

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

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.

2.0 Scope: after consultation

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.