

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Dementia

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

During the first scoping meeting, participants highlighted that there could be significant equity issues amongst minority ethnic and cultural groups, especially amongst those who are unable to speak or read English. These populations are also likely to be from lower socio-economic status groups, and it was reasoned that being in a lower socio-economic group may mean that a person is at greater risk of being socially excluded. This may lead to difficulties in accessing dementia assessment, diagnosis and appropriate treatment. For this reason, the guideline has highlighted that it will be sensitive to those at greater risk of social exclusion, the diverse attitudes and responses to dementia of people from different ethnic and cultural groups and those who may not read or speak English as a first language.

The expert advisers at the first scoping meeting highlighted that people with low levels of educational attainment may experience inequality with regard to diagnosis and assessment of dementia. People within this group may need greater support to understand and complete dementia assessment tools and be at increased risk of an incorrect diagnosis. The intention at present is to ensure that this issue is discussed by the guideline committee during development.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

The preliminary view of the scoping group was that the specific groups listed in 1.1 will need thorough consideration by the committee during guidance development. The scoping group discussed populations who are currently excluded from the scope.

In the previous guideline, the term ‘other rarer forms of dementia’ had been used as exclusion criteria. The scoping group felt this was unhelpful and sought to remove it so that people with almost any type of dementia may have access to helpful guidance to support their diagnosis, treatment and ongoing care.

The group discussed provision for dementia services for people with learning disabilities. There is a guideline currently in development which focusses specifically on care and support for people with learning disabilities and it was agreed any dementia related issues should be covered here.

Mild Cognitive Impairment (MCI) was also moved into the excluded section of the scope although it had been included in the previous guideline. This is because the group felt that assessment and diagnosis of MCI were different to those for dementia and understanding of this clinical area had moved on significantly over the last decade. It was deemed unsatisfactory for people with MCI to have small bits of ad hoc guidance within a dementia guideline. Participants at the first scoping meeting felt that MCI should be recommended as the topic of a guideline in itself.

Completed by Developer: Sue Spiers

Date: 26/06/15

Approved by NICE quality assurance lead: Mark Baker

Date: 28/08/15

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

A number of potential equality issues were identified through both the stakeholder workshop and formal consultation process. These issues are outlined below:

- Consideration of gender issues for carers (the context being that there are more women carers)
- Ensuring that people with a learning disability are not disadvantaged in terms of benefiting from the broad range of recommendations in the guideline (by covering dementia in people with a learning disability in a separate, non-dementia specific guideline)
- Consideration of the specific needs of adults with an earlier onset of degenerative dementia in terms of suitability of care environments in particular
- People with sensory impairments and those with impairments affecting speech and language (in terms of challenges in assessment, diagnosis and support)
- Sexual orientation & transgender (ensuring that care is sensitive to the needs of LGBT people with dementia)
- Homeless people
- People with dysphagia (swallowing difficulties)
- Consideration of peoples spiritual or religious needs (particularly in the context of end of life care)

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

Following consideration of the comments received during consultation, a number of changes have been made to the scope. People with a learning disability have now been included in the population covered by the guideline update. In addition, the following groups of people have been included for special consideration of evidence for relevant review questions. The guideline (update) committee will be asked to clarify which of the groups should be considered for which questions, as part of the review protocol development:

- People with sensory impairments
- People with communication impairments
- People with dysphagia (swallowing difficulties)

- LGBT communities
- Spiritual and religious beliefs
- People with early onset dementia (aged 40-64 years)

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'Information for the Public' document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

Due to the focus of the guideline, it is recommended that an alternative 'easy read' version of the 'information for the public' document is produced, suitable for people with cognitive impairment.

Updated by Developer: Sue Spiers

Date: 21/08/15

Approved by NICE quality assurance lead: Mark Baker

Date: 28/08/15

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

People with learning disabilities – it was agreed that for the majority of people with learning disabilities who are subsequently diagnosed with dementia, their diagnosis and management of dementia would primarily sit within the learning disability pathway rather than the dementia one, and therefore recommendations on how those services should be organised fit better within a learning disabilities guideline. This guideline does make recommendations on designing services to be accessible to as many people living with dementia as possible, and people with learning disabilities would be one important population to consider in that context. The guideline also cross-refers to a recommendation on diagnosing dementia within the mental health in people with learning disabilities guideline, but the committee noted that a lack of evidence meant it was not possible to provide recommendations on dementia diagnosis that were as detailed as those for people within learning disabilities.

Language – this guideline makes reference to both the NICE patient experience guideline, which includes recommendations on how best to make information accessible to different groups of people, and the NHS accessible information standard, which sets minimum standards with regard to the accessibility of information.

Different ethnic and cultural groups (including different spiritual and religious groups) – as well as making recommendations on how information provided to people should be relevant to their individual circumstances, the guideline also recommends that all staff should be given training in person-centred care, including “respecting the person's individual identity and culture”.

Lower socio-economic status – specific consideration was given to that fact that groups of people may struggle to access services as a result of financial constraints. A recommendation was made around maximising the number of people who are able to attend services that are offered, including people who may struggle with transport.

Younger people living with dementia/people with an earlier onset of dementia – a qualitative review question was included in the guideline looking at the specific needs of younger people living with dementia. A number of recommendations were modified based on the results of that review, to include specific comments on people living with dementia who are still working or looking for work, and people

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

living with dementia who are themselves carers for others, or who still have dependent children. No evidence was identified around specific ways to ensure the suitability of care environments for this group, and therefore no specific additional recommendations were made on this topic. These issues are however addressed in the guideline as part of the more general recommendations around designing services to be accessible to as many people living with dementia as possible

Multimorbidity (including sensory impairment) – only limited evidence was found addressing the issue of managing comorbidities (including sensory impairment) in people living with dementia, and much of the evidence found suggested that the same approaches as used for people without dementia would be expected to also be effective in people living with dementia. A recommendation was therefore made that people living with dementia should be offered equivalent treatment for comorbidities as people without dementia, as the main problem in practice is not that fundamentally different services need to be offered, but simply that there may need to be modifications to how they are delivered to ensure that people living with dementia are able to access them. The guideline also includes cross-references to the NICE guideline on multimorbidity, and other NICE guidelines felt to be relevant.

LGBT+ - as well as making recommendations on how information provided to people should be relevant to their individual circumstances, the guideline also recommends that all staff should be given training in person-centred care, including “respecting the person's individual identity, sexuality and culture”

Dysphagia – the guideline includes a recommendation on supporting oral eating and drinking for as long as possible in people living with dementia.

Carers – the guideline includes a specific set of recommendations around the support that should be provided to carers, including the way that support should be tailored to the individual's circumstances and needs.

3.2 Have any other potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

All issues are discussed in section 3.1 above.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

The Committee's consideration of relevant equality issues is documented in the LETR table for each review question.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

Provided the recommendations about providing tailored information in an appropriate format, and designing services to be accessible to as many people living with dementia as possible are followed, then no groups should be disadvantaged by the recommendations made.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

Provided the recommendations about providing tailored information in an appropriate format, and designing services to be accessible to as many people living with dementia as possible are followed, then no groups should be disadvantaged by the recommendations made.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

Recommendations made to address these issues are detailed in section 3.1

Completed by Developer: Sue Spiers

Date: 18/12/17

Approved by NICE quality assurance lead: Nichole Taske

Date: 08/01/18

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

The only new issue raised during consultation was that of people living with dementia in prisons, and the difficulties in obtaining appropriate access to care. No evidence was identified on this care setting, and it was agreed that this was a sufficiently specialist setting that it was not possible to extrapolate findings from evidence in other settings to make specific recommendations.

Stakeholders also raised many issues that had previously been discussed during scoping and development, including people with learning disabilities, people with communication difficulties or whose first language is not English, people from different ethnic or cultural groups, younger people living with dementia, people with comorbidities (in particular sensory impairment), LGBT+ individuals, people with dysphagia and carers of people living with dementia.

The committee made the following changes to the recommendations in the draft guideline to address the issues raised at consultation:

People with learning disabilities – These were added as a specific group in the recommendation about groups to whom dementia services should be made accessible.

Communication difficulties – The committee added training in “adapting communication styles” to the recommendation on staff training.

Comorbidities – A cross-reference was added to the NICE guideline on hearing loss, which contains recommendations on audiology assessments for people with suspected or diagnosed dementia. An equivalent recommendation was also added around eye examinations for people living with dementia. People with comorbidities was also added to the recommendation about groups to whom dementia services should be made accessible.

People with dysphagia – A new recommendation was added to the guideline around involving a speech and language therapist in situations where there were concerns about the safety of oral eating and drinking.

The other issues raised were addressed as discussed in section 3.1.

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

Stakeholders also raised the issue of mental capacity, with issues raised around the Mental Capacity Act, capacity assessments and other safeguards that are commonly used for people living with dementia as the condition progresses. It was therefore agreed it was appropriate not to include these recommendations within the guideline itself, but to include links to the various relevant pieces of legislation (the Mental Capacity Act, the Care Act, the Equality Act and so on), as well as a cross-reference to the NICE guideline on Decision-making and mental capacity.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

Provided the recommendations about providing tailored information in an appropriate format, and designing services to be accessible to as many people living with dementia as possible are followed, then no groups should be disadvantaged by the recommendations made.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

Provided the recommendations about providing tailored information in an appropriate format, and designing services to be accessible to as many people living with dementia as possible are followed, then no groups should be disadvantaged by the recommendations made.

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

Recommendation changes made to address these issues are detailed in section 4.1

4.5 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

The committee's discussions of equality issues are reported in the 'other considerations' section of the linking evidence to recommendations table for each question.

Updated by Developer: Sue Spiers

Date: 12/03/18

Approved by NICE quality assurance lead: Nichole Taske

Date: 03/04/18

5.0 After Guidance Executive amendments – if applicable (To be completed by appropriate NICE staff member after Guidance Executive)

5.1 Outline amendments agreed by Guidance Executive below, if applicable:

Guidance Executive highlighted that the guideline should ensure that when people with Dementia are admitted to hospital care there should be careful consideration of their needs in that particular environment. It was suggested that recommendations 1.10.9 and 1.10.10 should be moved into section 1.9 to extrapolate the need for a review in situations beyond palliative care.

Approved by Developer: Caroline Mulvihill

Date: 22/05/18

Approved by NICE quality assurance lead: Nichole Taske

Date: 06/06/18