Medway Community Healthcare	4	General	Areas that will be removed: The draft says one of the area from the published guideline that will be removed is about " Inpatient dementia service " Are we referring then to the care homes? If so, WHY? It is well established that 2/3 of all people with dementia live in care homes. I understand there is a government drive to promote/ support people to live/ stay in their own homes	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.

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			longer but I believe, the expertise are mostly found in the care homes hence, this is something that we should equally focus on ( standardized care/ expectations )	
Medway Community Healthcare	5	1.5	On 1. Ethics, consent and advance decision making: I feel, we can better fully support people with dementia and their carers during the very early stages of their " journey", which is upon diagnosis, that it is made clear for them about " What to do Next"... I mean capitalize on the fact that if the person is in its early stages of dementia, though may be really sensitive, conversations about Advance Directives, Lasting Power of attorney, My Wishes ( End of Life care ) should happen. Present expectations in the long run and clarify limitations/ assessments when person with dementia can no longer make decisions/ consent for carer to take over	Thank you for your comment. We have inserted a review question which directly addresses advance planning and decision making.
Medway Community Healthcare	5	1.5	On 3. Training and development of health & social care staff: To start with, do we have a pool of high quality, recognized training providers/ packages? If so, what are the strengths such as practicality , reach, I mean is it easily understood, is it effective? How do	Thank you for your comment. We will look for the evidence relating to training providers/packages and analyse accordingly. We will consider various outcomes to assess effectiveness of interventions and these may include Health and social care staff satisfaction, Patient satisfaction with care received

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			we assess/ evaluate this. Another thing, it would be ideal if there will be a clear, standardized training model meaning same content or coverage being taught/ cascaded across staff	and Health related quality of life of people living with dementia and their informal carers.
Medway Community Healthcare	6	1.5	On 5: Initial assessments for suspected dementia: I will comment on the Test questionnaires which can be limiting in terms of the educational background of the person with dementia	Thank you for your comment.
Medway Community Healthcare	6	1.5	On 6: Referral criteria for specialist dementia assessment: We should not only talk about the indicators but time frames as well. Moreover, I feel the inclusion and education of our local GPs should be tapped on this very crucial matter because half the time, the poor people with dementia with their carers are being given several diagnosis before arriving to the actual diagnosis of dementia hence, wherein the dementia overtime has already progressed ( because sadly, their GPs didn't have a clue in the first place)	Thank you for your comment. The guideline committee will take into consideration these issues when looking at the evidence for this section.
Medway Community Healthcare	6	1.5	On 10: Multimorbidity in people with dementia: For all 4 areas mentioned, there should be clear PATHWAYS/ Flowchart indicating proper sign posting and time frames	Thank you for your comment.

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Medway Community Healthcare	7	1.5	On16-17: Assessing the needs of carers and Social interventions for carers: After assessment of needs, it would be ideal to have time frames for interventions to be accessed and a system of monitoring/ evaluating effectivity of interventions	Thank you for your comment. The guideline committee will take into consideration these issues when looking at the evidence for this section.
Medway Community Healthcare	8	1.6	On 5. Choice and control for people with dementia: I would just like to mention where does the ETHiCAL bearing lie wherein people with dementia residing in a care home for more than a year are being moved ( to another setting/ care home ) just because they no longer meet the eligibility criteria for CHS funding? As carers/ care providers, I just feel , we ought to have a say in the decision making when it comes to the best interest of the people with dementia, acting as advocates.	Thank you for your comment. Our intention is that ethical issues will be considered when drafting recommendations for the guideline. It is likely that these issues will include evidence relating to advocacy and choice at key decision points in the care pathway.
Medway Community Healthcare	3	General	Managing dementia: There isn't any recognition of spiritual or religious features. In today's multi-cultural society these play a vital role in ensuring a dementia sufferer receives care and support that is person centred	Thank you for your comment. Spiritual and religious issues will be considered within our equality impact assessment and addressed appropriately within the guideline.
National Community Hearing Association & British Society of Hearing Aid Audiologists	General	General	NHS England recently published its Accessible Information Standard. All NHS providers are legally required to implement the Standard by July 2016. The Standard	Thank you for your comment. We have highlighted people with sensory impairment and communication difficulties among the groups requiring special consideration within this guideline

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			<ul style="list-style-type: none"> <li>“directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss” (NHS England, 2015).</li> </ul> <p>We appreciate that the scoping guideline for dementia cannot list every condition, but in our view it should consider the impact hearing loss has on this group. Failing to do this risks worsening health inequalities and the final guideline (when published) being inconsistent with the Accessible Information Standard and therefore also inconsistent with the Health and Social Care Act 2012 and Equality Act 2010.</p> <p>The risks associated with dementia can be reduced by early detection of hearing loss and appropriate intervention, including provision of hearing aids with effective support to overcome psychological and physical barriers to take-up – e.g. support with</p>	<p>and will therefore search for appropriate evidence pertaining to this group,</p> <p>The draft review questions now include the assessment of needs for people living with dementia which will include issues relating to sensory impairment including hearing loss.</p>

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			<p>familiarisation, regular review and reprogramming.</p> <p>Evidence:</p> <ul style="list-style-type: none"> <li>• Hearing loss increases exponentially with age – e.g. 1.8% of people aged 17-30 have a hearing loss, compared to 93% of people aged 80 and over</li> <li>• age-related hearing loss is a long-term condition and the main cause of hearing loss</li> <li>• in England, adult hearing loss is the 6th leading cause of years lived with disability</li> <li>• unsupported hearing loss increases the risk of depression , social isolation , loneliness , cognitive decline , early retirement and reduced quality of life - NB hearing loss might mask diagnosis of dementia (p.4)</li> <li>• therefore, many of those with dementia will have some degree of hearing loss with the prevalence of hearing loss increasing significantly with age and, other things being equal, will experience reduced quality of life unless their hearing needs are met</li> <li>• it has been suggested that people with</li> </ul>	

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			<p>unsupported hearing loss and dementia or mental health problems are more likely to go straight to expensive care packages</p> <ul style="list-style-type: none"> <li>NHS England and Department of Health note that "hearing loss is associated with an increased risk of developing dementia in over 60 year olds. People with mild hearing loss have nearly twice the risk of developing dementia compared to people with normal hearing; and the risk increases threefold for people with moderate and fivefold for people with severe hearing loss"</li> </ul> <p>Ensuring people with dementia are given the communication tools and support they need – including hearing aids and spectacles – to communicate with health and social care workers, family members and carers is therefore fundamental to helping them stay independent (p.3). For example it is difficult to imagine how diagnosing and assessing dementia (p.3) can be validly and accurately completed if the individual cannot hear well, or is not supported to understand, the health professional's questions.</p>	

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			We believe that not accommodating peoples' communication needs – including hearing – could create barriers to delivering the updated NICE dementia guideline.	
National Community Hearing Association & British Society of Hearing Aid Audiologists	2	1.5	<p>We support the guideline giving special consideration to the identified groups.</p> <p>We would however like to see people with sensory impairment – given the prevalence of sensory impairment in people with dementia – to also be given special consideration.</p> <p>Please note, the NHS Accessible Information Standard acknowledges that the NHS has to do more for people with sensory loss and disabilities, and consistency in NICE guidelines would be helpful here.</p> <p>We particularly support focusing on “people at risk of social exclusion”, but would we would like the scope to clarify that this includes “social isolation”. It is noteworthy that NHS England and Department of Health state:</p>	<p>Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.</p> <p>We have also added isolation as a consideration alongside social exclusion</p>

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			<p>"In older age, hearing loss becomes a major challenge and people with hearing loss can find it difficult to follow speech without hearing aids and are at greater risk of social isolation and reduced mental wellbeing. Social isolation has an effect on health and in older people there is a strong correlation between hearing loss and cognitive decline, mental illness and dementia."</p>	
National Community Hearing Association & British Society of Hearing Aid Audiologists	3	General	<p>Areas to be included:</p> <p>We support the items listed under "areas from the published guideline that will be updated".</p> <p>Whilst the original guideline mentioned hearing therapy it overlooked age-related hearing loss and effective communication strategies for people with sensory loss (hearing or sight).</p> <p>Despite the high prevalence of hearing loss in older people awareness is still poor amongst patients, staff and carers.</p> <p>Unsupported hearing loss also presents safety risks in health care. For example a survey of 600 people with hearing loss found that after attending a GP</p>	<p>Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.</p>

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			<p>appointment</p> <ul style="list-style-type: none"> <li>• 28% had been unclear about their diagnosis</li> <li>• 26% had been unclear about the advice given</li> <li>• 19% had been unclear about their medication</li> </ul> <p>- NB a clear challenge to delivering high quality and safe care for people that have dementia and unsupported hearing loss.</p> <p>So although we appreciate that this is only a scoping document, we would like the committee to consider specifically looking into the impact that sensory loss has on the feasibility of the rest of the guidance – e.g. it is not clear how one can support somebody with dementia to exercise choice (p.5) unless they are first enabled to participate in decision-making by having their sensory needs met.</p>	
National Community Hearing Association & British Society of Hearing	4	General	We support including comorbidities in the updated guideline.	Thank you for your comment. We have highlighted people with sensory impairment, including hearing loss, as a group requiring special consideration

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Aid Audiologists			<p>Please note, unsupported hearing loss increases the risk of depression , social isolation , loneliness , cognitive decline , early retirement and reduced quality of life and can therefore mask the diagnosis of dementia – i.e. hearing loss itself might be a differential diagnosis.</p> <p>Unfortunately a common theme in NICE documents is to mention visual impairment and overlook hearing impairment. This despite adult hearing loss accounting for a greater number of years lived with disability in England . We think that based on the evidence – including higher prevalence of hearing loss in this group and hearing loss being strongly associated with dementia - hearing impairment should be noted as an example alongside visual impairment.</p>	and we will search for appropriate evidence in this area.
National Community Hearing Association & British Society of Hearing Aid Audiologists	5 -7	General	<p>Sections 4-15:</p> <p>We recommend that hearing loss – because it is strongly associated with dementia , –is included in the search terms during the evidence-based review of sections 4 to 15.</p>	Thank you for your comment. We have highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
National Community Hearing Association &	6	General	Section 10:	Thank you for your comment. We have taken this into consideration and amended the scope

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British Society of Hearing Aid Audiologists			<p>We support researching risk factors and specialist diagnostics tests, and what interventions should be done when people have dementia.</p> <p>However, we do not think that each of the sections should state, "should be done for people with dementia <u>who have a sudden deterioration of functioning</u>".</p> <p>This risks making the guideline reactive to adverse events. We feel an approach that focuses on prevention as well as intervention would be more consistent with the Five Year Forward View - i.e. "taking preventative and public health more seriously".</p>	accordingly.
National Community Hearing Association & British Society of Hearing Aid Audiologists	8	1.6	We appreciate that NICE cannot list all conditions, but given the evidence above we feel that sensory loss, and particularly hearing loss, should be included because it is intrinsically linked to all of the main outcomes. This would also align the guideline scope with NHS England's Accessible Information Standard (thus the Health and Social Care Act 2012 and the Equality Act 2010).	Thank you for your comment. We have now highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence and outcomes pertaining to this group.
National Community Hearing Association &	11	3.1	Please note that - language impairment, disorientation,	Thank you for your comment we have amended the scope to include reference to sensory

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British Society of Hearing Aid Audiologists			difficulties in daily living, behavioural change and disorientation might be caused by, or exacerbated by, unsupported hearing loss.	impairment.
National Community Hearing Association & British Society of Hearing Aid Audiologists	13	3.1	NHS England's Accessible Information Standard 2015 should be added to this list and considered in the development of this and future guidelines for groups that will have a high prevalence of sensory impairment (i.e. all guidelines that involve health and social care for older people, where good communication is linked to outcomes, should consider the hearing needs of service users and their carers).	Thank you for your comment. We have now amended the scope to include this.
National Community Hearing Association & British Society of Hearing Aid Audiologists	5	General	Question 3:  We agree that "training and development of health and social care staff" is key to ensuring the guideline delivers positive outcomes for people with dementia (p.5). This training should include training on sensory impairment and especially hearing loss (as per NHS England's Accessible Information Standard). Despite the prevalence of hearing loss in settings where people are likely to be at greater risk of dementia or have dementia, awareness of hearing loss remains limited. For example the Department of Health and NHS England state:	Thank you for your comment. We have not excluded training on sensory impairment from the range of possible training for health and social care staff and we will consider the inclusion of evidence for this element within the context of health and social care staff training.

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			<p><i>“There is a significant socioeconomic gradient associated with hearing loss bringing greater inequality and an impact that can go unrecognised. Hearing loss is a major reason for poorer and less frequent social interaction, is often a contributor to depression and is independently associated with dementia (8,9,24). <u>People with unmanaged hearing loss and either dementia or mental health problems are more likely to go straight to a higher cost intervention, such as a care home, than would be the case if their hearing loss were effectively managed (10,27)</u> Research in care homes suggests high levels of undiagnosed hearing loss, and under-optimisation of hearing aid benefits for users. Staff have a limited understanding of the assistive technology available to people with hearing loss. By 2032, there will be around 620,000 older people living in care homes in England and of these, almost 500,000 will have a hearing loss and will need support to maximise their independence and wellbeing”.</i></p>	
National Community Hearing Association & British Society of Hearing	General	General	<p>References: NHS England (2015). SCCI1605 Accessible</p>	Thank you for highlighting these references.

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			Action Plan on Hearing Loss. <a href="http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf">http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf</a>	
National Council for Palliative Care	General	General	<p>NCPC, as a registered stakeholder with NICE, would like to submit the following comments regarding 'Dementia (update): consultation on the draft scope, compiled by one of our subscribers (Dr xxxxxxx xxxxxxx, Consultant in Palliative Medicine at xxxxxxx).</p> <p>Through Dr xxxxxx's role with the Dementia Strategic clinical network group in xxxxxx, Dr xxxxxx was directed to the recruitment of committee members to review the NICE Guidance on dementia and encouraged to apply. When reviewing the role description of committee members it was made apparent that the group were not looking to recruit a Palliative Medicine Consultant. We were surprised as from our experience a palliative approach is integral to the holistic care of people with dementia. Dr xxxxxx applied for the role anyway outlining why she felt palliative medicine input would be a useful addition to their committee.</p>	Thank you for your comment. We are currently seeking representation of a consultant in palliative care to join the guideline committee on a co-opted basis.

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			<p>She was informed their rationale for not recruiting palliative medicine representation to the committee was that the scope of the update did not include the "end of life" section as there was no new evidence in that area hence no update required. This in itself seems reasonable.</p> <p>She was directed to review the scope of the consultation document to see which specific areas were to be reviewed and updated. She was also advised that she could via a stakeholder such as NCPC request them to consider extending their membership to include palliative medicine if it was still felt it beneficial after reviewing the scope consultation.</p> <p>Dr xxxxxx reviewed the scope consultation document and argues that many of the other areas that are within the scope of the update would benefit from the perspective and expertise of Palliative Medicine. They reflect many of the areas of dementia related care that we get asked to be involved with to provide a specialist perspective and second opinion, and as such they represent</p>	

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			the challenging areas of care.  <b>See the row below the areas from the published guidelines to which we feel that palliative medicine input would be beneficial.</b>	
National Council for Palliative Care	5	1.5	(1) Principles of care for people with dementia <ul style="list-style-type: none"> <li>- Ethics, consent and advance decision-making <i>Is it ever appropriate to act when a person with dementia has not been able to give or has withheld consent?</i></li> <li>- Supporting people with dementia to exercise choice <i>How can it be ensured that people with dementia can exercise choice in decisions about their care?</i> <i>How can it be ensured that people with dementia are able to make use of advance decision making (advance care plans)?</i></li> <li>- Training and development of health and social care staff <i>What models of training for health and social care staff have positive outcomes for people with dementia?</i></li> </ul>	Thank you for your comment.

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			<p>(5) Managing dementia - <i>Behavioural features - frequently attributed to disease yet evidence to suggest often due to poorly recognised and poorly controlled symptoms such as pain</i></p> <p>(10) Multi-morbidity in people with dementia - <i>What assessments should be done for people with dementia who have a sudden deterioration in functioning?</i> - <i>How should inter current illness (for example, infection) be managed in people with dementia who have a sudden deterioration of functioning?</i> - <i>How should medical co-morbidities be managed in people with dementia who have a sudden deterioration of functioning?</i></p>	
National Council for Palliative Care	General	General	Palliative medicine does not relate simply to “end of life”: the remit is much wider. In order to facilitate good end of life care it must first be recognised when that stage has been reached and this should be planned for in advance. Therefore, the palliative aspects of dementia related care need to be considered throughout the whole trajectory from diagnosis onwards.	Thank you for your comment. We are currently seeking representation from a consultant in palliative care to join the guideline committee on a co-opted basis.

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			<p>From both the experience of NCPC, and Dr xxxxx's work on the xxxxxx Dementia Strategic Clinical Network Group and the xxxxxx Frail Elderly MDT she attends, whilst the concepts of palliative care are intellectually accepted and understood by the wider team involved in managing and caring for people with dementia, there is often a gap in terms of understanding how to apply this knowledge and implement a palliative approach. Dr xxxxx's role in these meetings has actually primarily been focused on helping people to understand the nuances of advance care planning and challenging how to balancing the competing ethical principles in such a complex patient population.</p> <p>From a clinical practice perspective, the role of a palliative care physician is usually related to ethical decision making around managing deterioration in relation to complex multi morbidity then supporting appropriate and effective communication with patients and family members.</p> <p>On this basis we would be grateful if consideration can be given to extending the committee to include palliative medicine representation.</p>	

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NHS England	General	General	Thank you for the opportunity to comment on the above consultation. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you for your comment
Northumberland Tyne and Wear NHSFT	2	12	<p>We welcome that the update will consider people with dementia of all ages. In the original guidance CG42 it stated under Section 1.1.2.1: "Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care"</p> <p>We are concerned that this is relatively vague and needs refinement. Accurate and "timely" diagnosis of early onset dementia can be difficult due to lack of professional awareness and at a NHS Trust level age related barriers may exclude the person with younger person with dementia from appropriate services; yet these individuals may have very significant impacts on their lives as a result of the diagnosis e.g. have a partner who still works, dependent children who may struggle to understand the problem as well as lose support, ageing parents who they need to care for, have heavy financial commitments, etc.</p>	Thank you for your comment. We have now highlighted people with early onset dementia (aged 40-64 years) as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.

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			Therefore they may need services which more closely align with those of working age adults. Therefore either specialist teams providing consultative input to mainstream services and/or up-skilling of the latter in the diagnosis and management of young onset dementia as well as overcoming service divisions demarcated on age are needed to best meet the needs of this challenging patient group. We would therefore ask that this particular area is considered under the scope of the review.	
Northumberland Tyne and Wear NHSFT	3	18	In the original guidance CG42 it stated under Section 1.1.9.5 "Evidence-based educational interventions, such as decision-support software and practice-based workshops,[8] to improve the diagnosis and management of dementia should be made widely available and implemented in primary care". We feel that it is highly laudable that primary care are intimately involved in dementia diagnosis and management. However clear unequivocal guidance needs to be given in terms of what will be seen to be the responsibility of primary care in the patient journey and what should be the responsibility of the secondary care provider. Our general consensus is	Thank you for your comment. We will consider educational interventions and decision support software for both primary care and secondary care when looking at the evidence for our review question addressing models of training for health and social care staff.

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			<p>that primary care should be able to define the diagnosis of dementia, but that secondary care should provide sub-type classification (which is highly important given different management strategies for dementia subtypes) as well as diagnosis of early (e.g. mild cognitive impairment) and complex cases.</p> <p>Specifically with regard to decision-support software and practice-based workshops this needs clarity as the evidence base appears quite mixed on the utility of these approaches. Therefore we would ask that this issue is considered in the revision of the guidelines.</p>	
Northumberland Tyne and Wear NHSFT	2	25 -26	<p>In CG42 it states that “1.3.3.3 Memory assessment services that identify people with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementias) should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage.”</p> <p>Furthermore the scope for the review indicates that “People with mild cognitive impairment who are not suspected of having dementia” will not be covered.</p>	<p>Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.</p>

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			<p>However we believe these areas need careful consideration given the increasing patient throughput in memory clinics yet significant resource limitations at present and the fact that MCI and its management/follow-up are often not counted/considered by commissioners and thus many NHS Trusts now discharge these patients as they are unable to provide ongoing support.</p> <p>However, for some, ongoing issues with MCI (despite no clear evidence of being at risk of dementia) mean that they have negative sequelae in terms of subtle functional impairment as well as dealing with the uncertainty the aetiology of their symptoms. Furthermore clearer articulation needs to be made of how we identify, stratify and manage those people with MCI with the highest risk of conversion to dementia. What role should secondary services have in this relative to primary care and what will be the investigative modalities employed to investigate this group of patients (See comment below regarding imaging)? How should these patients be followed up? In primary or secondary care?</p>	

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			Clearly this will be significant commissioning issue given the substantial resources needed to deal with this area.	
Northumberland Tyne and Wear NHSFT	3	18	<p>Could the panel carefully consider what should be the most appropriate screening tools for detecting cognitive impairment in primary care and what they would recommend for any subsequent detailed neuropsychological test at the secondary care level (e.g. we use Addenbrookes Cognitive Examination revised in our local memory clinics).</p> <p>In addition copyrighting issues have limited the use of the MMSE- we would ask that the panel in its update consider what alternatives should be considered for screening and monitoring cognitive response to treatment.</p>	Thank you for your comment. The guideline committee will consider all screening tools when looking at the evidence for the methods used in diagnosing dementia.
Northumberland Tyne and Wear NHSFT	3	18	<p>Section 1.4.2 of CG42 advises that "A basic dementia screen should be performed at the time of presentation, usually within primary care." We would strongly advocate that the basic dementia screen should be done in primary care to facilitate and speed the diagnostic work-up in secondary care (where availability of access to phlebotomy services esp. in mental health trusts may be limited). This should be coupled of course with a basic cognitive screen / test score which is</p>	Thank you for your comment.

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			provided in the primary care referral letter.	
Northumberland Tyne and Wear NHSFT	4	3 -5	<p>We are pleased that the panel will be considering revisions to the sections of assessment of carers' needs and carer interventions. From the previous guidance care plans were suggested for carers including things such as psychoeducation, peer support groups, use of the internet, etc. However such components, we feel, were too briefly described in the previous guidance and they need more detail in the revision. For example if psychoeducation for carers is advised – what should it be about and who should deliver it? How should carer support organisations fit into the broader structure of these interventions?</p> <p>We also think that there should be a clearer expression of the patient journey and what ongoing psycho-social support will be needed for patients. For example, what is the minimum a patient should receive e.g. memory remediation advice? Post-diagnostic counselling? Cognitive stimulation therapy? Future planning (e.g. end of life, financial etc.)?</p> <p>Local commissioners, at present, tend to prioritise different elements and a clear steer from the updated guidelines would help improve uniformity</p>	Thank you for your comment. We will be considering psychoeducation, peer support groups and internet use within the section addressing interventions for carers. This is however, not an exhaustive list.

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			of service provision and ameliorate service gaps in this area.	
Northumberland Tyne and Wear NHSFT	4	7 -14	In the scoping document it is made clear that a number of areas will not be covered e.g. "Managing comorbidities that may affect the progression of dementia (for example diabetes mellitus or cardiovascular disease)" or "How vascular risk factors (for example hypertension and diabetes mellitus) affect the diagnosis and management of dementia" However this seems somewhat contradictory to the strong focus on dementia prevention described later in the scoping document – surely these areas will need to be covered to some degree to address appropriate prevention strategies?	Thank you for your comment. We will be considering these issues within the guideline update. Managing multi-morbidities was not included in the original guideline but will be included in the guideline update.
Northumberland Tyne and Wear NHSFT	4	15 -17	The scope indicates that "Co-morbidities that may require treating differently because of the presence of dementia (for example incontinence or visual impairment)."  However we would ask that the inverse perspective is considered i.e. how these co-morbidities might impact upon the dementia. For example, poor vision/hearing may compromise cognitive function and exacerbate behavioural disturbances.	Thank you for your comment. These issues will be addressed within the section focusing on co-morbidities and multi-morbidities. We have two review questions addressing these issues: "How should medical co-morbidities /multi-morbidities be managed in people living with dementia?" and "How should psychiatric co-morbidities/multi-morbidities be managed in people living with dementia?"

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Northumberland Tyne and Wear NHSFT	4	19	We note that the pharmacological management of Parkinson's disease dementia will not be covered in the updated guideline. Can we clarify that management guidance on the related condition of dementia with Lewy bodies will be covered? Also it seems a little artificial to split these diseases as frequently there are commonalities in the management of both Parkinson's disease dementia and dementia with Lewy bodies.	Thank you for your comment. We intend to consider all forms of dementia within this guideline including Lewy body dementia. With reference to the management of Parkinson's disease we will cross refer to the Parkinson's disease guideline for recommendations associated to the pharmacological management of Parkinson's disease dementia.
Northumberland Tyne and Wear NHSFT	6	7 -10	In Section 1.3.1.2 in CG42 it states that "In middle-aged and older people, vascular and other modifiable risk factors for dementia (for example, smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) should be reviewed and, if appropriate...." Could the update clarify who will have responsibility for advising on and management of life-style factors? We feel that this could be something which might be accommodated in primary care. We would also ask whether Public Health may have a role?	Thank you for your comment. It is likely that the guideline will address these issues. This is likely to be considered when reviewing the evidence relating to risk factors and slowing the progression of dementia.
Northumberland Tyne and Wear NHSFT	6	15 -17	We are pleased that the panel are re-evaluating the role of imaging and other investigative modalities in dementia diagnosis. In particular we would look for clarity on the use of amyloid imaging and CSF sampling. These are both modalities which are not	Thank you for your comment. The guideline committee will review these imaging techniques when looking at the evidence relating to this section.

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			typically done in the UK at present but ones which would require significant amount of service reconfiguration and resource investment to accommodate.	
Northumberland Tyne and Wear NHSFT	General	General	We would urge the panel to consider in more detail who the target audience of the different sections of the revised guidance will be so that commissioners and providers can easily identify the elements for which they are responsible for and therefore how they might objectively benchmark outcomes.	Thank you for your comment. Once the guideline is written NICE's editorial team will work with the guideline committee to ensure that the intended audience for any recommendations is clear. Where permitted, by NICE methodology, the guideline committee will signpost specific recommendations to professional groups, for example, health or social care professionals and commissioners.
Nutricia Advanced Medical Nutrition	General	General	Nutrition is not mentioned at all and should be integral to the management of; an individuals' nutritional needs should be taken into consideration which could be cultural or related to their condition eg some may have difficulties with swallowing as the condition progresses, some may have food refusal, some may overeat, reference to NICE CG32 could be made where appropriate and the associated NICE QS 24. Individuals (and carers) should be screened for malnutrition risk – using the BAPEN Malnutrition Universal Screening Tool 'MUST' ...	Thank you for your comment. We have now highlighted people with dysphagia as a group requiring special consideration within this guideline and will therefore search for appropriate evidence pertaining to this group.
Old People's Advocacy	5	General	The original Clinical Guidance (CG) for Dementia	Thank you for your comment. The guideline

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Alliance			<p>makes a single reference to advocacy - "Health and social care professionals should inform people with dementia and their carers about advocacy services and voluntary support, and should encourage their use. If required, such services should be available for both people with dementia and their carers independently of each other."</p> <p>The new guideline update makes extensive reference to supporting people with dementia to make choices relating to their care.</p> <p>Changes to legislation around advocacy under the Care Act mean that the original CG wording around advocacy will require updating.</p>	committee will consider advocacy services when looking at the evidence for non-pharmacological interventions and, where appropriate will reference relevant legislation.
Old People's Advocacy Alliance	5	General	<p>Furthermore OPAAL would like to see this guideline make a greater reference to the effectiveness of independent dementia advocacy support in supporting this decision making.</p> <p>Dementia advocacy is a specialist type of advocacy; dementia advocates are able to ensure that the person with dementia's voice is heard and their rights are protected. Dementia advocates can work in a non-instructed capacity with people who</p>	Thank you for your comment. The guideline committee will consider advocacy services when looking at the evidence for non-pharmacological interventions. Any recommendations regarding the use of dementia advocacy services will be determined following a review of all the relevant evidence.

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			<p>are unable to tell the advocate what they want, which can be particularly valuable for some people with dementia.</p> <p>OPAAL would like to highlight resources that could usefully inform references to dementia advocacy:</p> <p><a href="http://www.bjf.org.uk/projects/dementia-advocacy">http://www.bjf.org.uk/projects/dementia-advocacy</a></p> <p><a href="http://revaluingcare.net/a-stronger-voice-for-people-with-dementia-by-the-dementia-advocacy-network-dan/">http://revaluingcare.net/a-stronger-voice-for-people-with-dementia-by-the-dementia-advocacy-network-dan/</a></p>	
Old People's Advocacy Alliance	5 6	General	Scoping highlights staff competency and training issues, OPAAL recommends that these competencies should include a) knowledge of local independent advocacy services, and b) highlight the importance of making a timely referral to dementia advocacy services	Thank you for your comment. The decision to include knowledge of advocacy services in training competencies depends on the evidence base when the guideline committee addresses the non-pharmacological interventions and assessment of needs for people living with dementia.
Old People's Advocacy Alliance	8	General	<p>The guideline asks how care should be arranged to optimise the independence of people with dementia, their family and carers.</p> <p>Again advocacy support can be hugely supportive in ensuring that the person with dementia is placed in the centre of decisions about their care and</p>	Thank you for your comment. The guideline committee will take into consideration the inclusion of assistive advocacy services when looking at the evidence.

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			support.	
Old People's Advocacy Alliance	2	General	Groups covered should include growing numbers of younger people being diagnosed with dementia	Thank you for your comment. We have highlighted people aged 40-64 years with early onset dementia as a group requiring special consideration. People living with juvenile dementias are however excluded from the scope of the guideline due to the differences in presentation, progression and treatment of juvenile dementia.
Old People's Advocacy Alliance	11	General	Carers - The dementia overview pathway indicates support carers should have on the pathway. Whilst this section on carers is relatively comprehensive, and indeed support for carers is important, the guideline assumes older people with dementia have someone in their lives acting in a caring role. Dementia advocacy becomes even more essential when no carer is involved, the person with dementia should have access to a dementia advocate who can ensure that their voice is heard.	Thank you for your comment. It is likely that advocacy services for carers of people living with dementia can be considered within the section addressing carers support.
Optical Confederation	1	15	We believe "Primary Care" should be added to the list under ' <i>Health and social care staff who have direct contact with people with dementia in</i> '. "The community" is listed, but it would be better to be explicit about primary care being included.	Thank you for your comment. It is intended that this guideline would be appropriate for people who work in primary care as part of the NHS.
Optical Confederation	3	11	<i>Promoting and maintaining independence of people</i>	Thank you for your comment. We have included a

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			<p><i>with dementia</i> should be added to the list of areas from the published guideline that will be updated, as the current guideline does not refer to the importance of assessment and care-planning advice regarding vision and eye health from an optometrist.</p> <p>Supporting evidence:</p> <p>The potential effects of dementia and visual impairment comorbidity are considerable. The ability of someone with dementia to cope with visual impairment is reduced when compared to someone with an otherwise similar health profile, but without dementia. This can impact significantly on activities of daily living and cognitive performance (McKeefry and Bartlett 2010). In a study of over 9000 participants, those with a cognitive impairment were significantly more likely to have falls (odds ratio for falls of 2.3) when compared with those with no cognitive impairment (Yamashita et al. 2012). Dementia alone has a significant impact on quality of life, and visual impairment in older people can lead to functional impairment which may adversely affect quality of</p>	<p>draft review question to address the issues of promoting and maintaining independence of people with dementia. We have also now highlighted people with sensory impairment as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.</p>

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			life (Binns et al. 2012). The effects of having both sight loss and dementia concurrently are much more severe than those resulting from either dementia or sight loss alone (Trigg and Jones 2007).	
Parkinson's UK	1	0	4 <sup>th</sup> bullet: Does 'the community' include homeless people? Using the rationale applied in the health inequality work around exclusion of people of low socioeconomic status, it is important to ensure homeless people have access to dementia care and support.	Thank you for your comment. It is intended that the recommendations in the guideline would be relevant for homeless people.
Parkinson's UK	2	1.1	This should also cover family members and carers of people with suspected dementia because of the need for support, including pre-assessment counselling and information-giving before diagnosis	Thank you for your comment. We will include family members and carers of people living with dementia within the guideline update.
Parkinson's UK	3	1.3 Point1	We particularly support the focus on advance decision-making as people with Parkinson's have up to six times the population risk of developing dementia. Up to 80% of people who have lived with Parkinson's 10 years or more may develop dementia see: Rodnitzky RL: <b>Cognitive impairment and dementia in Parkinson's disease</b> (UpToDate, April 2015) accessed online at <a href="http://www.uptodate.com/contents/cognitive-">http://www.uptodate.com/contents/cognitive-</a>	Thank you for your comment and for providing this reference.

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Parkinson's UK	3	1.3 Points1-5	<p><a href="#">impairment-and-dementia-in-parkinson-disease</a></p> <p>We welcome the emphasis on training health and social care staff, both in identifying and managing dementia subtypes. Especially the Lewy body dementias (Parkinson's dementia and dementia with Lewy bodies) as these have different cognitive, emotional and behaviour features from Alzheimer's and Vascular Dementia (most common subtypes). In the early stages there is a greater impact on autonomic nervous system (more continence and digestion problems), more mobility problems, a higher rate of falls, more visual hallucinations and visuo-spatial problems, greater sleep disturbance and a higher rate of delusional thinking, which cause a higher rate of carer burden than Alzheimer's. See: LBDA: <b>Caregiver Burden in Lewy Body Dementias</b> (2009) accessed online at <a href="http://www.lbda.org/content/caregiver-burden-lewy-body-dementias-03/08/05">http://www.lbda.org/content/caregiver-burden-lewy-body-dementias-03/08/05</a></p>	Thank you for your comment.
Parkinson's UK	4	1.3 Point6	<p>'Interventions' should include training to enable carers to provide the full range of support needed including: communicating effectively with the person with dementia; medication management; managing personal care; supporting wellbeing through exercise, meaningful activity and leisure;</p>	Thank you for your comment. We do have a review question that will be considering the training of health and social care staff. Although we will not be explicitly looking at training for informal carers of people living with dementia within this section, we have included review questions on assessing

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			advocating for themselves and for the person with dementia to access health, social care, family and community support; planning ahead (legal, financial and long term care provision); preparing for end of life and self-care.	the needs of carers of people living with dementia and therefore, if appropriate, the training needs of carers may be included when considering these review questions.
Parkinson's UK	4	1.3	<p>Areas not covered: We urge strongly that information about the pharmacological management of Parkinson's disease dementia is included in the Dementia Guideline as well as the Parkinson's Disease Guideline because of the risk of severe neuroleptic sensitivity reactions, see: <a href="#">J Clin Psychiatry</a>. 2005 May; 66(5):633-7.</p> <p><b>Neuroleptic sensitivity in Parkinson's disease and parkinsonian dementias.</b> <a href="#">Aarsland D<sup>1</sup></a>, <a href="#">Perry R</a>, <a href="#">Larsen JP</a>, <a href="#">McKeith IG</a>, <a href="#">O'Brien JT</a>, <a href="#">Perry EK</a>, <a href="#">Burn D</a>, <a href="#">Ballard CG</a> accessed online at <a href="http://www.ncbi.nlm.nih.gov/pubmed/15889951">http://www.ncbi.nlm.nih.gov/pubmed/15889951</a></p>	Thank you for your comment. The pharmacological management of Parkinson's disease dementia will be included in the Parkinson's disease updated guideline. We will however be able to cross refer to pertinent recommendations. Alongside this the NICE pathway brings together all related NICE guidance and when the dementia guideline is published, the recommendations will be added to a new NICE pathway which will cross refer to the recommendations within the Parkinson's disease guideline.
Parkinson's UK	4	1.3	<p>Areas removed: We are concerned that removing 'Inpatient dementia services' may weaken the guideline as an instrument for achieving high quality dementia services across the whole pathway of care for people with Lewy body dementia. When residential</p>	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.

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			care placements break down because of the hallucinations and delusions that can be a feature of Lewy body dementias, residents are sometimes placed in mental health facilities (including locked wards) which are wholly unsuitable for them. Commissioners need to identify a more suitable range of facilities (including 'step up, step down' beds) which may be missed if the need for more intensive mental health support is not shown as part of the whole dementia pathway, especially for care home residents.	
Parkinson's UK	5	1.4	The guideline should address the variability in access to NHS Continuing Healthcare funding for people with dementia, see Failing to care: All Party Parliamentary Group on Parkinson's, <b>NHS continuing care in England</b> (London, 2013) <a href="http://www.parkinsons.org.uk/sites/default/files/failin_gtocare_appgfullreport.pdf">http://www.parkinsons.org.uk/sites/default/files/failin_gtocare_appgfullreport.pdf</a>	Thank you for your comment. Whilst NICE guidelines do not address funding mechanisms, this update will look at how integrated health and social care should be arranged to optimise the independence of people with dementia and their family members and carers.
Parkinson's UK	6	8	The guideline should include pre-assessment counselling, communication of dementia diagnosis and post-diagnostic support to ensure that people with Parkinson's dementias are supported appropriately, see: Guss R et al, <b>Clinical psychology in the early stage dementia care pathway</b> (British Psychological Society, Leicester,	Thank you for your comment. Our intention is that the guideline will consider post diagnosis support. A number of areas in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia.

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			November 2014), accessed online via <a href="http://www.psige.org/info/home">http://www.psige.org/info/home</a>	The guideline committee will take into consideration the issues you have highlighted when looking at the evidence for this section.
Piramal Imaging	General	General	<p>Page 22 1.4.3.1</p> <p>Diagnostic criteria:</p> <p><i>We feel the current diagnostic criteria should acknowledge the followin bodies, as they provide guidance on the most appropriate use of amyloid PET imaging that may be considered within the scope of mainstream clinical practice within the NHS</i></p> <ul style="list-style-type: none"> <li>• The Society of Nuclear Medicine &amp; Molecular Imaging (SNMMI) and the Alzheimer's Association have jointly developed guidance on the appropriate use of amyloid-PET imaging to avoid overuse in clinical practice <sup>1,2</sup></li> <li>• The European Federation of Neurological Societies (EFNS) have also developed guidelines on the use of neuroimaging in</li> </ul>	Thank you for your comment. We have included two draft review questions to consider the methods used to diagnose dementia and identify dementia sub-types. The guideline committee will consider these imaging techniques when looking at the evidence pertaining to these review questions.

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			<p>the diagnosis of dementia<sup>3</sup></p> <p>1. Johnson KA, Minoshima S, Bohnen NI, et al. Appropriate use criteria for amyloid PET: a report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. <i>J Nucl Med.</i> 2013; 54(3):476-490.</p> <p>2. Johnson KA, Minoshima S, Bohnen NI, et al. Update on Appropriate Use Criteria for Amyloid PET Imaging: Dementia Experts, Mild Cognitive Impairment, and Education. <i>J Nucl Med.</i> 2013; 54(7):1011-1013.</p> <p>3. Filippi M, Agosta F, Barkhof F, et al. EFNS task force: the use of neuroimaging in the diagnosis of dementia. <i>Eur J Neurol.</i> 2012;19(12):e131-140, 1487-1501</p>	
Piramal Imaging	General	General	<p>Page 22 1.4.3.2</p> <p>Structural Imaging:</p> <p><i>We believe amyloid imaging should be included as</i></p>	<p>Thank you for your comment and the references. We have included two draft review questions to consider the methods used to diagnose dementia and identify dementia sub-types. The guideline committee will consider all imaging techniques</p>

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			<p><i>part of the NHS structural imaging review of patients because of the following:</i></p> <p>Beta-amyloid deposition is one of the initial processes in the pathogenesis of Alzheimer's disease and therefore PET imaging with 18F labelled amyloid tracers offers the potential for accurate visualisation of amyloid plaques within the living brain, thereby assisting in the evaluation of Alzheimer's disease dementia and differentiation from other dementia types.</p> <ul style="list-style-type: none"> <li>• Amyloid PET imaging allows earlier diagnosis of Alzheimer disease and better differential diagnosis of dementia (1,2)</li> <li>• The high predictive values of beta-amyloid biomarkers can assist in <u>ruling out</u> cerebral amyloidosis, support timely and accurate diagnosis, improve patient management and may prompt clinicians to consider other causes of cognitive decline and determine appropriate intervention (2-5)</li> </ul>	<p>when looking at the evidence pertaining to these review questions and we can confirm that amyloid imaging has not been excluded from the options to be reviewed.</p>

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			<ul style="list-style-type: none"> <li>• The use of beta-amyloid biomarkers to effectively <u>confirm</u> cerebral amyloidosis can also support timely and accurate diagnosis, improving patient management and may enable appropriate therapies to be administered, while avoiding unnecessary treatments and adverse health outcomes, e.g. loss of functional status (6-10)</li> </ul> <ol style="list-style-type: none"> <li>1. Rowe CC, Villemagne VL. Amyloid imaging with PET in early Alzheimer disease diagnosis. <i>Med Clin North Am.</i> 2013;97(3):377-398</li> <li>2. Sabri O, Sabbagh MN et al. Florbetaben PET imaging to detect amyloid beta plaques in Alzheimer's Disease: Phase 3 study. <i>Alzheimer's &amp; Dementia.</i>2015; pii: S1552-5260(15)00060-6. doi: 10.1016/j.jalz.2015.02.004</li> <li>3. Baskys A, Cheng JX. Pharmacological prevention and treatment of vascular dementia: approaches and perspectives. <i>Exp Gerontol.</i> 2012; 47(11):887-891.</li> <li>4. Mioshi E, Foxe D, Leslie F, et al. The</li> </ol>	

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			<p>impact of dementia severity on caregiver burden in frontotemporal dementia and Alzheimer disease. <i>Alzheimer Dis Assoc Disord.</i> 2013; 27(1):68-73.</p> <p>5. Dines P, Hu W, Sajatovic M. Depression in Later-life: An Overview of Assessment and Management. <i>Psychiatria Danubina.</i> 2014; 26 Suppl 1:78-84.</p> <p>6. Harvard School of Public Health and Alzheimer Europe. <i>Five-country Alzheimer's disease survey: key findings from a five-country survey of public attitudes about Alzheimer's disease:</i> Harvard School of Public Health, Alzheimer Europe,; 2011</p> <p>7.Zwan M, Bouwman F, Van der Flier W, Lammertsma A, Van Berckel B, Scheltens P. Diagnostic value of amyloid imaging in early onset dementia (O4-01-01). <i>Oral Sessions: O4-01: Neuroimaging: Clinical Utility Studies of Imaging.</i> 2014.</p> <p>8.Grundman M, Pontecorvo MJ, Salloway SP, et al. Potential impact of amyloid imaging on diagnosis and intended management in patients with progressive</p>	

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			<p>cognitive decline. <i>Alzheimer Dis Assoc Disord.</i> 2013; 27(1):4-15.</p> <p>9.Laforce R, Jr., Buteau JP, Paquet N, Verret L, Houde M, Bouchard RW. The value of PET in mild cognitive impairment, typical and atypical/unclear dementias: A retrospective memory clinic study. <i>Am J Alzheimers Dis Other Demen.</i> 2010;25(4):324-332</p> <p>10. Gaugler, Characteristics of patients misdiagnosed with AD and their medication use: an analysis of the NACC-UDS database. <i>BMC Geriatrics</i> 2013. 13:137</p>	
Piramal Imaging	General	General	<p>Page 24 1.4.5.2</p> <p>Memory assessment services should offer the full range of diagnostic services.</p> <p><i>We believe amyloid PET imaging should be considered at this stage in the patient assessment because early and accurate clinical diagnosis of degenerative cortical brain disorders is a necessary prerequisite for patient management and care</i></p> <ul style="list-style-type: none"> <li>The use of amyloid PET imaging can</li> </ul>	<p>Thank you for your comment. We have included two draft review questions to consider the methods used to diagnose dementia and identify dementia sub-types. The guideline committee will consider these imaging techniques when looking at the evidence pertaining to these review questions.</p>

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			<p>support the clinician with the evaluation of AD and reduce the potential for misdiagnosis (1-9)</p> <ul style="list-style-type: none"> <li>• The use of amyloid PET imaging can also support differentiation of Alzheimer's disease from other forms of dementia (10)</li> <li>• Appropriate use of amyloid PET imaging has the potential to reduce healthcare, societal costs and provide appropriate medication at the right time (11-13)</li> </ul> <p>1. Schipke CG, Peters O, Heuser I, et al. Impact of beta-amyloid-specific florbetaben PET imaging on confidence in early diagnosis of Alzheimer's disease. <i>Dement Geriatr Cogn Disord.</i> 2012; 33(6):416-422.</p> <p>2. Piramal Imaging. <i>Data on file. A multinational physician survey: Expected Impact of Amyloid <math>\beta</math> Positron Emission Tomography Results on Diagnostic and Treatment Patterns for Suspected Alzheimer's Disease Patients</i> 2013.</p> <p>3. Grundman M, Pontecorvo MJ, Salloway SP, et al. Potential impact of amyloid imaging on diagnosis and intended management in patients</p>	

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			<p>with progressive cognitive decline. <i>Alzheimer Dis Assoc Disord.</i> 2013;27(1):4-15</p> <p>4. Picard C, Pasquier F, Martinaud O, Hannequin D, Godefroy O. Early onset dementia: characteristics in a large cohort from academic memory clinics. <i>Alzheimer Dis Assoc Disord.</i> 2011; 25(3):203-205.</p> <p>5. Kelley BJ, Boeve BF, Josephs KA. Young-onset dementia: demographic and etiologic characteristics of 235 patients. <i>Arch Neurol.</i> 2008; 65(11):1502-1508.</p> <p>6. Dubois B, Feldman HH, Jacova C, et al. Advancing research diagnostic criteria for Alzheimer's disease: the IWG-2 criteria. <i>Lancet Neurol.</i> 2014; 13(6):614-629.</p> <p>7. Jellinger KA. Pathogenesis and treatment of vascular cognitive impairment. <i>Neurodegenerative disease management.</i> 2014;4(6):471-490</p> <p>8. PIRAMAL Imaging. <i>Data on file. Project Number: A-13440-100: Impact of Time to Diagnosis on Healthcare Utilization and Direct Medical Care Costs among Diagnosed Dementia Patients in the United States: A Retrospective Database Study</i></p>	

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			<p>2014.</p> <p>9. Talbot, J. The contribution of single photon emission tomography to the clinical differentiation of degenerative cortical brain disorders. <i>Journal of Neurology</i> 242(9):579-86, 1995</p> <p>10, Villemagne VL, Ong K, Mulligan RS, et al. Amyloid imaging with (18) F-florbetaben in Alzheimer disease and other dementias. <i>J Nucl Med.</i> 2011;52(8):1210-1217</p> <p>11. Getsios D, Blume S, Ishak KJ, Maclaine G, Hernandez L. An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom. <i>Alzheimers Dement.</i> 2012; 8(1):22-30.</p> <p>12. Piramal Imaging. <i>Data on file. Amyloid PET in the early diagnosis of Alzheimer's disease budget impact model technical report</i> 2014.</p> <p>13. Gaugler, Characteristics of patients misdiagnosed with AD and their medication use: an analysis of the NACC-UDS database. <i>BMC Geriatrics</i> 2013. 13:137</p>	

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Public Health England	General	General	The scope misses the opportunity to incorporate much around the <b>community influence</b> and role of wider environmental issues. Housing is mentioned briefly but could be expanded upon, along with private organisations. These wider influences are important as there is also a link to mobility difficulties and falls & fractures associated with dementia. The return on investment component of this could be enhanced by incorporating some of this wider influence. For example, health and social care professionals could inform people about community interventions & housing options, not just advocacy services & voluntary support (see previous guidance 1.1.4.2)	Thank you for your comment. We will give special consideration to people with specific housing and supported living needs, including the need for a living environment adapted for people with cognitive impairment. We will search for appropriate evidence relating to this group when developing this guideline. In addition, we will consider evidence pertaining to dementia friendly living environments within the area of the guideline that looks at interventions to maximise the health and wellbeing of people living with dementia.
Public Health England	General	General	There is no reference to <b>NHS Healthchecks, Dementia Friends, Champions or Dementia Friendly Communities</b> . We feel these should be included as an opportunity to promote the role of raising awareness across the public and within communities (see section 1.3.3.2 of previous guidance)	Thank you for your comment. Our intention is that the needs of people living with dementia and their carers will be taken into consideration at every opportunity. The guideline committee will take into account various sources of support when looking at the evidence for the review questions that consider interventions to maximise the health and wellbeing of people living with dementia and this may include dementia support networks,

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				<p>awareness programmes such as dementia friends and dementia friendly issues.</p> <p>One of the draft review question in the scope will address slowing the progression of dementia. This will directly consider the modifiable risk factors of dementia and at the guideline committee will consider including evidence associated with NHS health checks when considering this question.</p>
Public Health England	General	General	The scope could be strengthened by building on the <b>OECD pathway</b> approach. Splitting of advanced versus early stage dementia would be helpful to understand the different needs across the pathway.	Thank you for your comment. Although we have not directly separated out advanced versus early stage dementia within the scope as detailed in the OECD approach, we have included a direct review question within the scope to incorporate the assessment of needs of people living with dementia. It is anticipated that the evidence will take into consideration the varying needs of people living with dementia and their carers at both early and advanced stages of dementia. Our aim is to ensure that the independence of people living with dementia is maintained throughout all stages of the dementia pathway.
Public Health England	2	1.3 Bullet 1	<b>Training &amp; education of professionals</b> other than just health and social care staff is important. It would be good to include a reference to Dementia	Thank you for your comment. One of our draft review questions will consider the models of training for health and social care, in line with the

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			Friends within this as a mechanism for general awareness raising. From pg 10 of previous guidance, we suggest complementing 'all staff working with older people to be given dementia-care training' to include 'all staff to receive basic awareness training (e.g. dementia Friends)	remit of the guideline. It is anticipated that this will include training for both carers of people living with dementia and staff involved in the care of older people. We will draw upon a broad range of evidence when considering this review question which may include reference to sources of information and support and dementia awareness networks such as Dementia Friends.
Public Health England	2	1.1	The audience for the document could also include <b>employers</b> . We feel this audience should be included as support for carers and those with dementia will help keep people in the workplace for longer. It could also include those at risk of getting dementia which is important for supporting the prevention & early intervention agenda.	Thank you for your comment. NICE Guidelines are generally for the NHS, local authorities and local and national organisations in the private and voluntary sectors. The guideline will be applicable to all people using the NHS and social care services, their families and carers and the public.
Public Health England	3	1.2	Wider settings where NHS care is provided have not been explicitly mentioned within the scope and this is a missed opportunity. <b>Prisons</b> for example are comprised of large volumes of people with high risk profiles for dementia. We also know that there is an ageing population across prisons. We would like to see this specific target group mentioned as part of addressing the inequalities agenda.	Thank you for your comment. The guideline will comprise all settings and this will be inclusive of people living with dementia in prisons.
Public Health England	2	1.1	We know that there are differences in dementia prevalence across males & females, and also	Thank you for your comment. Although we have not explicitly referenced gender within the scope,

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			<p>differences in terms of the issues affecting 'living well'.</p> <p><b>Gender</b> does not come through as a major theme of this scope and we feel it could be enhanced. People with sensory impairment should be another group given special consideration to.</p>	<p>sex and gender differences are protected equality characteristics described within our <a href="#">equality impact assessment</a> and this ensures that we will be mindful of these issues.</p> <p>We have now highlighted people with sensory impairment as a group requiring special consideration throughout the course of guideline development.</p>
Public Health England	4	Final point (2)	<p><b>Learning disabilities</b> will be covered in separate MH guidance. We feel that this scope should reference/ signpost to this guidance. We know that LD is a major risk factor for dementia.</p>	<p>Thank you for your comment. People with learning disabilities will now be included within the dementia guideline update. Where appropriate, we also intend to cross-refer to relevant recommendations for people with learning disabilities within the clinical guideline on mental health and learning disabilities.</p>
Public Health England	3	1.3 Bullets 2&3	<p><b>Mid-life approaches</b> have not been highlighted within the document. We feel it is important to strengthen the messages around mid-life as the evidence tells us that this is the most effective time to intervene.</p>	<p>Thank you for your comment. The guideline committee will take into consideration mid-life approaches when looking at the modifiable risk factors of dementia as part of the proposed review question associated with slowing the progression of dementia.</p>
Public Health England	General	General	<p>Inclusion of data and <b>evidence facts and figures on high risk groups</b> would strengthen the scope, and support the inequalities agenda</p>	<p>Thank you for your comment. The guideline will predominantly address the needs of people living with dementia, rather than those at risk of</p>

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				developing dementia. However, a number of draft review questions will consider people at high risk of developing dementia. This includes review questions addressing comorbidities and mulimorbidities, such as assessments for sudden deterioration of functioning; and slowing the progression of dementia, which will directly consider modifying cardiovascular risk factors. In addition, special consideration will be given to certain high risk groups (including people with learning disabilities and people with other comorbidities or conditions that may affect the treatment of dementia) and evidence directly pertaining to these groups will be sought.
Public Health England	General	General	It is good to see that <b>carers</b> play a key role across the document, but we feel that a more proactive approach could be given. We would like to see a shift towards preventing crisis & psychological distress by ensuring that carers have personalised health and wellbeing support plans that are built into the process right from the outset, and reviewed as they participate across the dementia pathway. To include a physical activity & nutrition plan etc (see 1.11.2 of previous guidance)	Thank you for your comment. We have included draft review questions which will directly consider the assessment of needs of carers and interventions to support carers of people living with dementia.
Public Health England	4	General	We would like to see the <b>End of Life Care</b>	Thank you for your comment. We have not

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			component being brought back in scope for the review. This has become a national priority and is a critical part of the pathway. We would like to see the role of carers within EoLC strengthened as per point 10, and also ensure that patient choice is factored in to this, building on post diagnosis care plans.	prioritised end of life care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
Public Health England	3	1.3 Bullet 1	We would like to see more emphasis on the <b>risk reduction &amp; promotion of healthy living</b> . Suggest that all care plans should include a review of healthy lifestyles and capture preferences around diet, physical activity, social preferences & cognitive stimulation (see 1.4.1.1 & 1.1.1.5 of previous guidance). All training and development modules could include risk reduction messages, both in terms of prevention and in delaying progression and living well for longer (see 1.1.1.9 of previous guidance). Other risk factors should be highlighted including depression, social isolation and loneliness (see 1.3.1.2 of previous guidance)	Thank you for your comment. The guideline will focus on the needs of people living with dementia and will incorporate recognition and risk factors of dementia as well as giving consideration to slowing the progression of dementia. We will draw upon a broad evidence base when looking at these issues and it is likely that this will include lifestyle issues and modifiable risk factors.
Public Health England	3	1.3 5	We would like to see carers and families receive written information about the impact of lifestyles factors on managing the progression of dementia, along with information on housing options & considerations (see 1.4.6.2 of previous guidance).	Thank you for your comment. It is likely we will consider the various support needs and provision of information for both people living with dementia and their carers to assist with managing the progression of dementia. Our aim is to ensure that

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			<b>Care plan advice</b> could also include advice on maintaining a familiar, safe and dementia friendly environment in terms of housing along with diet & nutrition advice to complement the physical activity assessment (see 1.5.1.1 of previous guidance)	the independence of people living with dementia is maintained throughout all stages of the dementia pathway and a draft review questions will directly address the assessment of needs of people living with dementia .
Public Health England	General	General	As good practice we would like to see all people with dementia & carers offered the opportunity to volunteer for <b>research participation</b> . We feel this could provide a rich source of information to feed into policy development and practice.	Thank you for your comment. We have not directly prioritised volunteering for research for inclusion in the scope of the guideline. However, during guideline development the committee has the option to make recommendations for research and this process is likely to increase opportunities for people with dementia and their carers to participate in appropriate research.
Public Health England	General	General	Prevention messages could be improved by shifting more towards <b>positive and proactive messaging</b> (e.g. physical activity & healthy diet) rather than condition focused (e.g. obesity). This is the approach we take across PHE based on our behavioural insights advice. There is evidence that this is more likely to drive behaviour change of an individual, rather than focussing on a medical	Thank you for your comment. We will be mindful of the language used to ensure the issues are addressed in a positive and proactive manner. We have now modified the language and structure of the scope to ensure the focus of the scope more prominently addresses the health and well-being of people living with dementia.

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			model to 'treat' a risk factor. (see 1.3.2.2 of previous guidance)	
Public Health England	General	General	It is important that we capture <b>robust data</b> for dementia & if this scope could provide any lever for ensuring that diagnosis is electronically recorded including for sub types that would be very welcomed (see section 1.4.3 of previous guidance)	Thank you for your comment. We will draw upon a broad evidence base while developing the guideline to ensure we capture robust data. We have draft review questions that consider the methods used to diagnose dementia and identify dementia sub-types.
Public Health England	4	1.3 1	We would like to see more emphasis on <b>co-morbid conditions</b> within the scope. For example, non-cognitive symptoms & behaviour assessments should also take into account co-morbid conditions (see section 1.7.1.1 of previous guidance)	Thank you for your comment. Our intention is that the guideline will address the management of co-morbidities and inter-current illnesses within the context of people living with dementia.
Public Health England	3	1.3 5	Suggest changing title to 'Living with dementia'.	Thank you for your comment. We have amended the guideline title so that it now reads: "Dementia: assessment, management and support for people living with dementia and their carers".
Research Institute for the Care of Older People	1	General	<b>Overall comment.</b> In general terms, this scoping document does not frame work with people affected by dementia as being underpinned by person centred principles (in this regard it is somewhat anachronistic as the previous guidance made this explicit). Person centred care within the 2006/7 guideline was defined as promoting:- <ul style="list-style-type: none"> <li>The human value of people with dementia,</li> </ul>	Thank you for your comment. We have amended the language and structure of the scope in light of stakeholder comments to focus on supporting people with dementia and their carers to maximise their health and wellbeing. In addition we have highlighted the importance of environments sensitive to cognitive impairment as an area requiring special consideration within the scope.

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			<p>regardless of age or cognitive impairment, and those who care for them;</p> <ul style="list-style-type: none"> <li>• The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia;</li> <li>• The importance of the perspective of the person with dementia;</li> <li>• The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.</li> </ul> <p>In particular the scoping document continues the tendency to represent the behaviour of people affected by dementia as a series of symptoms, which need to be managed (p 6-7), rather than viewing behaviour as a communication (for instance of distress) and framing this within a context of dependency on others. If it is not made explicit that people living with dementia have full rights of citizenship, then the risk of poor practice is heightened. We would therefore suggest the phrase "Managing Dementia" is replaced with "Responding to challenges of distressed behaviour". Similarly, responses to the impact of</p>	

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			dementia do not split neatly into cognitive, emotional, behavioural and functional sections.	
Research Institute for the Care of Older People	2	25	“People with mild cognitive impairment who are not suspected of having dementia”. To include groups that have suspected dementia and then to exclude people with MCI who are not suspected of having dementia will cause further confusion as to what should be done with people who fall between the cracks because of uncertainty over diagnosis. Increasingly services are not using the label MCI or are using it in an inconsistent way. It would be safer and more appropriate just to include people who have dementia or suspected dementia – rather than to specifically exclude those with MCI.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Research Institute for the Care of Older People	6	General	The process of diagnosing dementia is much more than just the technical issues about what tests to use. The use of even the most evidenced based tests, if delivered in an insensitive way, will not produce results of meaning, and may jeopardise future care by compromising the clinician-patient relationship. The diagnosis of dementia is life-changing and devastating. The way diagnosis is delivered is also likely to have an impact on how people adjust. The process by which the diagnosis is conveyed should be covered in the guidance.	Thank you for your comment. Our intention is that the guideline will consider issues of support post diagnosis. Many areas covered in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia. We have included a review question to address the training of health and social care staff and it is likely that the issue of how information is delivered may be considered within this review question.

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			Similarly, there should be guidance on post-diagnostic support and interventions tailored to individuals	
Research Institute for the Care of Older People	6 -7	General	There is a disconnect in the guidance about talking about supporting people to exercise choice and control and then in this section a rather objectifying stance on "managing" the dementia features as if they are somehow separate from the person. It would be better to have a section on helping people manage common symptoms and problems or adjust to the changes that dementia brings. We need to understand the impact of the dementia syndrome on the individual's health and well-being over time in the context of their family, their community and the health and social care interventions they receive.	Thank you for your comment. We have amended this section of the scope to more prominently address the health and wellbeing of people living with dementia.
Rotherham Doncaster and South Humber NHSFT	General	General	Agreed with the proposed scope of this guidance. Regarding questions proposed in draft, we have a member of staff attending the workshop who will provide our contribution there.	Thank you for your comment.
Royal College of General Practitioners	4	1.3	On page 4 of the draft scope, there is a section about areas from the published guideline that will be removed  <b>Areas from the published guideline that will be</b>	Thank you for your comment. People with learning disabilities will now be included within the guideline update. We have also included a review question focusing on inpatient services.

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			<p><i>removed</i></p> <p>1 Inpatient dementia services.</p> <p>2 Assessing and managing dementia for people who have learning disabilities. (N.B. It is proposed that this is covered by the guideline on mental health problems and learning disabilities currently in development.)</p> <p>The NICE mental health for people with LD final scope was published in October 2014  <a href="https://www.nice.org.uk/guidance/gid-cgwave0684/resources/mental-health-problems-in-people-with-learning-disabilities-final-scope2">https://www.nice.org.uk/guidance/gid-cgwave0684/resources/mental-health-problems-in-people-with-learning-disabilities-final-scope2</a></p> <p>It does not specifically address the issues of dementia in people with learning disabilities so this area needs to be included in the Dementia Update. Currently all people with learning disabilities with dementia receive care from their GP with relatively small numbers having additional specialist services. A considerable percentage of patients with dementia and learning disabilities will be taking drugs for long term conditions started in secondary</p>	

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			care such as epilepsy and behaviours that challenge that need adjustment or stopping in dementia. The care of people with Downs Syndrome needs specifically addressing including screening, care planning, recognition of trajectories and early signs such as myoclonic jerks and end of life care. This will ensure care in their homes and avoiding unnecessary unplanned admissions to acute hospitals in the final year of life.	
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals to update the Dementia guideline. It is timely.	Thank you for your comment.
Royal College of Nursing	General	General	The RCN invited staff and RCN members who work with and care for older people and people with dementia to review the draft scope on its behalf. The comments below reflect the views of our staff and members.	Thank you for your comment.
Royal College of Nursing	General	General	On the whole the document covers a broad aspect of issues relating to dementia.	Thank you for your comment.
Royal College of Nursing	General	General	There appears to be no direct references in the draft scope to the sexual or spiritual needs of the person with dementia. This is important to the mental wellbeing of the person and we consider that they should be included in the scope of the guideline.	Thank you for your comment. The guideline will look at assessment of needs of people with dementia and interventions to promote the health and wellbeing of people with dementia. Where appropriate this will include sexual and spiritual needs.

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Royal College of Nursing	2	1.1	<p><i>Groups that will not be covered:</i> Mild cognitive impairment as a diagnosis which is often misunderstood by both healthcare staff, patients and relatives.</p> <p>We accept that the guideline does not intend to fully explore the diagnosis of mild cognitive impairment, however, our members believe that it would be advantageous to add a brief explanation of the diagnosis and the possibility of progression toward dementia. This would fit with being able to recognise presentations of dementia early and seeking help and support in a timely fashion.</p>	<p>Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.</p> <p>However we have a question on risk factors for dementia and one would expect mild cognitive impairment to be an important consideration in this question.</p>
Royal College of Nursing	2	1.1	<p>The guidelines intend to consider people with all types of dementia and would not differentiate by sub group.</p> <p>Whilst this is reasonable, it would be useful to separate out working age dementia from older age dementia as the health needs are very different for this group.</p>	<p>Thank you for your comment. We have highlighted people with early on-set dementia (aged 40-64 years) as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.</p>
Royal College of Nursing	4	1.3	<p><i>Areas not in the published guideline that will be included in the update:</i></p> <p>Our members consider that emphasis should be</p>	<p>Thank you for your comment. We have amended the scope to incorporate this distinction.</p>

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			<p>placed not only on acute presentation masking dementia but also that acute presentation is often worse in a patient who already has a diagnosis of dementia.</p> <p>In the case of delirium identifying acute changes as soon as is possible can reduce the possibility of hospitalisation, physical decline and mortality.</p>	
Royal College of Nursing	5	1.4	It is important to capture non-health effects and to be mindful that using economic benefits such as ability to work may not be appropriate for this group but the impact on their family members and informal carers is important and should be taken into consideration.	<p>Thank you for your comment. In the <a href="#">NICE guidelines manual</a>, the reference case sets out when non-health benefits and benefits to carers will be considered.</p> <p>The NICE reference case to be used for questions in this guideline will be agreed with the GDG and NICE quality assurance staff.</p>
Royal College of Nursing	5	1.5 Point1	The question around decision making and consent, is largely answered in the Mental Capacity Act Guidance and reference should be made to the Act or the question rephrased.	Thank you for your comment. We have amended this question within the scope.
Royal College of Nursing	5	1.5 Point1	Ethical issues perhaps should include a section on vulnerability and safeguarding issues and Deprivation of Liberty Safeguards (DoLS). If this is not a full section then perhaps signposting to additional policy or information should be considered.	Thank you for your comment. We have since amended this question, to address the issues of when a diagnosis of dementia is made, what interventions are most effective in enabling people living with dementia to anticipate and plan for their future needs? The guideline committee may

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				consider these issues around deprivation of liberty safeguards when looking at the evidence for this section...
Royal College of Nursing	5	1.5 Point1	Also in relation to consent to finance and health issues reference to power of attorney (POA) and enduring POA would be helpful in long term decision making and for family and carers to understand when they become active. This may be a position that should be linked in with advanced care planning.	Thank you for your comment. We have since amended this question to address the issues of when a diagnosis of dementia is made, what interventions are most effective in enabling people living with dementia to anticipate and plan for their future needs? The guideline committee may consider the issues relating to power of attorney when looking at the evidence for this section.
Royal College of Nursing	7	1.5	It is important to assess the needs of carers, but it is also important to recognise the diverse group of people who care for people with dementia and that many do not see themselves as carers (even if they do provide a significant amount of care).	Thank you for your comment. Our intention is to consider both formal and informal carers of people living with dementia within the guideline update and this will also include the family members of people living with dementia.
Royal College of Nursing	8	1.6	When considering outcomes, special consideration needs to be given to dignity and quality of life versus safety. Too often, safety is seen as the main priority in institutional settings, and more guidance is needed for staff on how to balance these two important outcomes. Outcomes which are easy to measure (falls, mortality) are not necessarily the most important for people with dementia. Staff often follow highly restrictive practices to keep	Thank you for your comment we have now amended the section of the scope to reflect a broad range of outcomes.

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			people with dementia safe, but in so doing restrict the person with dementia's choices, dignity and quality of life.	
Royal College of Nursing	8	1.6	When reviewing the evidence, context in which the research was conducted is highly important and interventions which work in one setting, may not be effective in another.	Thank you for your comment. The guideline committee may choose to consider to sub-analyse the evidence relating to this section within this manner, if they think it is appropriate.
Royal College of Nursing	General	General	We note that the guideline development committee includes two mental health nurses, but no adult nurses. Given the high physical health needs of people with dementia, adult nurses are important to have on the committee.	Thank you for your comment. Although we do not currently have adult nurse representation on the guideline committee, if the committee believe that there is a need to seek expert opinion then they may decide to appoint a topic expert to inform decision making.
Royal College of Pathologists & British Neuropathological Society	General	General	The role of the neuropathologist is central to the understanding and management of patients with dementia. For this reason we feel it is essential that there is Neuropathologist representation on this project. We have identified specific points of note in the following comments, noted by your bullet point number, rather than line.	Thank you for your comment. Although we do not currently have neuropathology representation on the guideline committee, if the committee believe that there is a need to seek expert opinion, then they may decide to appoint a topic expert to inform decision making.
Royal College of Pathologists & British Neuropathological Society	3	1.3 Point2	Neuropathologists play a key role in the study of brains of patients with dementia and play a significant part in working with others to identify risk factors, in research	Thank you for your comment. Although we do not currently have neuropathology representation on the guideline committee, if the committee believe that there is a need to seek expert opinion then

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				they are able to appoint a topic expert to inform decision making.
Royal College of Pathologists & British Neuropathological Society	3	1.3 Point4	The accurate diagnosis and subtyping of dementia requires an expert neuropathological opinion. There is a host of evidence over the last 5 years that illustrates how the clinical diagnosis alone does not predict underlying pathology – and pathology is key to understanding biological processes, hence treatment. We play the definitive role in specialist dementia assessment.	Thank you for your comment. Although we do not currently have neuropathology representation on the guideline committee, if the committee believe that there is a need to seek expert opinion then they are able to appoint a topic expert to inform decision making.
Royal College of Pathologists & British Neuropathological Society	4	1.3 Point6	The dementia assessment described above includes analysis of heritability – which links directly into the assessment of needs for family members.	Thank you for your comment.
Royal College of Pathologists & British Neuropathological Society	4	1.3	Comorbidities; The extent of most of these comorbidities are most accurately assessed at post-mortem examination.	Thank you for your comment.
Royal College of Pathologists & British Neuropathological Society	4 5	1.3	Not updated point 2: The essential role of brain donation, to brain banks for detailed neuropathological study cannot be overemphasized if we are to fully understand the biology underlying dementia subtypes, in order to develop treatment.	Thank you for your comment.
Royal College of Pathologists & British Neuropathological Society	6	1.5 Point5	Diagnostic accuracy relies on detailed neuropathological assessment.	Thank you for your comment

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Royal College of Pathologists & British Neuropathological Society	6	1.5 Point8	This requires direct neuropathological contribution	Thank you for your comment. Although we do not currently have neuropathology representation on the guideline committee, if the committee believe that there is a need to seek expert opinion, then they may decide to appoint a topic expert to inform decision making.
Royal College of Pathologists & British Neuropathological Society	6	1.5 Point11	Infection risk in the case of transmissible spongiform encephalopathies is managed at post mortem by neuropathologists in order to reach a diagnosis.	Thank you for your comment.
Royal College of Pathologists & British Neuropathological Society	8	1.6 Point4	This should be linked with neuropathological findings.	Thank you for your comment. Although we do not currently have neuropathology representation on the guideline committee, if the committee believe that there is a need to seek expert opinion, then they may decide to appoint a topic expert to inform decision making
Royal College of Speech and Language Therapists	General	General	The RCSLT is very concerned at the lack of focus on language and communication abilities. The RCSLT strongly recommends that prominence is given to language and communication as a matter of priority.  Communication problems occur in all forms of dementia and in the later stages these become more challenging.	Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration and will search for appropriate evidence to support development of the guideline. We are seeking a speech and language therapist to join the committee as a full member to assist with the issues raised in your own and other comments.

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8<sup>th</sup> July – 5<sup>th</sup> August 2015

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Stakeholder	Page	Section / Line	Comments	Developer's response
			<p>The importance of communication is recognised:</p> <ul style="list-style-type: none"> <li>• The Alzheimer's Society found that 'the ability to communicate' is one of 10 key indicators of quality of life valued by people with dementia.</li> <li>• Care staff view communication problems as one of the greatest challenges in delivering good dementia care.</li> <li>• Communication difficulty is described as one of the most frequent and hardest to cope with experiences for the family and carers.</li> <li>• NICE says that people with speech problems must be able to participate as fully as possible in care.</li> </ul>	
Royal College of Speech and Language Therapists	General	General	<p>The RCSLT is disappointed at the lack of focus on eating, drinking and swallowing (dysphagia) and recommend that this is added to the key areas to be covered. These are integral to future decision making and should be addressed.</p> <p>Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, affecting most people during the course of the</p>	Thank you for your comment. We have highlighted people with dysphagia as a group requiring special consideration and will search for appropriate evidence to support development of the guideline.

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			<p>disease. Approximately 68% of older people with dementia in care homes have dysphagia. Studies show that over 29% of people with dementia have aspiration, with bronchopneumonia being a leading cause of death. If a person is having difficulty with swallowing, a referral to a speech and language therapist is crucial to support them to eat and drink safely and to prevent malnutrition, dehydration, aspiration, pneumonia, nutritional compromise and in some instances death from malnutrition, choking and aspiration.</p> <p>People with dementia, with dysphagia, are often admitted to hospital when they reach the stage of severe malnutrition or dehydration or aspiration – timely intervention can prevent this. Data suggests that up to 19% of hospital admission of people with dementia may be prevented by contributions from a speech and language therapist at an earlier point (Inpatient Hospital Episode Statistics, Health &amp; Social Care Information Centre, Public Health England, 2015).</p> <p>The importance of managing eating, drinking and swallowing needs is recognised:</p>	

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			<ul style="list-style-type: none"> <li>▪ NICE (2006) stated that the need to assess and manage eating and swallowing difficulties and identify potential aspiration is important particularly in those with more advanced dementia.</li> <li>▪ Royal College of Physicians state that multidisciplinary team working is essential in managing people with oral feeding difficulties and SLTs are key team members of the team</li> <li>▪ Royal College of Physicians state that multidisciplinary consideration of eating, drinking and swallowing needs is an integral part of a comprehensive life approach</li> </ul>	
Royal College of Speech and Language Therapists	2	1.1	<p>It is important that the guideline focuses on people who are at risk of social exclusion.</p> <p>When considering people who are at risk of social exclusion it is important to remember that there is a group of people with specific communication difficulties, where language is the domain most affected. These people are vulnerable to social exclusion and warrant specific service provision.</p> <p>People with language /communication problems struggle to integrate into communities as their</p>	Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration at risk of social exclusion or isolation and we will search for appropriate evidence pertaining to this group.

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			difficulties make it more difficult to undertake every day activities that we take for granted for example eating out in restaurants, going on holiday, interacting with the family and taking part in hobbies. People with communication problems may be at risk of isolation and social exclusion and if this is not managed, then depression.	
Royal College of Speech and Language Therapists	2	1.1	The RCSLT is very concerned that people with mild cognitive impairment will not be covered. If somebody has a diagnosis of cognitive impairment/age-related memory problem/or dementia this guidance would be appropriate. About 50% of people with Mild Cognitive Impairment (MCI) will go on to develop dementia. When services are cut it is easier to raise the bar and stop seeing people with MCI, despite there being strong evidence for intervention for people with MCI.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Royal College of Speech and Language Therapists	2	1.1	The RCSLT is concerned with the use of the term "mild" and how this will be defined. Does this mean that people with moderate or severe cognitive impairment will be included in the guideline? In the very early stages it is difficult to distinguish between MCI and dementia. Failure to have a consistent approach will result in equity to services	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have

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			and support across the country.	dementia.
Royal College of Speech and Language Therapists	2	1.1	If NICE concludes that people with MCI will not be included, then we strongly recommend that this is cross referenced and a guideline is developed for MCI as MCI must be recognised.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Royal College of Speech and Language Therapists	3	1.2	The RCSLT suggests that the guidance should apply to any service for people with dementia (even when privately funded or funded by third sector be). Much care is funded by a local authority and this statement gives the impression that such services are exempted. Furthermore, NHS or joint commissioning funds a large proportion of third sector care, however it is uncertain if the guideline covers services offered by the third sector.	Thank you for your comment. We have amended this section of the scope to cover all settings.
Royal College of Speech and Language Therapists	3	1.3	The RCSLT recommends cross-referencing with the guidelines for inpatient care.	Thank you for your comment. The scope document only allows reference to guidelines that are currently in development. The guideline committee may decide to cross-refer to these guidelines while writing recommendations.
Royal College of Speech and Language Therapists	3	1.3	RCSLT supports updating the sections on "supporting people to exercise choice" and "training	Thank you for your comment.

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		Point1	<p>of health and social care staff".</p> <p>There is a lot of evidence that attending to communication difficulties improves well-being and reduces challenging behaviour. Staff who are trained to recognise how people in their care communicate distress, pain and anxiety through their behaviour (verbal and non-verbal) are better equipped to respond to that individual.</p> <p>People with limited communication/language problems can make decisions on care, treatment and support with the right communication support. Speech and language therapists are qualified to assess an individual's ability to understand and then communicate that understanding for the purposes of establishing mental capacity for decision-making. This is essential to ensure that individuals can exercise control and ensure that consent is obtained. This is especially pertinent for decision making as the dementia advances and language becomes much more challenged and for making end of life decisions.</p>	
Royal College of Speech and Language Therapists	3	1.3	RCSLT welcomes the focus on diagnosing different dementias. It has long been recognised that	Thank you for your comment. We are currently seeking representation of a speech and language

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		Point4	different causes of dementia lead to different patterns of cognitive decline. Speech and language therapy input is crucial to support the accurate identification and diagnosis of dementia. This is especially important to determine the language/communication impairment that the person will have and to determine the pattern of impairment and decline. Correctly identifying this and providing strategies to support communication will enable the individual and their family / carer to be able to communicate for longer and slow the deterioration in abilities. Detailed language profiling is particularly important in assessing frontotemporal dementia and progressive aphasia. Speech and language therapists are also able to monitor the course of dementia including changes to language skills and communication as a result of the pharmacological intervention.	therapist to join the guideline committee.
Royal College of Speech and Language Therapists	3	1.3 Point4	The RCSLT recommends a broad approach to "risk management". Those with communication difficulties are particularly vulnerable to abuse or neglect and are least able to report it. Communication skills are vital for independence and input can maximise communication skills and independence for longer.	Thank you for your comment. We have now amended the scope to highlight that people with communication difficulties and people with difficulties eating, drinking or swallowing are a group requiring consideration throughout the guideline. The guideline committee will consider

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			<p>People with dementia are at risk of being unable to communicate that they are hungry or thirsty resulting in dehydration and malnutrition and possible subsequent hospital admission. Weight loss can be common in people with dementia, caused by a lack of appetite, problems with communicating they are hungry or disliking the food that they are given, being unable to communicate that they are in pain, poor co-ordination and difficulties with chewing and swallowing.</p> <p>Will the risk management include contingency feeding (risk feeding) where aspiration is an acknowledged risk?</p>	these issues when looking at the evidence.
Royal College of Speech and Language Therapists	3	1.3 Point5	<p>The RCSLT is concerned that a greater focus is not given to communication abilities. We recommend that communication is added to the features to manage in dementia. Communication problems occur in all forms of dementia and in the later stages these become more challenging. Communication difficulty is described as one of the most frequent and hardest to cope with experiences for the family and careers. The</p>	Thank you for your comment. We have now highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.

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			Alzheimer's Society found that 'the ability to communicate' is one of 10 key indicators of quality of life valued by people with dementia" (Alzheimer's Society 2014). Communication difficulty affects the individual's identity and relationships.	
Royal College of Speech and Language Therapists	3	1.3 Point5	The RCSLT recommends that eating, drinking and swallowing (dysphagia) is added to the features to manage.  Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, particularly in the later stages. Approximately 68% of older people with dementia in care homes have dysphagia. The need to assess and manage eating, drinking and swallowing difficulties is important. Failure to manage dysphagia results in an increased risk of aspiration, pneumonia, nutritional compromise and in some instances death from malnutrition, choking and aspiration.	Thank you for your comment. We have now highlighted people with dysphagia as a group requiring special consideration and we will therefore search for appropriate evidence pertaining to this group.
Royal College of Speech and Language Therapists	3	1.3 Point5	The RCSLT recommends defining the features to manage more clearly. Different professions may view "cognitive" and "behaviour" differently.	Thank you for your comment. We have amended this section of the scope.
Royal College of Speech and Language Therapists	3	1.3 Point6	The support for family members and carers needs to distinguish between family and professional carers as their cultures and needs are different.	Thank you for your comment. We will look at both formal and informal carers in addressing this question.

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Royal College of Speech and Language Therapists	4	1.3	<u>Areas that will not be updated</u> We are concerned that palliative care and pain relief will not be updated. There has been significant change in understanding of best practice associated with palliative care and pain relief. These are important areas and cause much distress to family members as well as individuals themselves.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
Royal College of Speech and Language Therapists	4	1.3	<u>Areas that will be removed</u> We disagree that people with learning disabilities who have dementia will be removed. People with LD are likely to acquire dementia earlier than normal population.  Furthermore we are not sure that managing dementia for people with learning disability should be added to the guideline on mental health (unless it has a very clear focus on LD).	Thank you for your comment. People with learning disabilities will now be included within the guideline update.
Royal College of Speech and Language Therapists	5	1.5	As stated in section 1.3 the guideline is lacking focus on language and communication. The RCSLT strongly recommends that prominence is given to language and communication as a matter of priority. All the key issues identified in section 1.5 will depend on the communication ability of the individual. Communication underpins how good	Thank you for your comment. We have now highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.

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			<p>dementia care is delivered.</p> <p>The importance of communication is recognised:</p> <ul style="list-style-type: none"> <li>• The Alzheimer's Society found that 'the ability to communicate' is one of 10 key indicators of quality of life valued by people with dementia.</li> <li>• Care staff view communication problems as one of the greatest challenges in delivering good dementia care.</li> <li>• NICE says that people with speech problems must be able to participate as fully as possible in care.</li> </ul>	
Royal College of Speech and Language Therapists	5	1.5	<p><b>Language should be included as a category with the question:</b> <u>What pharmacological or non-pharmacological interventions are available for managing language and communication in dementia?</u></p>	Thank you for your comment. We have now highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
Royal College of Speech and Language Therapists	5	1.5	<p>As stated above the RCSLT recommends that eating, drinking and swallowing (dysphagia) is added to the key areas to be covered.</p> <p>Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, affecting most people during the course of the</p>	Thank you for your comment. We have now highlighted people with dysphagia as a group requiring special consideration and we will therefore search for appropriate evidence pertaining to this group.

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			disease. Approximately 68% of older people with dementia in care homes have dysphagia. If a person is having difficulty with swallowing a referral to a speech and language therapist is crucial to support them to eat and drink safely and to prevent malnutrition, dehydration, aspiration, pneumonia, nutritional compromise and in some instances death from malnutrition, choking and aspiration.	
Royal College of Speech and Language Therapists	5	1.5 Point1-2	<p>1.5.1 and 1.5.2 are very pertinent around how someone can exercise choice and give consent and the communication support needed to enable them to do this. The code of practice for the implementation of the Mental Capacity Act in England recommends seeking the professional opinion of a speech and language therapist.</p> <p>This area might benefit from specific questions around:</p> <ul style="list-style-type: none"> <li>• How can people with dementia be appropriately supported in their communication to ensure they are able to access medical, financial and welfare related decision-making if they are still able to?</li> <li>• How can people with dementia access the</li> </ul>	Thank you for your comment. We have amended this section within the scope. We have taken on board stakeholder feedback and sought to recruit a speech and language therapist as part of the guideline committee to ensure that these issues are included within the final guideline.

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			expertise to ensure an accessible assessment of their decision-making capacity (including a speech and language therapist)?	
Royal College of Speech and Language Therapists	5	1.5 Point1	<p><u>Consent</u> People with limited communication/language problems can make decisions on care, treatment and support with the right communication support. Speech and language therapists assess individual's capacity to consent to treatment and care. This is essential to ensure that individual can exercise control and ensure that consent is obtained.</p> <p>It is pertinent to ask follow-up questions if consent was not given:</p> <ul style="list-style-type: none"> <li>• What attempts were made to ascertain the communication abilities of the individual?</li> <li>• What support with communication was the individual given?</li> </ul>	Thank you for your comment. This question will address the issues of when a diagnosis of dementia is made, what interventions are most effective in enabling people living with dementia to anticipate and plan for their future needs? The guideline committee may consider the issues relating to communication abilities when looking at the evidence for this section. Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence.
Royal College of Speech and Language Therapists	5	1.5 Point2	<p><u>Choice &amp; Advanced decision making</u></p> <p>NICE QS clearly states that people with speech problems must be able to participate as fully as possible in care.</p>	Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.

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			<p>People with limited communication/language problems can make decisions on care, treatment and support with the right communication support. Speech and language therapists are qualified to assess an individual's ability to understand and then communicate that understanding for the purposes of establishing mental capacity for decision-making. This is essential to ensure that an individual can exercise choice. This is especially pertinent for decision making as the dementia advances and language becomes much more challenged and for making end of life decisions.</p> <p>Accurate capacity assessments are important for people who are deemed unsafe for oral intake. If the patient does not have capacity then a best interest MDT discussion should be held. Next of kin should be provided with the sufficient information prior to making a decision for the patient to feed with acknowledged risk of developing aspiration pneumonia. In this way patient choice is enabled.</p> <p>This is highlighted in the following:</p> <ul style="list-style-type: none"> <li>▪ NICE guidelines: QS1 (2006) decision making</li> </ul>	

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			<p>around feeding should be made taking into account a patients individual beliefs, preferences, needs and best interests.</p> <ul style="list-style-type: none"> <li>▪ GMC (2000) Withholding and withdrawing life prolonging treatments – good practice in decision-making</li> <li>▪ RCP (2010) Guidelines on oral feeding difficulties and dilemmas.</li> </ul>	
Royal College of Speech and Language Therapists	6	1.5 Point9	Differential diagnosis of dementia The RCSLT recommends adding the importance of specific assessments to differentially diagnosing between language variants to ensure appropriate treatment of pathology.	Thank you for your comment. The guideline committee will take into consideration this differentiation when looking at the evidence for this section.
Royal College of Speech and Language Therapists	6	1.5 Point11	As stated above we recommend a broad approach to risk management.	Thank you for your comment. We have now amended this question in the scope.
Royal College of Speech and Language Therapists	7	1.5 Point16	Carer support is especially important at times of crisis for example when the carer has to suddenly go into hospital or is ill and we hope that this will be taken into account.	Thank you for your comment. We will be considering interventions to maximise the health and wellbeing of family members and carers of people living with dementia within the guideline and it is likely that this will consider interventions pertinent to carer support.
Royal College of Speech and Language Therapists	7	1.5 Point12	Furthermore, if language is an outcome then this should be included above as a category with the question: "What pharmacological or non-pharmacological	Thank you for your comment. We have highlighted people with language and communication difficulties as a group requiring special consideration and we will therefore search for

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			interventions are available for managing language and communication in dementia?"	appropriate evidence pertaining to this group.
Royal College of Speech and Language Therapists	7	1.5 Point17	We recommend adding the following question: What therapeutic options are available for supporting/training carers in managing people with dementia?	Thank you for your comment. Our intention is that these issues will be considered within the guideline. The guideline committee will take into consideration various interventions when looking at the evidence for this section.
Royal College of Speech and Language Therapists	7	1.5 Point17	With regards to nutrition, a risk feeding pathway from acute to community is used by speech and language therapists. This pathway acknowledges the risks associated with swallowing difficulties resulting in the development of aspiration pneumonia within this population. Rather than the patient being repeatedly admitted with aspiration related chest infections, speech and language therapists advocate risk managing the patient in the comfort of their home/care home. On discharge from the acute setting speech and language therapists ensure advanced care plans are completed and management is handed over to the GP/Community teams in order to complete this loop of care.	Thank you for your comment. The guideline committee will take into consideration a broad range of interventions when looking at the evidence for this section.
Royal College of Speech and Language Therapists	8	1.6 Point1	If language is listed as an outcome then it must also be recognised as a key area and in the key issues section.	Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration and we will search

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				for appropriate evidence pertaining to this group.
Royal College of Speech and Language Therapists	8	1.6 Point1	As well as recognising language this must recognise aspects of communication.	Thank you for your comment. We have highlighted people with communication difficulties as a group requiring special consideration and we will search for appropriate evidence pertaining to this.
Royal College of Speech and Language Therapists	8	1.6 Point1	The RCSLT recommend the inclusion of eating, drinking and swallowing to the main outcome list	Thank you for your comment. We have highlighted people with dysphagia as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
Royal College of Speech and Language Therapists	11	2.2	The RCSLT recommends adding language/communication to the pathway under management, and adding the need for assessment and management.	Thank you for your comment. The pathway has been revised to reflect the changes within section 1.3.
Royal College of Speech and Language Therapists	11	2.2	The RCSLT recommends adding eating, drinking and swallowing to the pathway and screening for dysphagia at regular intervals during the course of the disorder.	Thank you for your comment. The pathway has been revised to reflect the changes within section 1.3
Royal College of Surgeons of England	General	General	The RCS will not be sending a consultation response to this scoping consultation.	Thank you for your comment
Royal Pharmaceutical Society	4	2	We believe that given the current focus on learning disabilities the current area on assessing and managing dementia for people who have learning disabilities should continue to be included in this guideline.	Thank you for your comment. We have taken this into consideration and people with learning disabilities will now be included within the guideline update.
Royal Pharmaceutical	5	1.5	The question concerning people with dementia	Thank you for your comment. We have amended

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Society		Point2	being able to exercise choice in decisions about their care should also specifically be asked in relation to people with dementia being able to exercise choice in decisions about their medicines.	this section within the scope.
Sheffcare	2	11	Does carer refer to a paid carer such as a care worker in a residential care home or a carer who is unpaid i.e a family member	Thank you for your comment. We intend to consider family members and both formal and informal carers of people living with dementia. We have now amended the scope to clarify this and now refer to family members and/or informal carers.
Sheffcare	3	General	There is very limited reference to social care and the significant contribution this area makes to the care and support of people living with dementia. The focus seems very much on a medical/clinical focus and less about supporting people to live well with dementia. In 2011, more than a quarter of a million (291,000) people aged 65 and over were living in care homes in England and Wales, A significant majority of these people have some level of dementia which is often not diagnosed. There needs to be more emphasis on diagnosing this group, providing treatment and more importantly how this group of people can be supported by social care to live a meaningful life which supports there well being	Thank you for your comment. We intend to consider social care and health related issues within the guideline update. We have taken on board your comments and amended the language and structure of the scope so that social care issues are more prominently addressed.

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Sheffcare	4	19	Why was this decision made?	Thank you for your comment. Pharmacological management of dementia in Parkinson's disease is being covered in the current update of the Parkinson's Disease guideline. To ensure that guidance relating to the pharmacological management of Parkinson's Disease is consistent across NICE guidance we will cross refer to relevant recommendations in the of Parkinson's disease guideline.
Sheffcare	5	19	This area needs to be expanded to include a much wider area in relation to not only choice but person centred care for people living with dementia, for example life story work, dementia mapping tools etc. Again a bias towards medical/clinical aspects of dementia.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline. The language and the structure of the scope has been modified in the light of stakeholder feedback. The guideline committee may choose to consider these interventions when looking at the evidence for this section of the guideline if they think this is appropriate.
Sheffcare	8	General	Could other areas of evidence be explored which are specific to social care and improved social care outcomes, again very focused on medical/clinical aspects rather than what really help a person to live a good life with dementia.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline.
Sheffcare	12	23 24	Current Practice only refers to medical management, can we not have some practice	Thank you for your comment. We have amended the scope to include reference to non-

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			examples of social care to ensure balance	pharmacological interventions
South London and Maudsley NHSFT	2	General	<p>Section 1.1 last few lines – <i>people with mild cognitive impairment who are not suspected of having a dementia will not be covered</i>. This requires some clarity. The term mci is used inconsistently and there is large regional variation in the services this patient group and their relatives receive. The group needs to be aware</p> <ol style="list-style-type: none"> <li>1. that people with “mild cognitive impairment” are at a higher risk of developing dementia</li> <li>2. an increasing body of evidence shows that biological and neuroimaging markers can predict the likelihood of them developing dementia</li> <li>3. A diagnosis of “mci” without clarity can cause emotional distress and confusion for carer and patient</li> <li>4. There are some interventions being developed for this group, and many services offer support to people with mci- eg “mci groups”- CCGs will need to know whether such services should be commissioned and a NICE review of evidence would help</li> <li>5. Services need guidance on which patients</li> </ol>	<p>Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.</p>

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			with mci to follow up, how this should be done (eg what cognitive testing tools/ neuroimaging should be repeated) and how frequently We support some guidance being included in this document to include mild cognitive impairment	
South London and Maudsley NHSFT	1	1.1	Some Memory services differentiate between stable cognitive impairment (eg due to CVA, hypoxic brain damage or acquired brain injury) and "progressive" dementia, and do not accept referrals in the former group. The arbitrary exclusion of people with certain non-Alzheimer diagnoses from Memory Services is not helpful and new guidance should encourage an inclusive, needs-based approach to services.	Thank you for your comment. The scope of the guideline is inclusive of all people with suspected dementia up to the point of diagnosis. However once a diagnosis has been made then the guideline is solely concerned with people with a confirmed diagnosis of dementia. Those patients who receive a diagnosis of cognitive impairment with a different aetiology should be signposted to the appropriate care pathway.
South London and Maudsley NHSFT	4	General	Last para: Unclear why guidance on dementia inpatient services has been removed	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.
South London and Maudsley NHSFT	6	8	There is still confusion and national variation in the proportion of people attending Memory assessment services who have a brain scan and in terms of which type of brain scan should be ordered in which situation. New evidence should help the committee to make a decision on this but it should	Thank you for your comment.

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			be pragmatic and recognise patient choice.	
South London and Maudsley NHSFT	7	14	The section on BPSD needs to be revised with evidence from recent systematic reviews and stepped care guidance of non-drug treatments and the latest evidence on differential risk of different antipsychotic drugs. Advice on when to use drugs needs to be more precise.	Thank you for your comment. The guideline committee will take into consideration the inclusion of these issues when looking at the evidence for this section.
Surrey and Borders Partnership NHSFT	1	General	Should explicitly include supported living, residential and nursing homes and day opportunities settings.	Thank you for your comment. Our intention is that these settings are included within the guideline. We have highlighted the importance of the provision of environments which are sensitive to cognitive impairment as an area requiring special consideration and will search for appropriate evidence.
Surrey and Borders Partnership NHSFT	2	General	Please can this explicitly include people with learning disabilities and specifically people with Down's syndrome as this is a major area of concern. People with Down's syndrome are the only group with a genetic link to Alzheimer's disease. See BPS/RCPsych (2015) guidance on the assessment, diagnosis, interventions and support for people with intellectual disabilities and dementia.	Thank you for your comment. We have taken this into consideration and people with learning disabilities including people with Down syndrome will be included within the guideline update.
Surrey and Borders Partnership NHSFT	2	General	The exclusion of people with MCI who are not suspected of having dementia will add to confusion.	Thank you for your comment. We will be including people with mild cognitive impairment if they are

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				suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Surrey and Borders Partnership NHSFT	3	General	Principles of care should include personcentred care with a clear description of this from the person with dementia's perspective. It should also include giving staff a clear understanding of what it feels like for the person to be experiencing the symptoms of dementia. This is a vital prerequisite for delivering effective support for people with dementia.	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline.
Surrey and Borders Partnership NHSFT	4	General	New areas to be covered – we believe that there needs to be an explicit section on achieving good outcomes for people with dementia.	Thank you for your comment. We have amended the language and structure of the scope so the promotion of health and wellbeing of people with dementia is more prominently addressed.
Surrey and Borders Partnership NHSFT	4	General	New areas to be covered – under managing dementia we believe that there needs to be a section on the impact of the physical environment.	Thank you for your comment. We have highlighted the environmental and living needs of people living with dementia as an area requiring special consideration and we will therefore search for appropriate evidence pertaining to this area.
Surrey and Borders Partnership NHSFT	4	General	We have deep concern about the removal of people with intellectual disabilities from this guidance, and ask for this to be reversed. This is	Thank you for your comment. We have taken on board your comments and people with learning disabilities will now be included within the guideline

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			completely contrary from NHS England stance that people with learning disabilities should be able to access mainstream services as needed, and the need for joint work between mainstream dementia services and services for people with learning disabilities. We believe that the issues of dementia for people with learning disabilities will be lost within a general guideline for mental health problems.	update.
Surrey and Borders Partnership NHSFT	5	General	Training and development of staff. Should the guidance also be covering higher education programmes – Nursing, medical, OT, Physio, Clinical Psychology, Speech and Language Therapy training should include having the skills and competencies to support people with dementia and co-morbidities	Thank you for your comment. We will not be covering higher education programmes as part of the review question addressing training of staff. This is because it is likely our review question will address dementia specific training only.
Surrey and Borders Partnership NHSFT	6 7	General	The managing features sections. This needs to be seen from a personcentred viewpoint rather than individual sections focusing on specific symptoms. In reality it is the interaction between different issues that need to be understood and separating them in this way allows the continuation of seeing the dementia as a collection of symptoms, rather than helping people see that it is the interaction between biopsychosocial issues. It would be far	Thank you for your comment. We have amended this section of the scope to more prominently address the health and wellbeing of people living with dementia.

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			more helpful for staff and commissioners to understand how to support people as the dementia progresses.	
Tees Esk & Wear Valley NSHFT	2	1.1	Please can you also consider the needs of LGBT people with dementia more explicitly	Thank you for your comment. We have highlighted LGBT people as a group requiring special consideration and we will search for appropriate evidence pertaining to this group.
Tees Esk & Wear Valley NSHFT	2	25	Why is MCI omitted as this is just as important area to 'keep well' as the cardiovascular aspect.	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Tees Esk & Wear Valley NSHFT	4	19	Why is this being omitted in terms of the dementia? We are seeing more of these patients in clinics.	Thank you for your comment. Pharmacological management of dementia in Parkinson's Disease is being covered in the current update of the Parkinson's Disease guideline. To ensure that guidance relating to the pharmacological management of Parkinson's Disease is consistent across NICE guidance we will cross refer to relevant recommendations in the of Parkinson's disease guideline.
Tees Esk & Wear Valley NSHFT	4	24	Why are we omitting the inpatient areas as often this is where dementia can be first suspected.	Thank you for your comment. We have taken this into consideration and inpatient services will now

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				be included in the guideline update.
Tees Esk & Wear Valley NSHFT	5	22	Is there going to be a supported and comprehensive legal framework for this? Is the term advanced care plans universally clarified?	Thank you for your comment. The objective of this question is to explore opportunities for people living with dementia to make advance decisions about their care. The guideline committee will consider legal issues when looking at the evidence for this question.
Tees Esk & Wear Valley NSHFT	6	7	Why is good mental health not included here as well as cardiovascular factors?	Thank you for your comment. We have now amended this section of the scope. However, we have also included review questions that address the mental health of people living with dementia.
Tees Esk & Wear Valley NSHFT	7	3	Should this cover MCI too?	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
Tees Esk & Wear Valley NSHFT	4	General	Inpatient dementia services: This exclusion contradicts the previous statement in 1.2 <b>1.2 Settings</b> Settings that will be covered All settings in which NHS-funded health and social care is received.	Thank you for your comment. This has been taken into consideration and a review question considering inpatient services will now be included in the guideline update.

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			I think it is important that in patient services remain in the guidelines as it is an essential part of the dementia care pathway	
Tees Esk & Wear Valley NSHFT	14	General	Managing behavioural symptoms: Please can you consider the interface with Positive Behavioural Support ( PBS) as this is a national driver in Positive and Proactive care ( DoH 2014)	Thank you for your comment. The guideline committee will take into consideration the inclusion of positive behavioural support when looking at the evidence for the non-pharmacological interventions.
United Kingdom Homecare Association	2 3 5	1.1  1.3.2  1.5.4-7	there is a specific exclusion for people with mild cognitive impairment but there are well established probabilistic causative links between MCI and onset dementia that suggest this cluster should be included: the propensity to develop dementia suggests that this is precisely the cluster who should be prioritised and runs counter to the message in s1.3.2 on p3 of 14 and which is further reinforced in s1.5.4 to s1.5.7 when addressing risk factors	. Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia. However we have a question on risk factors for dementia and one would expect mild cognitive impairment to be an important consideration in this question.
United Kingdom Homecare Association	3 4 7	1.2  1.3.7  1.5.18	we consider that these guidelines should apply to all health economies and to differentiate or exclude people on the basis of their funding source is unfair and discriminatory for no good reason and runs counter to the message in s1.3.7 on p4 of 14 - see also the 'message' inherent or even implicit in	Thank you for your comment. The scope has been updated to cover all settings and this will include NHS funded and private or third party funded care.

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			s1.5.18 on p7 of 14	
United Kingdom Homecare Association	3	1.3	the introductory paragraph referring to prescribing of therapeutic substances appears out of place: no preamble or context that creates 'fit' - is it in the right place?	Thank you for your comment. We have amended this section of the scope to provide more clarity.
United Kingdom Homecare Association	4	1.3	we are inclined to the view that excluding "Palliative care, pain relief and care at the end of life for people with dementia" could frustrate the purpose of these guidelines for little benefit.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
United Kingdom Homecare Association	5	1.4	the statement "We will review the economic evidence and carry out economic analyses using an appropriate perspective" would be improved if there was some specificity around 'appropriate perspective' which, as a conceptual device, would benefit from contextualisation	Thank you for your comment. Once the areas of the scope have been prioritised for de novo economic analysis, the <a href="#">NICE reference case</a> to be used will be agreed with the GDG and NICE quality assurance staff. The areas prioritised and agreed perspective will be published in the economic plan.
United Kingdom Homecare Association	6	1.5 Point9	the role and value of radiological imaging as a diagnostic tool, definitive or indicative, could be usefully elaborated upon	Thank you for your comment. The guideline committee will take into consideration radiological imaging when looking at the evidence for this section.
United Kingdom Homecare	8	1.6	it may prove of value to include and differentiate	Thank you for your comment we have incorporated

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Association		Point2	between the Activities of Daily Living and Instrumental Acts of Daily Living which often give greater insight into the functional consequences of impaired cognition and/or superimposed depressive conditions	this distinction within the scope.
United Kingdom Homecare Association	8	1.6 Point6	could usefully include iatrogenic pharmacological situations	Thank you for your comment. Although we do not have a review question that directly addresses iatrogenic situations it is likely that any appropriate evidence pertaining to this will be taken into consideration by the guideline committee when considering the review questions around pharmacological interventions for people living with dementia and the section relating to multi-morbidity in people living with dementia.
United Kingdom Homecare Association	8	1.6 Point12	not sure what this means: elaboration would be helpful	Thank you for your comment. We have now provided examples to clarify health and social care service use. These include hospital admissions and readmissions; primary care health professional appointments; attendance at accident and emergency departments and other planned and unplanned contacts with health and social care services.
United Kingdom Homecare Association	9	2.1	it would be useful to understand what 1.3 in TA217 is and how it interacts with this scheme	Thank you for your comment. Recommendation 1.3 in <a href="#">TA217</a> refers to the initiation of

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				pharmacological treatment for the cognitive symptoms of Alzheimer's disease. We have amended the scope to include a review question which directly addresses this issue.
United Kingdom Homecare Association	General	General	In the introductory narrative it may prove helpful to have a description of what the Guidelines are intended to define: it is appreciated that s1 to s1.3.7 contain important information but it is not immediately clear what the document is intended as (for example) <b>a</b> ) a commissioners handbook <b>b</b> ) a service managers guide to best practice <b>c</b> ) a family or informal carers support tool <b>d</b> ) an integrated care pathway definition <b>e</b> ) a 'map of medicine' decision tool <b>f</b> ) a clinicians guide to best practice <b>g</b> ) a multifactorial interventions guide <b>h</b> ) a care systems design template. If the intention is to create a universal guide to all aspects of dementia care we are concerned that the force of NICE branded tools may be diluted by creating a hybrid approach to such a diverse range of differentiated requirements.	Thank you for your comment. We do not provide this detail within the scope. However, during development and following consultation the developer will work closely with NICE's editorial and implementation teams to ensure that the guideline and its recommendations are suitable for a broad range of stakeholders.
University of Bradford	1	8	Might you consider including people who work in hospice?	Thank you for your comment. It is intended that this guideline would be appropriate for people who work in a hospice as a specialist setting.
University of Bradford	2	10	What about people with young onset dementia?	Thank you for your comment. We have highlighted people with early-onset dementia (aged 40-64

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				years) as a group requiring special consideration and we will search for appropriate evidence pertaining to this group. However, the scope has been amended to make it clear that people with juvenile onset dementia will not be covered by the guideline due to the different presentation, progression and treatment.
University of Bradford	3	11	Under principles of care: It would be timely to update the section on person-centred care to include an up to date evidence base for the effectiveness of this approach	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline.
University of Bradford	3	3	Rather than managing dementia and to ensure consistency with the ambitions of the prime minister's challenge, I think supporting people to live well with dementia would be more appropriate language	Thank you for your comment. We have amended this section of the scope so it more prominently addresses the health and wellbeing of people living with dementia.
University of Bradford	4	1	Understanding behaviour as communication of unmet need is a more contemporary perspective on behavioural aspects of dementia. It would be good if the language reflected this.	Thank you for your comment. We will be mindful of the language used within the guideline.
University of Bradford	General	General	Integrated health and social care is mentioned several times yet the guideline omits guidance on social care	Thank you for your comment. We will be considering social care and health related issues within the guideline update. We have taken on board your comments and amended the language and structure of the scope so that social care

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				issues are more prominently addressed.
University of Bradford	4	8	Palliative and end of life care, including pain relief, should be updated. There have been high quality evidence based studies published since the last guideline. For example, by Sampson and colleagues.	Thank you for your comment. We have not prioritised palliative care for update within the guideline. This is because palliative care was not highlighted as an area where there was significant new evidence that would lead to a change in the current recommendations. We propose to carry forward the previous recommendations relating to palliative care.
University of Bradford	4	5	I think the guideline should cover acute care settings – where up to 25% of the beds are occupied by people living with dementia; similarly I think the guideline should include people with learning disabilities	Thank you for your comment. A review question considering inpatient services has now been included in the guideline update which will include acute care settings. We will now also be looking at people with learning disabilities within this guideline.
University of Bradford	General	General	Will the social model of disability presented in the previous guideline be included in this version. I hope so.	Thank you for your comment. We will search for appropriate evidence pertaining to issues highlighted by the social model of disability.
University of Bradford	General	General	I think the conceptual framework for understanding behaviour is limited to a biomedical perspective in the proposed guideline. I think a social model of dementia may be more helpful to emphasise (and guide practice), for which there is a significant evidence base (eg Fossey et al 2006).	Thank you for your comment. Our intention is that person centred care is incorporated within the guideline. In response to stakeholder feedback we have modified the language and the structure of the scope to reflect this.
University of Bradford	General	General	I would like to see an emphasis on transitional care	Thank you for your comment. This is an issue

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			for people living with dementia – drawing on the evidence base from Mary Naylor and colleagues.	which we will aim to cover in the review question on the assessment of needs for people with dementia.
University of Bradford	5 -8	General	I think each of these questions should ask do these differ for people from minority ethnic communities or for people with young onset dementia; and how?	Thank you for your comment. We have highlighted the diverse attitudes and responses of different ethnic and cultural groups and people aged 40-64 years with young onset dementia as an area requiring special consideration and we will search for appropriate evidence pertaining to these groups.
University of Bradford	General	General	Is there any merit in better understanding how inequalities affect people living with dementia?	Thank you for your comment. We will address equality issues within the guideline. In line with NICE's policy on equality a full equality impact assessment has been carried out during the scoping period and will be monitored throughout development of the guideline and drafting of recommendations
University of Worcester	1	General	Should explicitly include residential and nursing homes Increasing number of people with dementia are part of the prison population which health services have responsibility for.	Thank you for your comment. The guideline is intended to be of use to staff working in all residential settings.
University of Worcester	2	General	To include groups that have suspected dementia and then to exclude people with MCI not suspected of having dementia will cause further confusion as	Thank you for your comment. We will be including people with mild cognitive impairment if they are suspected of having dementia and also those with

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			to what should be done with people who fall between the cracks because of uncertainty over diagnosis. Increasingly services are not using the label MCI or are using it in a non-consistent way. It would be safer just to include people who <b>have dementia or suspected dementia</b> – rather than to specifically exclude those with MCI. I led a work-package under the ALzheimer's COoperative Valuation in Europe (ALCOVE) programme that recommended that Public Health Guidance gave specific mention to MDI/suspected dementia because of the uncertainly of many of how to respond to this group. By making this group explicitly covered by the new guidance could ameliorate a lot of confusion for many patients, families and professionals Ref Brooker, D.et al (2014) Public health guidance to facilitate timely diagnosis of dementia: ALzheimer's COoperative Valuation in Europe (ALCOVE) Recommendations, <i>International Journal of Geriatric Psychiatry</i> , <b>29</b> : 682–693	MCI if they are confirmed to have a diagnosis of dementia, within the guideline. We will not be covering people with MCI if they do not have dementia.
University of Worcester	3	General	The 2007 guidance was explicit in that the underpinning principle of care for people with dementia was that it should be person centred. People living with dementia are at serious risk of	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline.

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## Dementia (update)

### Consultation on draft scope Stakeholder comments table

8<sup>th</sup> July – 5<sup>th</sup> August 2015

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			<p>abuse and neglect as any review of serious cases or reports on health and social care failing will demonstrate. If it is not made explicit that people living with dementia have full rights of citizenship, particular needs around communication and dependency on others then the risk of poor practice is heightened.</p> <p>Person centred care within the 2007 guideline was defined as promoting:-</p> <ul style="list-style-type: none"> <li>The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them;</li> <li>The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia;</li> <li>The importance of the perspective of the person with dementia;</li> <li>The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.</li> </ul> <p>This VIPS model of person-centred care which promotes the human rights of those living with dementia has been used extensively since the last guidance and it would be important to re-state this explicitly in the new guidance if we are to ensure</p>	

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			that all staff and professionals adhere to this value base.	
University of Worcester	3	General	Under diagnosing and assessing dementia – in our ALCOVE recommendations we differentiated between straightforward and complex diagnosis	Thank you for your comment. We will be mindful of these when considering the evidence for the assessment and diagnosis questions.
University of Worcester	3	General	Suggest the “Managing Dementia” is replaced with Managing the Symptoms of Dementia or Managing Common Problems in Dementia	Thank you for your comment. We have amended this section of the scope.
University of Worcester	5	General	Training and development of staff. Should the guidance also be covering higher education programmes – reflecting that nurse, medical, OT, Physio, Clinical Psychology teainign should include having the skills and competencies to support people with dementia and co-morbidities	Thank you for your comment. We will not be covering higher education programmes as part of the review question addressing training of staff. This is because it is likely our review question will address dementia specific training only
University of Worcester	6	General	Diagnosing dementia is more than just the technical issues about what tests to use. The guidance should cover issues of opportunity for pre-diagnostic discussions/counselling/ and some guidance about how the diagnosis should be delivered. The diagnosis of dementia is life-changing and devastating. The way diagnosis is delivered – the peri-diagnostic care - is likely to have an impact on how people adjust. How it is delivered (ie not by a receptionist over the phone – which is current practice in some clinics still) should be	Thank you for your comment. Our intention is that the guideline will consider issues of support post diagnosis. Many areas covered in the scope, particularly around reducing the risk of progression of dementia and supporting people to avoid harm and maintain independence, will address the ongoing care for people living with dementia The guideline committee will take into consideration post-diagnosis support when looking at the evidence for this section.

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			covered in the guidance. Under the risk management section there should be guidance on post-diagnostic support and interventions tailored to individuals	
University of Worcester	6 -7	General	<p>The managing features sections. There is a disconnect in the guidance about talking about supporting people to exercise choice and control and then in this section a rather objectifying stance on "managing" the dementia features as if they are somehow separate from the person who is experiencing this life changing diagnosis. I think it would be better to have a section on helping people manage common symptoms and problems or adjust to the changes that dementia brings. These do not split neatly into cognitive, emotional, behavioural and functional. There is no mention of the social or psychological support and interventions for which there is an evidence base.</p> <p>Likewise the splitting of interventions into a dichotomy of Pharmacological or Non-Pharmacological is to down-play the impact on the whole person and the multiplicity of interventions that fall into the non-pharma category. NON implies dominance of one over another. Dichotomies limit</p>	Thank you for your comment. Our intention is that person centred care is incorporated throughout the guideline. We have taken your comments into consideration and amended this section of the scope to more clearly address the health and wellbeing of people living with dementia.

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			<p>possibilities. Within the management of common issues for people living with dementia there is a place for pharmacological and psychological and social and physiological and nutritional and spiritual and creative and humanistic and systemic and public health interventions.</p> <p>In practice a strong bio-psycho-social model works best. To achieve best outcomes we need to work from a biomedical, a psychological and a societal model in combination</p> <p>We need to understand the impact of the dementia syndrome on the individual's health and well-being over time in the context of their family, their community and the health and social care interventions they receive. This is what we need guidance upon – not on how to manage a so-called symptom in isolation.</p>	

Registered stakeholders: <http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0792/documents>

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