

Multiple sclerosis

Quality standard

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This standard is based on CG186.

This standard should be read in conjunction with QS89, QS77, QS54, QS53, QS45, QS43, QS24, QS13 and QS8.

Introduction

This quality standard covers the diagnosis and management of multiple sclerosis (MS) in adults (18 years and over). For more information see the multiple sclerosis [topic overview](#).

Why this quality standard is needed

MS is an acquired chronic immune-mediated inflammatory condition of the central nervous system, affecting both the brain and spinal cord. People with MS typically develop symptoms in their late 20s, experiencing visual and sensory disturbances, limb weakness, gait problems, and bladder and bowel symptoms. They may initially have partial recovery, but over time develop progressive disability.

The cause of MS is unknown but is believed to be related to an abnormal immune response to environmental triggers in people with a genetic predisposition. The initial phase of inflammation is followed by a phase of progressive degeneration of the affected cells in the nervous system.

MS affects approximately 100,000 people in the UK. It is the commonest cause of serious physical disability in adults of working age.

The most common pattern of disease is relapsing–remitting MS (RRMS), in which periods of stability (remission) are followed by periods when symptoms are worse (relapses). About 85% of people with MS have RRMS at onset. Around two-thirds of people who start with RRMS may develop secondary progressive MS (the disability gradually gets worse over time but this is not related to any relapses, which become less frequent or stop completely). About 10–15% of people with MS have primary progressive MS. Symptoms develop gradually and get worse over time, but these people never experience relapses and remissions.

MS can lead to a high level of disability with considerable personal, social and economic consequences. People with MS may live for many years after diagnosis with significant impact on their ability to work, as well as an adverse and often highly debilitating effect on their quality of life and that of their families.

Management of MS includes treatment to reduce the frequency and severity of relapses, managing symptoms, and lifestyle changes to manage relapses or disease progression.

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

- patient experience of the diagnostic process and support
- frequency of relapse
- severity of relapse
- emergency hospital admissions
- length of hospital stay
- severity of disability
- carer quality of life.

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 – patient safety, patient experience and clinical effectiveness – 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:

- [NHS Outcomes Framework 2015–16](#)
- [Adult Social Care Outcomes Framework 2015–16](#)
- [Public Health Outcomes Framework 2013–16.](#)

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

Table 1 [NHS Outcomes Framework 2015–16](#)

Domain	Overarching indicators and improvement areas
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<p>2 Enhancing quality of life for people with long-term conditions</p>	<p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p>Improvement areas</p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition (ASCOF 1A**)</p> <p>Improving functional ability in people with long-term conditions</p> <p>2.2 Employment of people with long-term conditions (ASCOF 1E** and PHOF 1.8*)</p> <p>Improving quality of life for people with multiple long-term conditions</p> <p>2.7 Health-related quality of life for people with three or more long-term conditions (ASCOF 1A**)</p>
<p>4 Ensuring that people have a positive experience of care</p>	<p>Overarching indicator</p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>4b Patient experience of hospital care</p> <p>4c Friends and family test</p> <p>4d Patient experience characterised as poor or worse</p> <p>i. Primary care</p> <p>ii. Hospital care</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 people's experience of integrated care</p> <p>4.9 People's experience of integrated care (ASCOF 3E**)</p>

Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework

* Indicator is shared

** Indicator is complementary

Table 2 The Adult Social Care Outcomes Framework 2015–16

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	<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>1D Carer-reported quality of life</p>
3 Ensuring that people have a positive experience of care and support	<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 of carers.</p> <p><i>Placeholder 3E: The effectiveness of integrated care*</i></p> <p>Outcome measures</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>Aligning with NHS Outcomes Framework and/or Public Health Outcomes Framework</p> <p>* Indicator complementary</p>	

Table 3 Public Health Outcomes Framework for England, 2013–16

Domain	Objectives and indicators
1 Improving the wider determinants of health	<p>Objective</p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities</p> <p>Indicators</p> <p>1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services*</p> <p>1.9 Sickness absence rate</p>
2 Health improvement	<p>Objective</p> <p>People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p>Indicators</p> <p>2.13 Proportion of physically active and inactive adults</p> <p>2.23 Self-reported well-being</p> <p>2.24 Injuries due to falls in people aged 65 and over</p>
<p>Alignment with NHS Outcomes Framework and/or Adult Social Care Outcomes Framework</p> <p>* Indicator shared with the NHS Outcomes Framework</p>	

Patient experience and safety issues

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 MS.

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 are supported to understand their options and make fully informed decisions. They also cover the provision of information to patients and service users. 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 patient experience and are specific to

the topic are considered during quality statement development. Statement 1 covers the provision of information and the offer of support at the time of diagnosis. Statements 9, 12 and 14 from the NICE quality standard on patient experience in adult NHS services are particularly relevant to this topic, and relate to statements 3 and 5 in this quality standard.

Coordinated services

The quality standard for MS specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole MS care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults with MS.

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 MS service are listed in [related 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 adults with MS 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(s) 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 adults with MS. If appropriate, healthcare professionals 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 with multiple sclerosis (MS) are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

Statement 2. Adults with MS are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

Statement 3. Adults with MS have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Statement 4. Adults with MS who have problems with mobility or fatigue are offered support to remain physically active.

Statement 5. Adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Statement 6. Adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

Quality statement 1: Support at diagnosis

Quality statement

Adults with multiple sclerosis (MS) are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

Rationale

Receiving a diagnosis of a long-term condition like MS is life changing and stressful. It is important that consultant neurologists offer information, advice and support at the time of diagnosis so that the person with MS has a sense of control over their own life, is more able to make decisions about how their condition is managed, and is less anxious.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MS are supported at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

Data source: Local data collection.

Process

Proportion of adults with MS who are given information about MS, its progression and the ways it can be managed by the consultant neurologist at the time of diagnosis.

Numerator – The number in the denominator who are given information about the condition by the consultant neurologist at the time of diagnosis.

Denominator – The number of adults receiving a new diagnosis of MS from a consultant neurologist.

Data source: Local data collection.

Outcome

Patient satisfaction with the support provided at diagnosis.

Data source: Local data collection.

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

Service providers (neurology services) ensure that systems are in place for adults with MS to be supported at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

Healthcare professionals (consultant neurologists) ensure that at the time of making the diagnosis, they support adults with MS to understand the condition, its progression and the ways it can be managed.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that they commission services that support adults with MS at the time of diagnosis to understand the condition, its progression and the ways it can be managed.

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

Adults with MS are given support by the consultant when first told that they have MS. This early support helps people with MS (and their families and carers) to begin to understand what MS is, what treatments are available and how the symptoms can be managed.

Source guidance

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186, recommendation 1.2.2 (key priority for implementation)

Definitions of terms used in this quality statement

Support

This should include oral and written information about:

- what MS is

- treatments, including disease-modifying therapies
- symptom management
- how support groups, local services, social services and national charities are organised and how to get in touch with them
- legal requirements such as notifying the Driver and Vehicle Licensing Agency (DVLA), and legal rights including social care, employment rights and benefits.

[[Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendation 1.2.2]

Equality and diversity considerations

Cognitive problems are a common symptom of MS. People can experience a wide range of difficulties, including problems with attention, memory and decision-making, and planning. All information should be accessible to people with cognitive problems. People receiving information about MS should have access to an interpreter or advocate if needed.

Quality statement 2: Follow-up after diagnosis

Quality statement

Adults with multiple sclerosis (MS) are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

Rationale

It can be difficult for people with MS to take in the information and advice they are given at the time of diagnosis. A follow-up appointment provides time for people with MS to adjust to their diagnosis. They can think about the information that they were given and any further information they want, and then can have any questions answered by a specialist. The appointment means that people with MS can meet healthcare professionals with expertise in MS, who may be involved in their future care, soon after diagnosis.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MS have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Data source: Local data collection.

Process

Proportion of adults with MS who have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Numerator – The number in the denominator who have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Denominator – The number of adults receiving a new diagnosis of MS.

Data source: Local data collection.

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

Service providers (neurology services) ensure that systems are in place for adults with MS to have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Healthcare professionals (consultant neurologists) ensure that they offer adults with MS a face-to-face follow-up appointment with themselves or another healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that they commission services in which adults with MS are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

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

Adults with MS are offered an appointment with a specialist to take place within 6 weeks of their diagnosis. This gives them time to read and think about the information they were given at the time of diagnosis and the opportunity to have any questions answered by a healthcare professional with experience in MS. They can also ask for more information and support if they need it. The appointment also gives them the opportunity to meet a healthcare professional who will be involved in their care and to find out how and when to contact them in the future.

Source guidance

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186, recommendation 1.2.4 (key priority for implementation).

Definitions of terms used in this quality statement

Healthcare professional with expertise in MS

The neurologist responsible for making the diagnosis of MS should ensure that a formal face-to-face follow-up within 6 weeks is provided by themselves or another healthcare professional with expertise in MS (such as an MS nurse), depending on the local service organisation.

[Adapted from [Multiple sclerosis in adults: management](#) (NICE full guideline CG186) section 6.6].

Equality and diversity considerations

Cognitive problems are a common symptom of MS. People can experience a wide range of difficulties, including problems with attention, memory and decision-making, and planning. This might mean that people with MS forget that they have an appointment, so they should be reminded about the appointment and contacted if they do not attend.

Quality statement 3: Coordinated care

Quality statement

Adults with multiple sclerosis (MS) have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Rationale

Adults with MS have different needs for information, advice and support, and this will change as their condition progresses. Support should be tailored to the individual person and responsive to changing needs, including relapses, acute deteriorating symptoms and progression. A single point of contact will ensure that adults with MS can access care and support from health and social care practitioners, which is relevant to their specific needs.

Quality measures

Structure

a) Evidence of local arrangements to provide adults with MS with a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Data source: Local data collection.

b) Evidence of local arrangements for a multidisciplinary team with expertise in MS to care for adults with MS.

Data source: Local data collection.

Process

Proportion of adults with MS with a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Numerator – The number in the denominator with a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Denominator – The number of adults with MS.

Data source: Local data collection.

Outcome

a) Patient satisfaction with a single point of contact for coordination of access to care.

Data source: Local data collection.

b) Patient satisfaction with timeliness of access to care from the multidisciplinary team with expertise in MS.

Data source: Local data collection.

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

Service providers (neurology services) ensure that adults with MS have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Health and social care practitioners (members of the multidisciplinary team) provide coordinated care for adults with MS through a single point of contact.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that, for adults with MS, they commission neurology services that have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

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

Adults with MS have someone they can contact to help them get the care they need from health and care services. They know when and how to contact this person. They can talk about any changes in their condition and any extra or different support they might need. Support should be available from a team with training and skills in managing MS.

Source guidance

- [Multiple sclerosis in adults: management \(2014\) NICE guideline CG186, recommendations 1.3.1 \(key priority for implementation\) and 1.3.2.](#)

Definitions of terms used in this quality statement

Multidisciplinary team with expertise in MS

The team should involve professionals who have expertise in managing MS, including consultant neurologists, MS nurses, physiotherapists and occupational therapists.

Other professionals should be involved, according to the needs of the individual adult with MS, such as rehabilitation physicians, speech and language therapists, psychologists, dietitians, GPs, social care and continence specialists. A multidisciplinary team approach should encompass all these perspectives as well as those of the person with MS and their family.

[[Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendation 1.3.1 and full guideline section 7.6]

Quality statement 4: Physical activity

Quality statement

Adults with multiple sclerosis (MS) who have problems with mobility or fatigue are offered support to remain physically active.

Rationale

Remaining physically active can improve mobility and fatigue, which are common problems experienced by adults with MS. It can also help to reduce the secondary complications of inactivity, such as pressure sores, and help adults with MS to regain or maintain their strength.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MS who have problems with mobility or fatigue are supported to remain physically active.

Data source: Local data collection.

Process

Proportion of adults with MS who are offered support to remain physically active.

Numerator – the number in the denominator who are offered support to remain physically active.

Denominator – the number of adults with MS who have problems with mobility or fatigue.

Data source: Local data collection.

Outcome

a) Adults with MS who have problems with mobility or fatigue feel supported by healthcare professionals to remain physically active.

Data source: Local data collection.

b) Levels of physical activity among adults with MS.

Data source: Local data collection

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

Service providers (GPs, community health teams and neurology services) ensure that adults with MS who have problems with mobility or fatigue are offered support to remain physically active. It may be useful to compile information about local exercise classes, groups and facilities, so that people can be given information about any that are suitable.

Healthcare professionals (members of the multidisciplinary team) ensure that they offer adults with MS who have problems with mobility or fatigue support to remain physically active.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that they commission services in which adults with MS who have problems with mobility or fatigue are offered support to remain physically active. The services commissioned should include provision of supervised exercise programmes for adults with MS who may benefit because of problems with mobility or fatigue.

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

Adults with MS who have problems with movement or fatigue are helped to do some exercise because this can improve these symptoms. Healthcare professionals should explain what types of exercise are suitable, what activities are available and ask which the person prefers.

Source guidance

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186, recommendations 1.5.6, 1.5.8, 1.5.11 (key priority for implementation), 1.5.13 and 1.5.14

Definitions of terms used in this quality statement

Support to remain physically active

Healthcare professionals should discuss the potential benefits of exercise with adults with MS who have problems with mobility or fatigue. Programmes or courses of exercise therapy should be supported by a competent professional, such as a physiotherapist with expertise in MS, who can

suggest the most suitable exercises and monitor the effects. Types of suitable physical activity may include the following:

- aerobic, balance and stretching exercises, including yoga
- a comprehensive programme of aerobic and moderate progressive resistance activity combined with cognitive behavioural techniques for fatigue in adults with MS with an Expanded Disability Status Scale score of greater than or equal to 4
- supervised exercise programmes involving moderate progressive resistance training and aerobic exercise
- exercise referral schemes.

People with MS should also be encouraged to keep exercising after programmes end for longer term benefits.

[Adapted from [Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendations 1.5.6, 1.5.8, 1.5.11, 1.5.13 and 1.5.14, full guideline sections 10.3.6 and 10.4.6 and expert opinion]

Quality statement 5: Managing relapses

Quality statement

Adults with multiple sclerosis (MS) who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Rationale

Rapid treatment of relapse can improve recovery and long-term outcomes of people with MS and prevent unplanned hospital admissions. Local pathways for managing relapse can help to identify relapses early and improve response times. Recognition of relapses by the multidisciplinary team, based on effective assessment, is important because relapse frequency may influence which disease-modifying therapies are chosen and whether they need to be changed.

Quality measures

Structure

Evidence of local pathways to ensure that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Data source: Local data collection.

Process

a) Length of time between onset of symptoms of relapse and receiving treatment for adults with MS.

Data source: Local data collection.

b) Proportion of relapses in adults with MS that would benefit from treatment and are treated within 14 days of the onset of symptoms.

Numerator – The number in the denominator treated within 14 days of the onset of symptoms.

Denominator – The number of relapses in adults with MS that would benefit from treatment.

Data source: Local data collection.

Outcome

Unplanned hospital admissions for MS.

Data source: Hospital Episode Statistics, Admitted Patient Care, England – 2013–14, using ICD-10 code G35, from The Health and Social Care Information Centre.

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

Service providers (GPs, community health teams, and neurology services) ensure that local pathways for managing relapse are in place so that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Health and social care practitioners (those involved in the care of adults with MS) ensure that they are aware of local pathways for managing relapse so that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that they commission services that have local pathways for managing relapse for adults with MS so that treatment is offered, for relapses that would benefit, as soon as possible and within 14 days of the onset of symptoms.

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

Adults with MS who have new symptoms or symptoms that suddenly get worse (a relapse) are offered treatment if this is likely to help. The treatment is offered as soon as possible and within 14 days of the symptoms starting. They can get the treatment through their single point of contact. Quicker treatment should help them get better sooner and may mean they don't have to go to hospital.

Source guidance

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186, recommendation 1.7.5.

Definitions of terms used in this quality statement

Relapse

A relapse should be diagnosed if the person develops new symptoms or their existing symptoms get worse and last for more than 24 hours in the absence of infection or any other cause after a stable period of at least 1 month. Relapses should be assessed and diagnosed by a healthcare professional with expertise in MS because not all relapses need treating with steroids.

[[Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendations 1.7.2 and 1.7.3]

Treatment for relapse

Treatment should be offered for relapses of MS that affect the person's ability to perform their usual tasks. Adults with MS who have a relapse should be offered treatment with oral methylprednisolone 0.5 g daily for 5 days. Intravenous methylprednisolone should be considered if oral steroids have failed or are not tolerated or for people who need admitting to hospital for a severe relapse or monitoring of medical or psychological conditions. People should not be given a supply of steroids to self-administer at home for future relapses.

[[Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendations 1.7.5, 1.7.7, 1.7.8 and 1.7.10]

Quality statement 6: Comprehensive review

Quality statement

Adults with multiple sclerosis (MS) are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

Rationale

A comprehensive review for people with MS ensures that they have the opportunity to hear from healthcare professionals about any new treatments, to be kept informed of their options, and for any issues or changes that might need referral to different services or other healthcare professionals to be identified. A planned review will also pick up people who have not been in contact with services, whose condition is not being monitored and who are not receiving support. These people may have more unmet needs than those in regular contact.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

Data source: Local data collection.

Process

Proportion of adults with MS who have a comprehensive review by healthcare professionals with expertise in MS within 12 months of the previous review or diagnosis.

Numerator – The number in the denominator who have a comprehensive review by healthcare professionals with expertise in MS within 12 months of the previous review or diagnosis.

Denominator – The number of adults with MS.

Data source: Local data collection.

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

Service providers (GPs, community health teams and neurology services) ensure that adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

Healthcare professionals (members of the multidisciplinary team with expertise in MS) ensure that they offer adults with MS a comprehensive review at least once a year.

Commissioners (NHS England local area teams and clinical commissioning groups) ensure that they commission services that offer adults with MS a comprehensive review at least once a year by healthcare professionals with expertise in MS.

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

Adults with MS are offered an appointment at least once a year to discuss their condition with healthcare professionals with experience in MS. At this appointment they are asked about their symptoms, their medicines, their overall health and wellbeing, and how their condition affects their day-to-day life (family life, work and other activities). They can raise any problems and mention any extra support they need. A planned yearly appointment will also pick up people who have not been in contact with services over the past year but need some support.

Source guidance

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186, recommendations 1.6.1 and 1.6.2.

Definitions of terms used in this quality statement

Comprehensive review

A comprehensive review involves reviewing all aspects of care for a person with MS. The review should be carried out by healthcare professionals with expertise in MS and its complications, be tailored to the needs of the person with MS, and assess the following:

- MS symptoms
- the course of the disease and number of relapses in the past year

- general health, including mental health
- social activity and participation
- care and carers
- palliative care, when needed.

Other health and social care practitioners with expertise in specific areas of the review should be involved if needed. It is likely that the emphasis in the review may change over time and that different healthcare professionals may carry out the review. Any issues identified during the comprehensive review should be referred to other members of the MS multidisciplinary team and to other appropriate teams so that they can be managed. People with MS should also be offered a medication review.

[[Multiple sclerosis in adults: management](#) (NICE guideline CG186) recommendations 1.6.1, 1.6.2, 1.6.3, 1.6.4 and 1.6.5, full guideline section 11.6 and expert opinion]

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. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). 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.

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 and social care practitioners and adults with multiple sclerosis (MS) 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. Adults with MS 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.

- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186

Policy context

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

- NHS England (2014) [Clinical commissioning policy: disease modifying therapies for patients with multiple sclerosis \(MS\)](#)
- Department of Health (2011) [The risk sharing scheme for disease modifying therapies in MS](#)
- Department of Health (2005) [National service framework for long term conditions](#)

Definitions and data sources for the quality measures

- The Health and Social Care Information Centre (2015) [Hospital episode statistics](#)

Related NICE quality standards

Published

- [Pressure ulcers \(2015\) NICE quality standard 89](#)
- [Physical activity: for NHS staff, patients and carers \(2015\) NICE quality standard 84](#)
- [Urinary incontinence in women \(2015\) NICE quality standard 77](#)
- [Faecal incontinence in adults \(2014\) NICE quality standard 54](#)
- [Anxiety disorders \(2014\) NICE quality standard 53](#)
- [Lower urinary tract symptoms in men \(2013\) NICE quality standard 45](#)
- [Smoking: supporting people to stop \(2013\) NICE quality standard 43](#)
- [Nutrition support in adults \(2012\) NICE quality standard 24](#)
- [End of life care for adults \(2011\) NICE quality standard 13](#)
- [Depression in adults \(2011\) NICE quality standard 8](#)

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:

- Osteoporosis
- Pain management (young people and adults)
- Workplace: long-term sickness absence and management

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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Consultant Old Age Psychiatrist, Manchester Mental Health and Social Care Trust

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Independent Patient Safety Nurse, Palladium Patient Safety

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Head of Quality and Safety, North Kent Clinical Commissioning Group

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

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Mr Aleks de Gromoboy

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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 [multiple sclerosis](#).

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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.

- [Royal College of General Practitioners](#)
- [Royal College of Nursing](#)