

Motor neurone disease

Quality standard

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This standard is based on NG42.

This standard should be read in conjunction with QS123 and QS13.

Introduction

This quality standard covers the assessment and management of motor neurone disease. For more information see the [motor neurone disease topic overview](#).

Why this quality standard is needed

Motor neurone disease (MND) is a neurodegenerative condition affecting the brain and spinal cord. MND is characterised by the degeneration of primarily motor neurones, leading to muscle weakness.

Presentation of the condition varies. It can be as muscle weakness, wasting, cramps and stiffness of arms or legs; problems with speech or swallowing or, more rarely, with breathing. As the disease progresses, the pattern of symptoms and signs becomes similar, with increasing muscle weakness in the person's arms and legs, problems swallowing and communicating, and weakness of the muscles used for breathing, which ultimately leads to death. Most people die within 2–3 years of developing symptoms, but 25% are alive at 5 years and 5–10% at 10 years. The most common type of MND is amyotrophic lateral sclerosis (ALS). There are rarer forms, such as progressive muscular atrophy or primary lateral sclerosis, which may have a slower rate of progression.

Every person with MND has an individual progression of the disease. About 10–15% of people with MND will show signs of frontotemporal dementia, which causes cognitive dysfunction and issues in decision-making. A further 35% of people with MND show signs of mild cognitive change, which may affect their ability to make decisions and plan ahead.

MND can affect adults of any age, but mainly affects people aged 55 to 79. There are approximately 4,000 people with MND in England and Wales at any one time. The cause is unknown. About 5–10% of people with MND have a family history of the disease, and several abnormal genes have been identified.

There is no cure for MND. Therefore, care focuses on maintaining functional ability and enabling people with MND and their family members to live as full a life as possible.

The quality standard is expected to contribute to improvements in the following outcomes:

- quality of life
- functional ability
- patient-reported outcome: symptoms
- patient- and carer-reported outcome: satisfaction with care and support provided
- survival from onset of symptoms.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – safety, experience and effectiveness of care – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- [Adult Social Care Outcomes Framework 2015–16](#)
- [NHS Outcomes Framework 2016–17](#)
- [Public Health Outcomes Framework 2016–19](#).

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [The Adult Social Care Outcomes Framework 2015–16](#)

Domain	Overarching and outcome measures
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<p>1 Enhancing quality of life for people with care and support needs</p>	<p>Overarching measure</p> <p>1A Social care-related quality of life**</p> <p>Outcome measures</p> <p>People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</p> <p>1B Proportion of people who use services who have control over their daily life</p> <p>Carers can balance their caring roles and maintain their desired quality of life</p> <p>1D Carer-reported quality of life**</p>
<p>3 Ensuring that people have a positive experience of care and support</p>	<p>Overarching measure</p> <p>People who use social care and their carers are satisfied with their experience of care and support services</p> <p>3A Overall satisfaction of people who use services with their care and support</p> <p>3B Overall satisfaction of carers with social services</p> <p><i>Placeholder 3E The effectiveness of integrated care</i></p> <p>Outcome measures</p> <p>Carers feel that they are respected as equal partners throughout the care process</p> <p>3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for</p> <p>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help</p> <p>3D The proportion of people who use services and carers who find it easy to find information about support</p> <p>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual</p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level</p>

Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework

* Indicator is shared

** Indicator is complementary

Indicators in italics in development

Table 2 NHS Outcomes Framework 2016–17

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for people with long-term conditions	<p><i>Overarching indicator</i></p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p><i>Improvement areas</i></p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p>Improving functional ability in people with long-term conditions</p> <p>Enhancing quality of life for carers</p> <p>2.4 Health-related quality of life for carers**</p> <p>Enhancing quality of life for people with dementia</p> <p>2.6 i Estimated diagnosis rate for people with dementia*</p> <p>ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life***</p>

<p>4 Ensuring that people have a positive experience of care</p>	<p>Overarching indicators</p> <p>4b Patient experience of hospital care</p> <p>4c <i>Friends and family test</i></p> <p>4d <i>Patient experience characterised as poor or worse</i></p> <p><i>i Primary care</i></p> <p><i>ii Hospital care</i></p> <p>Improvement areas</p> <p>Improving people's experience of outpatient care</p> <p>4.1 Patient experience of outpatient services</p> <p>Improving the experience of care for people at the end of their lives</p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p>Improving people's experience of integrated care</p> <p>4.9 <i>People's experience of integrated care**</i></p>
<p>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

Table 3 Public Health Outcomes Framework 2016–19

Domain	Objectives and indicators
<p>4 Healthcare public health and preventing premature mortality</p>	<p>Objective</p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p>Indicators</p> <p>4.13 Health-related quality of life for older people</p>

Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework

* Indicator is shared

** Indicator is complementary

Indicators in italics in development

Safety and people's experience of care

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to MND.

NICE has developed guidance and an associated quality standard on patient experience in adult NHS services (see the NICE pathway on [patient experience in adult NHS services](#)), which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to people using services. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect people's experience of using services and are specific to the topic are considered during quality statement development.

Coordinated services

A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with MND. Services should be commissioned from, and coordinated across, all relevant agencies encompassing the whole MND care pathway.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality MND service are listed in [related NICE quality standards](#).

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and

competencies. All health, public health and social care practitioners involved in assessing, caring for and treating people with MND should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with MND. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

List of quality statements

Statement 1. Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Statement 2. Adults with MND who have respiratory impairment are offered non-invasive ventilation (NIV) based on regular assessments of respiratory function and symptoms.

Statement 3. Adults with MND receive tailored equipment and adaptations without delay, based on regular multidisciplinary team assessments.

Statement 4. Adults with MND receive personal care and support from a consistent team of workers who are familiar with their needs.

Statement 5. Adults with MND are given opportunities to discuss their preferences and concerns about end of life care at diagnosis and key stages of disease progression.

Quality statement 1: Information and support at diagnosis

Quality statement

Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Rationale

Receiving a diagnosis of MND is distressing for a person, and they (and their family members or carers) are likely to have a variety of questions and concerns. MND is rare and most healthcare professionals will have little experience and knowledge of it. A consultant neurologist with expertise in treating people with MND can provide accurate and up-to-date information on the diagnosis, prognosis and management of MND with compassion and understanding.

Quality measures

Structure

Evidence of local arrangements to ensure that people diagnosed with MND are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in MND.

Data source: Local data collection.

Process

Of adults with MND, the number who are given information at diagnosis about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

Outcome

a) Adults diagnosed with MND understand how the condition is likely to affect them.

Data source: Local data collection.

b) Adults diagnosed with MND understand the type of care and support they can receive.

Data source: Local data collection.

c) Adults diagnosed with MND, and their families or carers, feel able to cope.

Data source: Local data collection. National data on the proportion of people who felt supported through the consultation when receiving a diagnosis are available from the [Improving MND Care](#) survey.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (such as neurology services) ensure that adults who are diagnosed with MND are given information about the diagnosis, prognosis and management by a consultant neurologist with up-to-date knowledge and experience of treating people with MND.

Healthcare professionals (such as consultant neurologists with expertise in treating people with MND) ensure that they give adults who are diagnosed with MND information about the diagnosis, prognosis and management, and deliver the information with compassion and understanding. They give information according to the person's needs.

Commissioners (such as clinical commissioning groups and NHS England) ensure that commissioning responsibilities for people with MND are clear, and that they commission services in which adults who are diagnosed with MND are given information about the diagnosis, prognosis and management by a neurologist with up-to-date knowledge and experience of treating people with MND.

What the quality statement means for patients, service users and carers

Adults who are diagnosed with MND receive information about the diagnosis, how MND is likely to

progress and what will happen next, from a consultant neurologist with expertise in treating people with MND. A neurologist is a hospital doctor who specialises in disorders of the nervous system, including the brain, spinal cord and nerves.

Source guidance

- [Motor neurone disease](#) (2016) NICE guideline NG42, recommendation 1.2.1

Definitions of terms used in this quality statement

Consultant neurologist with expertise in treating people with MND

A consultant neurologist with up-to-date knowledge and experience of treating people with MND. They should have knowledge and expertise in:

- symptoms
- types and possible causes
- treatment options
- how MND may progress (including cognitive and behavioural changes) and how progression may affect the treatments offered
- crisis prevention (for example, if there is an acute hospital admission or a breakdown in care arrangements)
- opportunities for people with MND to be involved in research
- likely needs and concerns of people with MND and their family members and/or carers (as appropriate)
- advance care planning.

[Adapted from [Motor neurone disease](#) (NICE guideline NG42), recommendation 1.2.1]

Equality and diversity considerations

People with MND can experience cognitive problems. Cognitive change can occur early in the disease progression and may be present at diagnosis. All information should therefore be

accessible, as much as possible, to people with cognitive problems. People receiving information about MND should have access to an interpreter or advocate if needed.

In some geographical areas, consultant neurologists without MND expertise may be involved in investigations and testing for suspected MND. 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.

Quality statement 2: Respiratory assessment and non-invasive ventilation

Quality statement

Adults with motor neurone disease (MND) who have respiratory impairment are offered non-invasive ventilation (NIV) based on regular assessments of respiratory function and symptoms.

Rationale

Progressive respiratory muscle weakness resulting in respiratory impairment is a major feature of MND. The onset of respiratory failure (when a person is unable to breathe adequately to maintain normal oxygen levels and clear waste gases without support) can be sudden and unexpected, and may lead to emergency ventilation or death. Regular monitoring of respiratory function by MND multidisciplinary teams allows respiratory muscle weakness to be identified before symptoms of respiratory impairment appear. It also means that strategies such as NIV can be offered and started before an emergency situation occurs. NIV can improve symptoms and signs related to respiratory impairment, and improve quality of life and survival. Decisions to offer NIV are made between the MND multidisciplinary team, the respiratory ventilation service and the person with MND.

Quality measures

Structure

a) Evidence that MND multidisciplinary teams include respiratory physiologists or healthcare professionals who can assess respiratory function.

Data source: Local data collection.

b) Evidence of local arrangements and written protocols to ensure that adults with MND have their respiratory function and symptoms assessed at diagnosis and then every 2–3 months.

Data source: Local data collection.

c) Evidence of established relationships and decision making arrangements between MND multidisciplinary teams and respiratory ventilation services.

Data source: Local data collection.

d) Evidence of local arrangements to provide NIV for adults with MND who have respiratory impairment.

Data source: Local data collection.

Process

a) Of adults diagnosed with MND, the number of adults who had their respiratory function and symptoms assessed as part of the initial assessment to diagnose MND.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

b) Of adults with MND, the number who have had their respiratory function and symptoms assessed within the past 3 months.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers. At national level, self-reported information on the frequency of breathing monitoring and assessments is presented in the [Improving MND Care](#) survey.

c) Of adults with MND who have respiratory impairment, the number who are established on NIV.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

Outcome

a) Survival of adults with MND from diagnosis.

Data source: Local data collection.

b) Adults with MND able to maintain activities of daily living.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (such as MND multidisciplinary teams and respiratory ventilation services) ensure that they assess people's respiratory function and symptoms as part of the initial assessment to diagnose MND, or soon after diagnosis, and then every 2–3 months. Providers ensure that there are local arrangements for timely provision of NIV and agreed local protocols for referral to this service.

Healthcare professionals (members of the MND multidisciplinary team, such as respiratory physiologists or healthcare professionals who can assess respiratory function) ensure that they assess respiratory function and symptoms as part of the initial assessment to diagnose MND, or soon after diagnosis, and then every 2–3 months. Members of the MND multidisciplinary team should make decisions to offer NIV in conjunction with the respiratory ventilation service and the person with MND.

Commissioners (such as clinical commissioning groups and NHS England) ensure that the services they commission have MND multidisciplinary teams that include healthcare professionals with appropriate competencies to perform respiratory function tests and monitor signs and symptoms of potential respiratory impairment. Decisions to offer NIV should be taken by MND multidisciplinary teams in conjunction with respiratory ventilation services, and based on the respiratory assessments.

What the quality statement means for patients, service users and carers

Adults with MND are regularly checked to see if they are having any problems with their breathing. These checks should happen when they are diagnosed with MND (or shortly afterwards) and then in regular appointments with a team of specialists called an MND multidisciplinary team (usually every 2–3 months). Adults with MND who are having difficulty breathing are offered non-invasive ventilation using a portable ventilator – a machine that supports the person's breathing. Decisions about non-invasive ventilation are shared between the multidisciplinary team, the respiratory ventilation service and the person with MND.

Source guidance

- [Motor neurone disease \(2016\) NICE guideline NG42](#), recommendations 1.5.3, 1.12.1, 1.12.2, 1.14.7, and 1.14.8–1.14.15

Definitions of terms used in this quality statement

Non-invasive ventilation

Non-invasive ventilation refers to methods of providing ventilatory support to a patient without placing an artificial airway in the main windpipe (trachea). This is usually achieved by fitting a mask covering the nose, or mouth and nose, or using nasal tubes or a mouthpiece, which is connected to a ventilator by tubing. The ventilator detects when the patient tries to take a breath in and delivers an extra flow of air to increase the volume of air inhaled.

[[Motor neurone disease](#) (NICE guideline NG42), full guideline glossary]

Regular assessments of respiratory function and symptoms

Respiratory function tests performed as part of the initial assessment to diagnose MND, or soon after diagnosis, by MND multidisciplinary team members such as respiratory physiologists or healthcare professionals who can assess respiratory function. Thereafter respiratory function tests are performed every 2–3 months, although occasionally tests may be performed more or less often depending on:

- whether there are any symptoms and signs of respiratory impairment
- the rate of progression of MND
- the person's preference and circumstances.

[Adapted from [Motor neurone disease](#) (NICE guideline NG42), recommendations 1.14.7, 1.14.8 and 1.14.10, and expert opinion]

Respiratory function tests to be undertaken at diagnosis and ongoing assessment are those detailed in [motor neurone disease](#) (NICE guideline NG42), section 1.14.

Symptoms and signs monitored in an assessment to detect potential respiratory impairment are set out in box 1 [motor neurone disease](#) (NICE guideline NG42), recommendation 1.14.7.

Assessment in the context of this statement also includes assessment of bulbar function, because this affects the type tests performed and the response to NIV.

[[Motor neurone disease](#) (NICE guideline NG42), recommendations 1.14.9, 1.14.18; expert opinion]

Assessment for potential respiratory impairment includes monitoring cough effectiveness (weak cough being a sign of potential respiratory impairment) potentially by measuring cough peak flow.

[[Motor neurone disease](#) (NICE guideline NG42), recommendation 1.14.7; expert opinion]

Quality statement 3: Provision of equipment and adaptations based on multidisciplinary team assessment

Quality statement

Adults with motor neurone disease (MND) receive tailored equipment and adaptations without delay, based on regular multidisciplinary team assessments.

Rationale

People with MND can have multiple functional problems and may therefore have complex equipment needs that will change as MND progresses. Regular assessment by the MND multidisciplinary team can ensure the provision of equipment and adaptations is responsive to a person's changing needs. Providing equipment and adaptations without delay maximises the impact on the person's quality of life, allowing them to continue with usual activities and reduce the likelihood of harm from adverse events such as falls.

Quality measures

Structure

a) Evidence of local arrangements to ensure that adults with MND have regular assessments from MND multidisciplinary teams.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that equipment is provided, or adapted, in a timely way to meet the individual needs identified for adults with MND.

Data source: Local data collection.

Process

a) Of adults with MND, the number who have had a comprehensive assessment by the MND

multidisciplinary team in the past 3 months.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

b) The length of time in days between an equipment need or an adaption need being identified in a comprehensive multidisciplinary team assessment, and the equipment being provided or adaption made.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

Outcome

a) Adults with MND able to maintain activities of daily living.

Data source: Local data collection. National data on whether people with MND feel that the equipment or adaption they are using meets their needs is available from the [Improving MND Care](#) survey.

b) Adults with MND feel they are able to maintain their quality of life.

Data source: Local data collection.

c) Number of injuries to adults in the home associated with functions impaired by MND.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and social care practitioners, and commissioners

Service providers (such as MND multidisciplinary teams) ensure that they assess people's needs, including mobility and daily living needs and abilities every 2–3 months, and that services are integrated between providers so that equipment and adaptations can be provided to meet people's changing needs without delay.

Healthcare professionals and social care practitioners (such as members of MND multidisciplinary

teams) ensure that they assess and anticipate changes in the person's needs, including mobility and daily living needs and abilities, every 2–3 months, and provide, or refer to services that can provide, equipment and adaptations to meet the person's individual needs without delay.

Commissioners (such as clinical commissioning groups and NHS England) ensure that they commission MND services in which MND multidisciplinary teams assess people's needs, encompassing mobility and daily living needs and abilities, every 2–3 months, and provide tailored equipment and adaptations without delay.

What the quality statement means for patients, service users and carers

Adults with MND have regular checks to make sure that any equipment they have been given to help them manage their condition, such as a wheelchair, is still meeting their needs. These checks also help to anticipate any future changes in their needs, including whether any changes to existing equipment or new equipment will be needed. The checks should happen in appointments with a team of specialists called an MND multidisciplinary team (usually every 2–3 months).

Source guidance

- [Motor neurone disease](#) (2016) NICE guideline NG42, recommendations 1.5.3, 1.9.1, 1.9.2 and 1.9.6

Definitions of terms used in this quality statement

Tailored equipment and adaptations

Daily living aids, assistive technology and adaptations that can be integrated and adapted to meet the changing needs of the person with MND and their family or carers. Examples include wheelchairs, hoists, head supports, arm supports, riser–recliner chairs, drinking and eating aids, environmental controls, and home adaptations.

[[Motor neurone disease](#) (NICE guideline NG42), recommendations 1.9.5, 1.9.6 and 1.9.7]

Regular assessments

Assessments carried out by the multidisciplinary team every 2–3 months unless the person's symptoms and needs require more or less frequent assessment. Assessments cover the areas set

out in recommendation 1.5.3 in NICE's guideline on [motor neurone disease](#) that include mobility and activities of daily living, communication, nutritional intake, swallowing, muscle problems, physical function, pain, respiratory function, cognition and behaviour, and social care needs.

Assessments include assessing and anticipating changes in the person's daily living needs, taking into account:

- activities of daily living, including personal care, dressing and bathing, housework, shopping, food preparation, eating and drinking, and ability to continue with current work and usual activities
- mobility and avoiding falls and problems from loss of dexterity
- the home environment and the need for adaptations
- the need for assistive technology, such as environmental control systems
- a person's ability to use equipment.

[Adapted from [Motor neurone disease](#) (NICE guideline NG42), recommendations 1.5.2, 1.5.6, 1.9.1 and 1.9.6]

Multidisciplinary team

An MND multidisciplinary team that:

- includes healthcare professionals and social care practitioners with expertise in MND, including staff who see people in their home
- ensures effective communication and coordination between all healthcare professionals and social care practitioners involved in the person's care (and their family members and/or carers, as appropriate)
- provides coordinated care for people who cannot attend a clinic, according to the person's needs.

The core multidisciplinary team should consist of healthcare professionals and other professionals with expertise in MND, and should include:

- neurologist

- specialist nurse
- dietitian
- physiotherapist
- occupational therapist
- respiratory physiologist or a healthcare professional who can assess respiratory function
- speech and language therapist
- a healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional).

The multidisciplinary team should have established relationships with, and prompt access to:

- clinical psychology and neuropsychology
- social care
- counselling
- respiratory ventilation services
- specialist palliative care
- gastroenterology
- orthotics
- wheelchair services
- assistive technology services
- alternative and augmentative communication (AAC) services
- community neurological care teams.

[[Motor neurone disease](#) (NICE guideline NG42), recommendations 1.5.2, 1.5.4 and 1.5.5]

Quality statement 4: Continuity of care

Quality statement

Adults with motor neurone disease (MND) receive personal care and support from a consistent team of workers who are familiar with their needs.

Rationale

A consistent team of personal care workers can ensure familiarity with the person with MND and their specific needs. This avoids care needs having to be repeatedly explained to new workers. Such explanations can be difficult for people with MND, who may have reduced communication abilities and need a family member or carer to be present to help them. Ensuring continuity of care can avoid this additional burden or source of stress on the person with MND, and their family or carers.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MND receive personal care and support from a consistent team of care workers who are familiar with their needs.

Data source: Local data collection.

Process

a) Number of workers providing personal care and support for an adult with MND.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or local authority group level, data collection will involve small numbers.

b) Number of first visits of workers providing personal care and support for an adult with MND.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or local authority group level, data collection will involve small numbers.

Outcome

a) Adults with MND feel they receive the personal care and support they need.

Data source: Local data collection. National data on the proportion of people with MND who feel they get the social care services they need, are available from the [Improving MND Care](#) survey.

b) Adults with MND feel they are treated with dignity and respect.

Data source: Local data collection. National data on the proportion of people with MND who feel their independence/autonomy is respected when receiving social care services are available from the [Improving MND Care](#) survey.

What the quality statement means for service providers, social care practitioners and commissioners

Service providers (such as independent home care agencies, voluntary sector organisations and local authorities) ensure that personal care and support for adults with MND is provided by a consistent team of workers who are familiar with the person's needs.

Social care practitioners (such as care workers and personal assistants) should ensure that they get to know the person they care for, what their needs are and provide care in the way that person wants.

Commissioners (such as local authorities) ensure that services they commission provide personal care and support for adults with MND from a consistent team of workers who are familiar with the person's needs.

What the quality statement means for patients, service users and carers

Adults with MND have their personal care and support provided by the same workers, who are familiar with their needs.

Source guidance

- [Motor neurone disease](#) (2016) NICE guideline NG42, recommendation 1.6.5

Quality statement 5: Planning for end of life care

Quality statement

Adults with motor neurone disease (MND) are given opportunities to discuss their preferences and concerns about end of life care at diagnosis and key stages of disease progression.

Rationale

MND can present in different ways and the prognosis may be variable, but the majority of people with MND die within 2–3 years of diagnosis. Discussions about end of life are difficult, but sensitive discussions can address concerns and result in increased support, control and choice for the person and their families and carers. Such discussions can take place at any time, but there are particular times when people should be given the chance to discuss the topics. These times include at diagnosis, if there is a significant change in respiratory function, or if interventions such as gastrostomy or non-invasive ventilation are needed. Early planning for care at the end of life also ensures that families and professionals can be made aware of a person's wishes for end of life care before communication or cognitive changes make this difficult or impossible.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MND are given opportunities to discuss their preferences and concerns about end of life care at diagnosis and key stages of disease progression.

Data source: Local data collection.

Process

a) Of adults with MND, the number given opportunities to discuss their preferences and concerns about end of life care at diagnosis.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

b) Of adults with MND, the number given opportunities to discuss their preferences and concerns about end of life care at key stages of disease progression.

Data source: Local data collection based on extracts from or reviews of individual care records. At provider or clinical commissioning group level, data collection will involve small numbers.

Outcome

a) Adults with MND feel they have choice and control over their end of life care.

Data source: Local data collection.

b) Adults with MND receive end of life care informed by their wishes and preferences if they lose the ability to communicate.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (such as MND multidisciplinary teams) ensure that healthcare professionals are able to provide support and advice on advance care planning for end of life to people with MND and their family members and carers, and that they give people with MND the opportunity to discuss their preferences and concerns about end of life care at diagnosis and key stages of the disease progression.

Healthcare professionals (such as members of the MND multidisciplinary team) ensure that they give people with MND the opportunity to discuss their preferences and concerns about end of life care at diagnosis and key stages of the disease progression. Healthcare professionals should ensure that they are sensitive about the timing of discussions and take into account the person's current communication ability, cognitive status and mental capacity.

Commissioners (such as clinical commissioning groups and NHS England) ensure that they commission services that have staff that are able to provide support and advice on advance care planning for end of life to people with MND and their family members and carers.

What the quality statement means for patients, service

users and carers

Adults with MND are asked if they would like to talk about any concerns they have about dying and what they would prefer to happen (or not happen) at the end of their life.

Source guidance

- [Motor neurone disease](#) (2016) NICE guideline NG42, recommendation 1.7.1

Definitions of terms used in this quality statement

Discuss preferences and concerns about end of life care

Discussions should involve providing support and advice on advance care planning for end of life to the person with MND and their family members and carers (as appropriate). The discussion should include:

- what could happen at end of life, for example how death may occur
- providing anticipatory medicines in the home
- advance care planning, including Advance Decisions to Refuse Treatment and Do Not Attempt Cardiopulmonary Resuscitation orders, and Lasting Power of Attorney
- areas that people might wish to plan for, such as:
 - what they want to happen (for example preferred place of death)
 - what they do not want to happen (for example being admitted to hospital)
 - who will represent their decisions, if necessary
 - what should happen if they develop an intercurrent illness.

Sensitivity is needed regarding to the timing of discussions, and the person's current communication ability, cognitive status and mental capacity should be taken into account.

[Adapted from [Motor neurone disease](#) (NICE guideline NG42), recommendations 1.7.1 and 1.7.3]

Key stages of the disease progression

Key stages of the disease progression include significant changes in the condition of the person with MND, and the trigger points set out in the guideline recommendation:

- when there is a significant change in respiratory function
- when interventions such as gastrostomy or non-invasive ventilation are needed.

[Adapted from [Motor neurone disease](#) (NICE guideline NG42), recommendation 1.7.1 and expert opinion]

Equality and diversity considerations

People with MND can experience cognitive problems. About 10% of people with MND show signs of frontotemporal dementia and a further 35% show signs of mild cognitive change. Cognitive or behavioural change does not mean that a person with MND will no longer be able to make decisions but rather that care should be provided in a way that accommodates the cognitive or behavioural changes. This could include allowing more time for decision making and an understanding of behaviour change. All information provided should be accessible, as far as possible, to people with cognitive problems. People receiving information about MND should have access to an interpreter or advocate if needed.

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [what makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

NICE's [quality standard service improvement template](#) helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement. This tool is updated monthly to include new quality standards.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health, public health and social care practitioners and people with MND, and their families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with MND and their families or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

Development sources

Further explanation of the methodology used can be found in the [quality standards process guide](#).

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the quality standards advisory committee to develop the quality standard statements and measures.

- [Motor neurone disease \(2016\) NICE guideline NG42](#)

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- National Audit Office (2015) [Services for people with neurological conditions: progress review](#)
- Health and Social Care Information Centre (2014) [Compendium of neurology data, England – 2012–13](#)
- Welsh Government (2014) [Neurological conditions](#)
- NHS England (2013) [Complex disability equipment alternative and augmentative communication/communication aids \(all ages\)](#)
- NHS England (2013) [Complex disability equipment specialised wheelchair and seating services \(all ages\)](#)
- NHS England (2013) [Neurosciences: specialised neurology \(adult\)](#)
- NHS England (2013) [Respiratory: complex home ventilation \(adult\)](#)
- Royal College of Physicians and Association of British Neurologists (2011) [Local adult neurology services for the next decade](#)

Definitions and data sources for the quality measures

- [Motor neurone disease \(2016\) NICE guideline NG42](#)

Related NICE quality standards

Published

- [Home care for older people](#) (2016) NICE quality standard 123
- [End of life care for adults](#) (2011) NICE quality standard 13

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Neurological problems (relatively uncommon neurological problems such as muscular dystrophy)
- Service user and carer experience: services user and carer experience of social care

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.

Quality standards advisory committee and NICE project team

Quality standards advisory committee

This quality standard has been developed by Quality Standards Advisory Committee 4. Membership of this committee is as follows:

Miss Alison Allam

Lay member

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The following specialist members joined the committee to develop this quality standard:

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Advanced Nurse Practitioner, Oxford University Hospital

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About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard has been incorporated into the NICE pathway on [motor neurone disease](#).

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- British Association of Prosthetists and Orthotists
- Royal College of Occupational Therapists (RCOT)
- Motor Neurone Disease Association
- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)