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

Consultation on draft guideline – deadline for comments 5pm on 12/02/2018 email: Dementia@nice.org.uk

| Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank): | [Alzheimer’s Research UK] |

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.

We would like to hear your views on these questions:

1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.
2. Would implementation of any of the draft recommendations have significant cost implications?
3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)
4. [Insert any specific questions about the recommendations from the Developer, or delete if not needed]

See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.

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Alzheimer’s Research UK is the world’s leading dementia research charity dedicated to causes, diagnosis, prevention, treatment and cure. Backed by our passionate scientists and supporters, we’re challenging the way people think about dementia, uniting the big thinkers in the field and funding the innovative science that will deliver a cure.

Our mission is to bring about the first life-changing dementia treatment by 2025. Our vision is a world where people are free from the fear, harm and heartbreak of dementia.

We focus our energies in four key areas of action to make this mission a reality.

- Understand the diseases that cause dementia.
- Diagnose people earlier and more accurately.
- Reduce risk, backed by the latest evidence.
- Treat dementia effectively.

Through these important strands of work, we’re bringing about breakthroughs that will change lives.
## 2 Full General General

Alzheimer’s Research UK welcomes the opportunity to comment on the revised ‘Dementia: assessment, management and support for people living with dementia and their carers’ guideline. We recognise there have been great advances in awareness and understanding of dementia in recent years, supported by initiatives such as the [Prime Minister's challenge on dementia](https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia) and associated [implementation plan](https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-implementation-plan), as well as a focus on awareness and training for all healthcare staff through Health Education England.

Overall, we are concerned that the revised guidelines for consultation somewhat retreat from the 2006 guideline, particularly in terms of ambition and breadth of coverage.

We are also concerned at the short timescale in which to review and respond to the revised guideline, we urge NICE to give organisations sufficient time to fully consider the impact of suggested changes, especially those that engage with people living with dementia.

## 3 Full General General

As part of practitioner skills and competencies we note that no mention is made of the potential to encourage people to participate in dementia research. Given that recruitment of people to dementia studies is a well-recognised challenge in the field, we would highlight the need for all practitioners to promote research opportunities. These may be local studies but there is also Join Dementia Research, which as a national initiative, offers all people (both those with and without a diagnosis of dementia) an opportunity to register their interest in getting involved in research. Given the current lack of disease modifying treatments for dementia, research is the only way that we are going to make progress.

According to a YouGov poll commissioned by Alzheimer’s Research UK in 2015, whilst almost two thirds of the general public (62 per cent) would be willing to take part in dementia research, more than four out of five people (81 per cent) would not know how to volunteer. This is improving with the introduction of Join Dementia Research and this Guideline should play a key role in further promoting and enabling opportunities to get involved in research. More than 34,000 people took part in dementia research in 2015/16, an increase of 156% over the previous two years. So far 187 NHS, University and commercial sites have used JDR. **There is a national target set by the Department of Health and Social Care for 25% of people with a diagnosis of dementia involved in research by 2020 (approximately 100,000 people), if we are to meet this target it is crucial that encouraging people to take part in research is part of the guideline.**

The willingness of people to help research is vital for us to make progress. Join Dementia Research makes it easier for people to get involved in dementia research studies, we must embed Join Dementia Research in core NHS diagnostic pathways to ensure all people with a dementia diagnosis are offered the opportunity to take part in research.

Alzheimer’s Research UK’s booklet ‘[Getting involved in dementia research](https://www.alz.co.uk/GettingInvolvedInResearch)’ is a useful resource for those working...
across healthcare. It also outlines the benefits and reasons why people choose to take part in research, which benefits not only research but critically the individual taking part:

- Studies can provide an opportunity to learn more about dementia and health.
- People often feel research is something positive they can do in the face of a progressive condition.
- Volunteers may feel part of a community with other people taking part.
- Some studies involving people with dementia include regular monitoring by doctors.
- Research will lead to outcomes that could benefit those taking part or future generations.

We would also urge the Guideline to align with the Dementia Statements, relaunched in 2017 led by Alzheimer’s Society alongside people living with dementia and their carers, which detail a right for people to know about research opportunities and be supported to take part:

“We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.”

In 2016 Alzheimer’s Research UK published ‘Treatments of Tomorrow: preparing for breakthroughs in dementia’. The report made a number of recommendations for the system, including the need to set the foundations for early detection of the diseases that cause dementia.

We urge the NICE Guideline to have a stronger focus and reference to the importance of early diagnosis, with the need to prepare the NHS for a cultural shift towards earlier detection of pathological changes in diseases like Alzheimer’s, as when new treatments become available they will be most effective in the early stages.

“As concluded by the National Screening Committee in 2015, it is not appropriate to introduce screening for dementia at this point, given the paucity of robust biological markers to identify those with or at risk of dementia, along with the lack of an effective early treatment that could improve outcomes. However, it is important that the health system is prepared for early detection when improvements in diagnostic technology make this a possibility. This is because the pathology of most of the diseases that cause dementia appear to develop years before symptoms occur and early treatments are likely to work best if they are given at the earliest possible stage. It is important to consider this now, because it is likely that capacity for infrastructure (e.g. brain imaging or cerebrospinal fluid testing) could be necessary, which will require additional resources, cultural changes and closer working between clinical disciplines.

Early detection of the hallmarks of Alzheimer’s disease is already required for several of the current large clinical trials of new treatments, learning from NHS sites where this is done well would help consider what changes could be
In England, the August 2017 diagnosis rate for over 65s was 68.2%, the diagnosis rate for under 65s was 39.2%.

We welcome the inclusion of cerebrospinal fluid examination (CSF) and FDG-PET as methods to help diagnose dementia. Alongside other tests, such as cognitive tests, these diagnostic tests are an important method to get a more accurate diagnosis of Alzheimer’s disease, especially in the earliest stages of the disease. Diagnosing dementia is a complex challenge, and doctors have to gather a range of clues to create a picture of what is going on in the brain. Most often, doctors will make a dementia diagnosis by assessing a person’s symptoms and ruling out other potential causes of memory and thinking problems, but this approach doesn’t always provide conclusive results.

Alzheimer’s disease is a progressive neurodegenerative disease, and the hallmarks of the disease are present years before any symptoms might occur. Current approaches to diagnosis are focused on the mild, moderate and severe stages and it is important healthcare professionals have a focus on diagnosing in the early stages. According to the Royal College of Psychiatrists’ most recent National Audit of Memory Clinics 2014, only 52% patients received an early diagnosis. This is important as when new treatments become available they will be most effective in the earliest stages. In addition to the inclusion of CSF and FDG-PET, the Guideline should reference the importance of the NHS being responsive to developments in technology and ways to diagnose dementia, as they become available.

A lumbar puncture is one of very few options available for getting a biological indication of processes that may be underway in the brain. As with any medical procedure, doctors need to carefully weigh the risk of side effects against the benefits a lumbar puncture can yield, and patients need to be fully informed about what is involved.

It is important that the introduction of tests such as CSF and FDG-PET, and the use of existing cognitive tests, are accompanied by training for healthcare professionals, as well as training to improve their understanding of the pathology of Alzheimer’s disease and being able to recognise the earliest signs.

There also needs to be a focus on building sufficient capacity in the system to be able to improve diagnosis and support the use of these tests. The most recent Audit of Memory Clinics found that between 2013 and 2014, the number of patients seen by memory clinics increased by 31% on average, although available capacity did not increase significantly. This is a concerning trend if we are going to effectively support better, earlier and more accurate diagnosis for people living with dementia.

We suggest there is a research recommendation focused on preparing the NHS for earlier diagnosis and the use of new technologies and cognitive assessment to develop the evidence base in this area.
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<th>We think the Guideline should have greater reference to the different stages and severity of dementia, recognising diseases such as Alzheimer’s as progressive neurodegenerative diseases. This includes greater reference to the mild, moderate and severe stages, and that the hallmarks of the disease are present years before any symptoms might occur. For example, recognising the difference between Alzheimer’s Dementia and Alzheimer’s disease. This will support greater understanding and awareness among healthcare professionals. Understanding severity of dementia is also important for the later guideline section on use of pharmacological interventions, as prescribing decisions are in part made according to the severity of the condition. In addition, given that the mental health care clusters, through which many mental health trusts, and therefore memory assessment clinics, get paid need to define stage of dementia, guidance on this would be helpful to support clinical practice.</th>
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| 7   | Short | 10 | 25 | We are concerned that the language in the revised Guideline may result in the reduction in use of structural imaging where it is appropriate, by changing the wording from ‘should’ to ‘consider’ (see below). It is important clinicians use a range of tests to make an accurate diagnosis and structural imaging plays an important part in building that picture. We recommend keeping the wording used in the 2006 Guideline.  
**2018 Guideline:**  
Dementia diagnosis in specialist dementia diagnostic services: “Consider structural imaging to rule out reversible causes of cognitive decline.”  
**2006 Guideline:**  
“Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear.” |
| 8   | Short | 9  | 16 | We are concerned that a routine physical examination, including blood tests, is no longer recommended in the guideline. It is important to be able to rule out other possible causes of memory loss. This was part of the 2006 guideline and we think it should be retained.  
- The 2006 Guideline included a recommendation for a “physical examination and other appropriate investigations” |

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The current phrasing of the guideline implies that all suspected cases of dementia should be referred to a specialist memory assessment service.

While we would support this approach, we would question whether there is sufficient current capacity in memory services to ensure all people with suspected dementia can be seen in a timely manner – especially if we are to improve diagnosing in the earliest stages.

According to the most recent audit of Memory Clinics, published by the Royal College of Psychiatrists:

- “Between 2013 and 2014, the number of patients seen by memory clinics increased by 31% on average, although available capacity did not increase significantly.”
- “The average waiting time from referral to assessment increased from 5.2 weeks in 2013 to 5.4 weeks in 2014, and waiting time from assessment to diagnosis increased from 8.4 to 8.6 weeks.”

While referral to a specialist memory service should be offered to all people with memory problems we recommend the Guideline allows more flexibility for people to be diagnosed in an appropriate setting, for example if a person is in the more severe stages, before being referred. This could speed up diagnosis for some patients and offers local level flexibility.

We note that a range of diagnostic assessments are recommended for primary care and that they have similar specificity and sensitivity. We also recognise that many of the tests focus on simple memory recall and therefore can be less helpful in cases where memory loss is not the predominant symptom.

We suggest there is a research recommendation made to develop the evidence base in this area.

The revised guidelines no longer make a recommendation regarding factors and interventions in mid-life for dementia risk reduction (2006 guidance 1.3.1.2), we think this should be reinstated. Given that risk factors for dementia are part of the scope of this guideline, and that since 2006 the evidence base in this area has been strengthened (ADI report 2014, Lancet Commission on Dementia 2017) there should be a reference to dementia risk reduction for all ages within the guideline.
We would also suggest that there should be a research recommendation to consider how individuals identified at high risk of developing dementia, through services such as the NHS Health Check, could be tracked and monitored to determine if they are at greater risk of developing dementia.

| 12 | Full | 189 | Quality of evidence | We are concerned that there is a lack of detail regarding the challenge of dementia as a multi-morbidity. While the NICE guidance on multi-morbidities offers an overview, there are specific and unique considerations of how dementia may impact on other conditions - for example someone may forget to take a prescription for diabetes or may not remember to attend a clinical appointment to manage their blood pressure. We would suggest that more detailed guidance should be developed on dementia and co-morbidities.

We recommend building on advice included in the 2006 Guideline: “At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions.” |

| 13 | Full | 376 | General | We are concerned that the recommendations in the guidelines do not reference the Dementia Core Skills Education and Training Framework (2015) that was developed by Skills for Health, Health Education England and Skills for Care. The framework offers a tiered approach to the range of skills and competencies that health and care practitioners should develop in a range of clinical settings for dementia care.

Given that many patients in a range of acute clinical settings have dementia it is crucial that health and care staff across the NHS have consistent skills and competencies. A more explicit reference to this Framework would strengthen the guideline. |

| 14 | Full | General | General | We support the approach that regularity of follow-up should be flexible according to need and preferences. However the guideline should specify a minimum follow-up interval to ensure patients are not lost in the system and are monitored. Including monitoring use of medications and care and support plans, and an individual’s ability to cope with their dementia.

We also note that there is no guidance about primary care responsibilities should a memory assessment service (or
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Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons). We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance that we have produced on topics related to this guideline by checking NICE Pathways.

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the

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Comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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