

**NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE**

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARDS

Quality standard topic: Motor neurone disease

Output: Equality analysis form – Meeting 2

Introduction

As outlined in the [Quality Standards process guide](http://www.nice.org.uk) (available from www.nice.org.uk), NICE has a duty to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations between people from different groups. The purpose of this form is to document the consideration of equality issues in each stage of the development process before reaching the final output that will be approved by the NICE Guidance Executive. This equality analysis is designed to support compliance with NICE's obligations under the Equality Act 2010 and Human Rights Act 1998.

Table 1 lists the equality characteristics and other equality factors NICE needs to consider, i.e. not just population groups sharing the 'protected characteristics' defined in the Equality Act but also those affected by health inequalities associated with socioeconomic factors or other forms of disadvantage. The table does not attempt to provide further interpretation of the protected characteristics. This is because it is likely to be simpler, and more efficient, to use the evidence underpinning the quality standard to define population groups within the broad protected characteristic categories rather than to start with possibly unsuitable checklists created for other purposes, such as social surveys or HR monitoring tools.

The form should be used to:

- confirm that equality issues have been considered and identify any relevant to the topic
- ensure that the quality standards outputs do not discriminate against any of the equality groups
- highlight planned action relevant to equality
- highlight areas where quality standards may advance equality of opportunity.

This form is completed by the NICE quality standards internal team at each stage within the development process:

- Topic overview (to elicit additional comments as part of active stakeholder engagement)
- Quality Standards Advisory Committee – meeting 1
- Quality Standards Advisory Committee – meeting 2

Table 1

Protected characteristics
Age
Disability
Gender reassignment
Pregnancy and maternity
Race
Religion or belief
Sex
Sexual orientation
Other characteristics
Socio-economic status Depending on policy or other context, this may cover factors such as social exclusion and deprivation associated with geographical areas or inequalities or variations associated with other geographical distinctions (e.g. the North/South divide, urban versus rural).
Marital status (including civil partnership)
Other categories Other groups in the population experience poor health because of circumstances often affected by, but going beyond, sharing a protected characteristic or socioeconomic status. Whether such groups are identifiable depends on the guidance topic and the evidence. The following are examples of groups covered in NICE guidance: <ul style="list-style-type: none">• Refugees and asylum seekers• Migrant workers

- Looked after children
- Homeless people.

Quality standards equality analysis

Stage: Meeting 2

Topic: Motor neurone disease

1. Have any equality issues impacting upon equality groups been identified during this stage of the development process?

- Please state briefly any relevant equality issues identified and the plans to tackle them during development.

Equality issues were identified prior to QSAC meeting 2. In brief, these related to the complex and changing needs arising from the individual progression of MND. In particular, people with MND can experience cognitive problems. About 10% of people with MND will show signs of frontotemporal dementia and a further 35% show signs of mild cognitive change. Geographical access to some aspects of care was also identified as a potential issue. Draft statements were constructed to address these issues. At QSAC meeting 2, decisions were made to remove and combine statements. The final quality statements address equality issues as follows:

Statement 1 recognises the need to make information about diagnosis, prognosis and management of motor neurone disease accessible to people, including those with cognitive problems. It also recognises that in some areas consultant neurologists without MND expertise may be involved in investigations and testing for suspected MND, and that arrangements should be made for information on a diagnosis of MND, prognosis and management to be given by a consultant neurologist with expertise in treating people with MND.

Statement 3 assesses mobility and daily living needs to ensure that tailored equipment is provided or adapted to meet changing individual needs.

Statement 4 seeks to ensure that personal care and support is carried out by a consistent team of workers who are familiar with the needs of the person they care for. This helps ensure that communication and care is tailored to the individual needs of a person.

Statement 5 recognises that discussions about end of life care should take into account the person's current communication ability, cognitive status and mental capacity.

2. Have relevant bodies and stakeholders been consulted, including those with a specific interest in equalities?

- Have comments highlighting potential for discrimination or advancing equality been considered?

This is the final stage of the process to refine the quality standard and statements following comments from stakeholders and discussion at the second QSAC meeting.

The topic overview and request for areas of quality improvement was published and wide stakeholder comment invited, including from those with a specific interest in equalities.

Standing members for Quality Standards Advisory Committees (QSACs) have been recruited by open advert with relevant bodies and stakeholders given the opportunity to apply. In addition to these standing committee members, specialist committee members from a range of professional and lay backgrounds relevant to the topic have been recruited and attended the first quality standards advisory committee to discuss this topic.

The draft quality standard was subsequently published and stakeholder comment invited, including from those with a specific interest in equalities. A wide range of stakeholder comments were received and provided to committee members. The comments, and the need to amend the standard in light of the responses, were considered at QSAC meeting 2.

3. Have any population groups, treatments or settings been excluded from coverage by the quality standard at this stage in the process? Are these exclusions legal and justified?

- Are the reasons for justifying any exclusion legitimate?

This quality standard relates to adults with MND and therefore does not include children and young people. This reflects the source guideline which excluded children and young people from the scope (as the excluded population has different management needs).

4. If applicable, do any of the quality statements make it impossible or unreasonably difficult in practice for a specific group to access a service or element of a service?

- Does access to a service or element of a service depend on membership of a specific group?
- Does a service or element of the service discriminate unlawfully against a group?
- Do people with disabilities find it impossible or unreasonably difficult to receive a service or element of a service?

The quality statements do not make it impossible or unreasonably difficult for a specific group to access a service or element of a service.

5. If applicable, does the quality standard advance equality?

- Please state if the quality standard, including statements, measures and indicators, as described will advance equality of opportunity, for example by making access more likely for certain groups, by tailoring the service to certain groups, or by making reasonable adjustments for people with disabilities?

The quality standard is expected to advance equality of opportunity.

The quality statements will ensure that information and care for people with motor neurone disease is tailored to meet their individual needs.