

**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 1

## **Introduction**

As outlined in the [Quality Standards process guide](http://www.nice.org.uk) (available from [www.nice.org.uk](http://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**

<b>Protected characteristics</b>
<b>Age</b>
<b>Disability</b>
<b>Gender reassignment</b>
<b>Pregnancy and maternity</b>
<b>Race</b>
<b>Religion or belief</b>
<b>Sex</b>
<b>Sexual orientation</b>
<b>Other characteristics</b>
<b>Socio-economic status</b> 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).
<b>Marital status (including civil partnership)</b>

**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:

- Refugees and asylum seekers
- Migrant workers
- Looked after children
- Homeless people.

## Quality standards equality analysis

### Stage: Meeting 1

#### 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.

People who have learning difficulties and people for whom English is not their 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. In addition, in some cases motor neurone disease is associated with frontotemporal dementia (a type of dementia that can affect personality and behaviour).

At this stage, no draft quality statements advocate the use of specific assessment tools. The draft statements do address the need to tailor information and care as follows:

Draft 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.

Draft statement 2 identifies people with cognitive changes so that communication, decision making and care can be tailored to their needs.

Draft statement 5 recognises the need to tailor assessments to individual circumstances, including making arrangements for those unable to access clinics.

Draft statement 6 assesses mobility and daily living needs to ensure that equipment can be provided or adapted to meet individual needs.

Draft statement 7 seeks to ensure that personal care is carried out by workers known to the person and thereby help ensure that communication and care is tailored to the individual needs of a person.

Draft statement 8 recognises that discussions about end of life care should take into account the person's current communication ability, cognitive status and mental capacity.

Potential equality issues will continue to be considered with the Quality Standards Advisory Committee as the quality standard is developed.

It is not envisaged that an alternative format of information for the public will be needed.

##### **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?

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 this topic were recruited.

The first stage of the process saw the topic overview and request for suggested areas for quality improvement published. Stakeholder comments were invited, including from those with a specific interest in equalities. Consultation responses were then considered by the QSAC.

The draft quality standard will be published for a 4 week consultation period for registered stakeholders to express their views on the proposed quality standard statements.

**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 will not exclude consideration of any population groups or settings. The source guideline relates to the assessment and management of motor neurone disease in adults, however the quality standard will not exclude consideration of people aged under-18 years with motor neurone disease if this is identified as a potential quality improvement area for the care of people with motor neurone disease.

**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 draft 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.

