

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## NICE guidelines

### Equality impact assessment

#### Assessment and management of motor neurone disease

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?

(Please specify if the issue has been highlighted by a stakeholder)

During development of the draft scope, stakeholders identified that people who had learning difficulties, and people in whom English was not the first language may require specific consideration as they may be unable to use some assessment tools and be unable to participate in some psychological and social therapies. It was agreed that these populations would not be specifically highlighted as a separate patient subgroup but, where relevant, this issue would be highlighted.

People with frontal temporal dementia were identified as requiring separate consideration and have been highlighted as a separate patient subgroup.

It was also highlighted that people in whom English was not the first language may have an increase in delay to diagnosis and this group will be considered separately.

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 guideline excludes children and young people with motor neurone disease. Stakeholders identified during development of the draft scope this population has different management needs.

**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?

n/a

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

n/a

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.

Yes – easy read version

**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?

The patient's family and/or carers are included in the patient's care throughout the draft recommendations and could assist with language barriers. Where the patient has no family or does not want to involve them the local trust will need to provide a translation service.

There are specific recommendations for people with frontotemporal dementia.

People who have limited or restricted medical and social care may have issues in receiving assessment and ongoing co-ordinated care – such as refugee and asylum seekers, homeless people, migrant workers. These issues have not been addressed in the recommendations directly, rather there is stress on the need for co-ordinated multidisciplinary team approach for all people with MND.

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?

None

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

Consideration of equality is reflected throughout the evidence reviews.

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?

People with learning difficulties and people whose first language is not English were identified at scoping as have potential problems with inability to use some

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?

assessment tools and to be unable to participate in some psychological and social therapies. However the preliminary recommendations do not recommend any specific tools for assessment and include the need to tailor appointments and discussions to needs of the patient.

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?

None

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?

None

**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?

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?

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?

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?

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

**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:

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