NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Multiple sclerosis

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 30 April 2015

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for multiple sclerosis. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Multiple sclerosis (2014) NICE guideline CG186.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the diagnosis, treatment and management of multiple sclerosis in adults (over 18s).

2.2 Definition

Multiple sclerosis (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. It is believed that an abnormal immune response to environmental triggers in people who are genetically predisposed results in immune-mediated acute, and then chronic inflammation. The initial phase of inflammation is followed by a phase of progressive degeneration of the affected cells in the nervous system.

2.3 Incidence and prevalence

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) where periods of stability (remission) are followed by episodes when there are exacerbations of symptoms (relapses). About 85 out of 100 people with MS have RRMS at onset. Around two-thirds of people who start with RRMS may develop secondary progressive MS: this occurs when there is a gradual accumulation of disability unrelated to relapses, which become less frequent or stop completely. Also about 10 to 15 out of 100 people with MS have primary progressive MS where symptoms gradually develop and worsen over time from the start, without ever experiencing relapses and remissions.

MS is a potentially highly disabling disorder 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.

2.4 Management

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

See appendix 1 for the associated care pathways for NICE clinical guideline 186.

2.5 National Outcome Frameworks

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**
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition** **Improving functional ability in people with long-term conditions** 2.2 Employment of people with long-term conditions (PHOF 1.8*) **Improving quality of life for people with multiple long-term conditions** 2.7 Health-related quality of life for people with three or more long-term conditions (ASCOF 1A**)
4 Ensuring that people have a positive experience of care	***Overarching indicator*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care 4c Friends and family test 4d Patient experience characterised as poor or worse i. Primary care ii. Hospital care **Improvement areas** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving experience of healthcare for people with mental illness** 4.7 Patient experience of community mental health services **Improving people's experience of integrated care** 4.9 People's experience of integrated care (ASCOF 3E**)
Alignment across the health and social care system * 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	***Overarching measure*** 1A Social care-related quality of life*

3 Ensuring that people have a positive experience of care and support	***Overarching measure*** People who use social care and their carers are satisfied with their experience of care and support services 3A Overall satisfaction of people who use services with their care and support. 3B Overall satisfaction of carers with social services Placeholder 3E: The effectiveness of integrated care* ***Outcome measures*** **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support.
Aligning across the health and care system * Indicator complementary	

Table 3 Public health outcomes framework for England, 2013–2016

Domain	**Objectives and indicators**
1 Improving the wider determinants of health	***Objective*** Improvements against wider factors which affect health and wellbeing and health inequalities ***Indicators*** 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* 1.9 Sickness absence rate
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.13 Proportion of physically active and inactive adults 2.23 Self-reported well-being
Alignment across the health and social care system * Indicator shared with the NHS Outcomes Framework. ** Complimentary indicators in the NHS Outcomes Framework	

3 Summary of suggestions

3.1 Responses

In total 15 stakeholders responded to the 2-week engagement exercise [04/03/15−18/03/15].

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 4 for further consideration by the Committee.

NHS England’s patient safety division did not submit any data for this topic.

Full details of all the suggestions provided are given in appendix 3 for information.

Table 4 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Diagnosing MS • Early diagnosis and rapid referral • Diagnosis by a consultant neurologist	ABN, BI Ltd., ECNS, MSS, MST, RCP, SCM 1, SRNFT
Providing information and support • Information at the time of diagnosis • Follow-up appointment within 6 weeks of diagnosis • Ongoing information and support • Access to MS nurse • Single point of contact	ABN, BI Ltd., ECNS, MSS, MST, NPUK Ltd., RCN, RCP, RP Ltd., SCM 1, SCM2, SRNFT, UKMSSNA
Coordination of care • Multidisciplinary care	ABN, BI Ltd., ECNS, MSS, MST, RP Ltd., RCN, RCP, SRNFT, SCM 1, SCM 2, UKMSSNA
Management, rehabilitation and relapse • Exercise • Annual review • Relapse and exacerbation	ABN, MSS, MST, NPUK Ltd., RCN, RCP, RP Ltd., SRNFT, SCM 2, UKMSSNA
Additional areas • Vitamin D • Use of MRI for diagnosis and monitoring • Respiratory abnormalities • Record treatment rates • Research and evidence appraisal suggestions • Disease modifying therapies	ABN, ARTP, BTS, BI Ltd., COTSSNP, ECNS, HQTD., NPUK Ltd., RP Ltd., RCP
ABN, Association of British Neurologists ARPT, Association for Respiratory Technology & Physiology BI Ltd., Biogen Idec Limited BTS, British Thoracic Society COTSSNP, College of Occupational Therapists Specialist Section - Neurological Practice ECNS, Essex Centre for Neurological Sciences HQTD, HQT Diagnostics MSS, MS Society MST, Multiple Sclerosis Trust NPUK Ltd., Novartis Pharmaceuticals (UK) Ltd RCN, Royal College of Nursing RCP, Royal College of Physicians RP Ltd., Roche Products Ltd SRNFT, Salford Royal NHS Foundation Trust SCM, Specialist Committee Member UKMSSNA, United Kingdom Multiple Sclerosis Specialist Nurse Association	

4 Suggested improvement areas

4.1 Diagnosing MS

4.1.1 Summary of suggestions

Early diagnosis and rapid referral

Stakeholders highlighted that referral of people with suspected MS by their GP or ophthalmologist to a specialist diagnostic service should be timely to enable earlier diagnosis and intervention and improve prognosis. This can be aided by better referral pathways and better information for GPs to help them recognise symptoms.

Diagnosis by a consultant neurologist

MS can be difficult to diagnose and so this should be done by a consultant neurologist. This will mean that diagnosis is done quickly and accurately and will minimise anxiety due to waiting.

4.1.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Early diagnosis and rapid referral	**Diagnosing MS** NICE CG186 Recommendations 1.1.1, 1.1.2, 1.1.3, 1.1.4, 1.1.6 (KPI) **Optic neuritis and neuromyelitis optica** NICE CG186 Recommendation 1.1.10
Diagnosis by a consultant neurologist	**Diagnosing MS** NICE CG186 Recommendations 1.1.6 (KPI), 1.1.7 (KPI)

Early diagnosis and rapid referral

Diagnosing MS

NICE CG186 – Recommendation 1.1.1

Be aware that clinical presentations in multiple sclerosis (MS) include:

- loss or reduction of vision in 1 eye with painful eye movements
- double vision
- ascending sensory disturbance and/or weakness
- problems with balance, unsteadiness or clumsiness
- altered sensation travelling down the back and sometimes into the limbs when
- bending the neck forwards (Lhermitte's symptom).

NICE CG186 – Recommendation 1.1.2

Be aware that usually people with MS present with neurological symptoms or signs as described in recommendation 1.1.1, and:

- are often aged under 50 **and**
- may have a history of previous neurological symptoms **and**
- have symptoms that have evolved over more than 24 hours **and**
- have symptoms that may persist over several days or weeks and then improve.

NICE CG186 – Recommendation 1.1.3

Do not routinely suspect MS if a person's main symptoms are fatigue, depression or dizziness unless they have a history or evidence of focal neurological symptoms or signs.

NICE CG186 – Recommendation 1.1.4

Before referring a person suspected of having MS to a neurologist, exclude alternative diagnoses by performing blood tests including:

- full blood count
- inflammatory markers for example erythrocyte sedimentation rate, C-reactive
- protein
- liver function tests
- renal function tests
- calcium
- glucose
- thyroid function tests
- vitamin B12
- HIV serology.

NICE CG186 – Recommendation 1.1.6 (key priority for implementation)

Refer people suspected of having MS to a consultant neurologist. Speak to the consultant neurologist if you think a person needs to be seen urgently.

Optic neuritis and neuromyelitis optica

NICE CG186 – Recommendation 1.1.10

If a person has an episode of isolated optic neuritis, confirmed by an ophthalmologist, refer them to a consultant neurologist for further assessment.

Diagnosis by a consultant neurologist

Diagnosing MS

NICE CG186 – Recommendation 1.1.6 (key priority for implementation)

Refer people suspected of having MS to a consultant neurologist. Speak to the consultant neurologist if you think a person needs to be seen urgently.

NICE CG186 – Recommendation 1.1.7 (key priority for implementation)

Only a consultant neurologist should make the diagnosis of MS on the basis of established up-to-date criteria, such as the revised 2010 McDonald criteria[1], after:

- assessing that episodes are consistent with an inflammatory process
- excluding alternative diagnoses
- establishing that lesions have developed at different times and are in different
- anatomical locations for a diagnosis of relapsing–remitting MS
- establishing progressive neurological deterioration over 1 year or more for a
- diagnosis of primary progressive MS.

4.1.3 Current UK practice

Early diagnosis and rapid referral

A patient experience survey by the Neurological Alliance[2] of 6,916 people with neurological conditions, 24.7% of whom had MS, which was the largest group of respondents, reports that:

- **31.5% (n=2,140)** of respondents had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist.
- **39.8% (n=2,357)** of respondents waited more than 12 months from when they first noticed their symptoms to seeing a neurological specialist.

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[1] Polman CH, Reingold SC, Banwell B et al. (2011) Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Annals of Neurology 69: 292–302.

[2] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

- **58.1% (n=3,402)** of respondents have experienced problems in accessing the services or treatment they need.

The MS Society and Salford Royal NHS Foundation Trust provided figures from the same survey specifically for people with MS, which were not published in the report:

- 25% (n=407) of people with MS had to see a GP 5 or more times regarding the health problems caused by their condition before they were referred to a consultant neurologist, whilst a further 23% (n=378) had to see a GP 3 or 4 times (total respondents=1628).
- 35% (n=547) of people with MS had to wait more than 12 months to see a neurologist, whilst a further 16% (n=256) had to wait between 6-12 months (total respondents=1560).
- 54% (n=786) of people with MS experienced problems or delays in accessing the treatment to help manage their condition (total number of respondents=1457).

Results from a survey of patients' experiences of health and social care in long-term neurological conditions in England[3] show that:

- 37% (n=375) of respondents with MS reported waiting more than 6 months from GP consultation to specialist consultation.
- 43% (448) reported being diagnosed only one year after initial GP consultation.

Responses to the national audit of services for people with multiple sclerosis 2011[4] from people diagnosed with MS in the previous 12 months showed that:

- Over half (58%) of all 84 newly diagnosed patients were seen by a neurologist within 6 weeks, and 61% had all tests completed within six weeks of first seeing a neurologist.
- The median time between initial referral and final diagnosis was 25 (8-46) weeks; this implies that half of all people took more than 25 weeks in total to achieve final diagnosis.

The same audit reported that only 25-30% of trusts and 6% of commissioners specifically consider the speed of finalising a diagnosis of MS. Additionally, although few general practices have guidance, most (71%) expect a patient with suspected MS to be seen within six weeks.

Diagnosis by a consultant neurologist

No current practice data was found for this area.

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[3] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

[4] Royal College of Physicians (2011) The national audit of services for people with multiple sclerosis 2011.

4.2 Providing information and support

4.2.1 Summary of suggestions

Information at the time of diagnosis

Stakeholders highlighted that a person receiving a new diagnosis of MS should receive comprehensive, tailored written and oral information about the condition, treatment, local support groups and services, driving, employment and social care information. This can help the person with MS to manage their condition and make informed choices.

Follow-up appointment within 6 weeks of diagnosis

People receiving a new diagnosis of MS should receive follow-up by a healthcare professional specialising in MS within 6 weeks of the diagnosis. This is important as receiving a diagnosis for a long-term condition like MS can be challenging and people might not seek information at first, so they should be offered it later as well.

Ongoing information and support

Ongoing information is important to help people with MS deal with challenges as they arise and help with decision making at key times, for example if the disease worsens. Information and support provision should not be a one off event as needs might change and should be reviewed. Stakeholders also highlighted that a personalised management plan for people with MS and their family members or carers, that takes into account their goals and preferences and says who to contact if their symptoms change, will help them manage their condition effectively.

Access to MS nurse

Stakeholders highlighted the importance of access to the expertise of MS nurse specialists. Provision varies between areas, with some nurses having high caseloads and people having to travel a long way to access services.

Single point of contact

People with MS should have access to a single point of contact with specialist knowledge of MS. This aids self-management and will avoid the use of the wrong services in times of symptom deterioration.

4.2.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Information at the time of diagnosis	**Information at the time of diagnosis** NICE CG186 Recommendation 1.2.2 (KPI)
Follow-up appointment within 6 weeks of diagnosis	**Information at the time of diagnosis** NICE CG186 Recommendation 1.2.4 (KPI)
Ongoing information and support	**Ongoing information and support** NICE CG186 Recommendations 1.2.5, 1.2.6, 1.2.7, 1.2.9
Access to MS nurse	**Coordination of care** **NICE CG186 Recommendation 1.3.1 (KPI)**
Single point of contact	**Coordination of care** **NICE CG186 Recommendation 1.3.2**

Information at the time of diagnosis

Information at the time of diagnosis

NICE CG186 Recommendation 1.2.2 (key priority for implementation)

The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written information at the time of diagnosis. This should include, but not be limited to, 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.

Follow-up appointment within 6 weeks of diagnosis

NICE CG186 Recommendation 1.2.4 (key priority for implementation)

Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis.

Ongoing information and support

Ongoing information and support

NICE CG186 Recommendation 1.2.5

Review information, support and social care needs regularly. Continue to offer information and support to people with MS or their family members or carers even if this has been declined previously.

NICE CG186 Recommendation 1.2.6

Ensure people with MS and their family members or carers have a management plan that includes who to contact if their symptoms change significantly.

NICE CG186 Recommendation 1.2.7

Explain to people with MS that the possible causes of symptom changes include:

- another illness such as an infection
- further relapse
- change of disease status (for example progression).

NICE CG186 Recommendation 1.2.9

When appropriate, explain to the person with MS (and their family members or carers if the person wishes) about advance care planning and power of attorney.

Access to MS nurse

Coordination of care

NICE CG186 Recommendation 1.3.1 (key priority for implementation)

Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including:

- consultant neurologists
- MS nurses
- physiotherapists and occupational therapists

- speech and language therapists, psychologists, dietitians, social care and
- continence specialists
- GPs.

Single point of contact

Coordination of care

NICE CG186 Recommendation 1.3.2

Offer the person with MS an appropriate single point of contact to coordinate care and help them access services.

4.2.3 Current UK practice

Information at the time of diagnosis

An MS Society survey of 10,530 people with MS in the UK[5] found that:

- Only 56% (n=3,096) of people with MS in England felt they had received enough information from health care professionals about drugs available to support the treatment of their MS (total number or respondents with a need for information = 5510).
- 71% of people with MS in England felt they had received sufficient information relating to their MS (total number of respondents with a need for information = 6366)

A survey of patients' experiences of health and social care in long-term neurological conditions in England[6] found that 70% of respondents with MS (n = 808) reported that they did not receive all the necessary information at diagnosis.

Responses to the national audit of services for people with multiple sclerosis 2011[7] from people diagnosed with MS in the previous 12 months showed that:

- Nearly two-thirds of people were given written information about the disease and information about national support organisations after diagnosis, and 70% were given contact details about a specialist neurologist or specialist nurse.
- Only 29% were given information on specialist therapists, 23% were given an opportunity to attend an educational course and only 42% were given information about local support groups.

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[5] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

[6] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

[7] Royal College of Physicians (2011) The national audit of services for people with multiple sclerosis 2011.

Follow-up appointment within 6 weeks of diagnosis

44% (n=505) of MS patients who responded to a survey of patients' experiences of health and social care in long-term neurological conditions in England[8] were not offered a follow-up appointment at diagnosis.

Ongoing information and support

An MS Society survey[9] found that, in response to the question 'How often did your health or social care professionals ask what is important to you when helping you to manage your MS?', 36% of people with MS in England (n=3,081) replied never, and a further 17% (n=1,440) replied rarely.

The Neurological Alliance survey[10] reports that the satisfaction of people with neurological conditions with the type of information received from healthcare professionals was as follows:

- 31% of respondents were unsatisfied, very unsatisfied or received no information about their condition
- 37% of respondents were unsatisfied, very unsatisfied or received no information about their care and treatment options
- 40% were unsatisfied, very unsatisfied or received no information about the risks and benefits of different types of treatment
- 36% were unsatisfied, very unsatisfied or received no information about contact details for a named healthcare professional in charge of their care
- 49% were unsatisfied, very unsatisfied or received no information about additional sources of support e.g. details of charity, patient support group or financial advice.

The Neurological Alliance survey[11] reports that people with neurological conditions are rarely offered a care plan to help manage their needs:

- **71.5% (n=4,603)** of respondents have not been offered a care plan to help manage their condition.
- **37.4% (n=651)** of respondents noted that at least to some extent their care plan responds well to their changing needs.

The MS Society provided figures from the same survey specifically for people with MS, which were not published in the report:

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[8] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

[9] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

[10] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

[11] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

- 74% (n=1159) of respondents stated that they were not offered a care plan (total number of respondents=1573).

84% of MS patients who responded to a survey of patients' experiences of health and social care in long-term neurological conditions in England[12] were not aware of having a formal care plan.

Access to MS nurse

An MS Society survey[13] found that:

- 82% (n=5,191) of people with MS in England that needed to had seen an MS specialist nurse in relation to their MS.

31% of respondents with neurological conditions to the Neurological Alliance survey[14] said that they regularly have contact with a specialist nurse to help them manage their condition.

Most people (93%) with MS who responded to the national audit of services for people with multiple sclerosis 2011[15] stated that they had access to specialist MS nurses.

According to a report by the MS Trust[16], based on a sustainable caseload of 358 people with MS per whole time specialist nurse, there is currently a shortfall of 62 MS specialist nurses across the UK, with significant shortfalls in England and Scotland. Also, 28% of people with MS (nearly 30,000 people) live in areas where MS specialist nurse caseloads are more than twice the level that is sustainable.

Single point of contact

The Neurological Alliance survey[17] reports that 36% of people with neurological conditions were unsatisfied, very unsatisfied or received no information about contact details for a named healthcare professional in charge of their care.

53% of MS patients who responded to a survey of patients' experiences of health and social care in long-term neurological conditions in England[18] said they were not

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[12] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

[13] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

[14] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

[15] Royal College of Physicians (2011) The national audit of services for people with multiple sclerosis 2011.

[16] Multiple Sclerosis trust (2014) MS Specialist Nursing in the UK 2014: The case for equitable provision

[17] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

assigned a named health or social care professional to contact when their needs change. 71% said they do not have a single health or social care professional who coordinates their care.

70% of people with MS who responded to the national audit of services for people with multiple sclerosis 2011[19] were given contact details about a specialist neurologist or specialist nurse.

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[18] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

[19] Royal College of Physicians (2011) The national audit of services for people with multiple sclerosis 2011.

4.3 Coordination of care

4.3.1 Summary of suggestions

Multidisciplinary care

MS is a complex long-term condition with varied symptoms that can fluctuate over time. People with MS need support from a multidisciplinary team to manage the condition and help them with different symptoms, such as mobility, pain, anxiety, speech, swallowing and spasticity, to aid health promotion and to prevent secondary complications, like pressure ulcers. Currently access to the multidisciplinary team and the membership of the team varies. Partnership and integrated working between primary and secondary care is also important for managing care.

4.3.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Multidisciplinary care	**Coordination of care** NICE CG186 Recommendation 1.3.1 (KPI)

Coordination of care

<u>NICE CG186 Recommendation 1.3.1 (key priority for implementation)</u>

Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including:

- consultant neurologists
- MS nurses
- physiotherapists and occupational therapists
- speech and language therapists, psychologists, dietitians, social care and
- continence specialists
- GPs.

4.3.3 Current UK practice

The Neurological Alliance survey[20] results for people with neurological conditions show that:

- **66.9% (n=3,913)** of respondents felt that the different people treating and caring for them worked well together to at least some extent. (Results for people with MS provided by the MS Society show that only 50% (n=727) of people with MS felt that the different people treating and caring for them work well together effectively most or all of the time (total number of respondents=1457))
- Only **38.7% (n=74)** of CCGs have taken action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions.

Also, respondents said they regularly have contact with the following professionals to help them manage their condition:

- GP (60.4%, n=3,537)
- A hospital doctor (including neurological specialist) (47.6%, n=2,788)
- District nurse (4.1%, n=237)
- Care home staff (1.8%, n=106)
- Physiotherapist (17.1%, n=999)
- Occupational therapist (10.3%, n=602)
- Counsellor (3.5%, n=205)
- Speech and language therapist (5.5%, n=321)
- Fatigue management team (1.3%, n=77)
- Dietician (3.0%, n=175)
- Pharmacist (10.6%, n=618)
- Palliative care team (1.2%, n=71)
- Wheelchair/mobility aids specialist (6.4%, n=377)
- Psychologist (3.8%, n=225)
- Social worker (3.6%, n=208)
- Pain service (2.8%, n=161)
- Tissue viability service (0.4%, n=25)
- Continence advisor (4.8%, n=281)
- Charity group/voluntary organisation (16.0%, n=935)

An MS Society survey[21] found that:

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[20] The Neurological Alliance (2015) The Invisible Patients: Revealing the state of neurology services

[21] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

- 21% of respondents rarely (n=905) and 10% never (n=832) find it easy to see healthcare professionals when they need to. 31% (n=2,590) sometimes find it easy.
- 84% (n=4,879) of people with MS in England that needed to had seen a neurologist in relation to their MS
- 69% (n=3,812) of people with MS in England that needed to had seen a physiotherapist in relation to their MS
- 70% (n=2,726) of people with MS in England that needed to had seen a continence adviser in relation to their MS

67% of MS patients who responded to a survey of patients' experiences of health and social care in long-term neurological conditions in England[22] did not feel there was good collaboration between health and social care services in planning care.

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[22] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

4.4 Management, rehabilitation and relapse

4.4.1 Summary of suggestions

Exercise

A stakeholder highlighted that exercise is an important way to treat mobility problems and fatigue and people with MS should be supported to exercise.

Annual review

People with MS should have at least one comprehensive review per year undertaken by a health care professional with expertise in MS and coordinated with other members of the MDT as necessary. The review should address symptoms, relapses experienced, treatment, emotional and social care needs and the needs of carers. Review is important to ensure that any changes in the care, support or treatment needs of the patient are addressed and that care and treatment stay up to date with developments in this area. Annual review would also prevent people with MS who have been discharged from neurology services being overlooked.

Relapse and exacerbation

There is variation in best practice for how relapses are managed in terms of time to assessment, recognising relapses and assessment methods, treatment and input of specialists. Local protocols and pathways that include patient triage, review and follow up would help with this.

4.4.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	**Suggested source guidance recommendations**
Exercise	**Modifiable risk factors for relapse or progression of MS – Exercise** NICE CG186 Recommendation 1.4.1 **MS symptom management and rehabilitation – Fatigue** NICE CG186 Recommendations 1.5.6, 1.5.8 **MS symptom management and rehabilitation – Mobility or fatigue** NICE CG186 Recommendation 1.5.11 (KPI) **MS symptom management and rehabilitation - Treatment programmes for mobility and/or fatigue** NICE CG186 Recommendations 1.5.13 and 1.5.14
Annual review	**Comprehensive review** NICE CG186 Recommendations 1.6.1, 1.6.2, 1.6.3, 1.6.4, 1.6.5, 1.6.9
Relapse and exacerbation	**Treating acute relapse of MS with steroids** NICE CG186 Recommendations 1.7.1 and 1.7.2 **Recognising a relapse** NICE CG186 Recommendations 1.7.3, 1.7.4, 1.7.5, 1.7.6 **Treating a relapse** NICE CG186 Recommendations 1.7.7 (KPI), 1.7.8, 1.7.9, 1.7.10

Exercise

Modifiable risk factors for relapse or progression of MS – Exercise

NICE CG186 Recommendation 1.4.1

Encourage people with MS to exercise. Advise them that regular exercise may have beneficial effects on their MS and does not have any harmful effects on their MS.

MS symptom management and rehabilitation – Fatigue

NICE CG186 Recommendation 1.5.6

Advise people that aerobic, balance and stretching exercises including yoga may be helpful in treating MS-related fatigue.

NICE CG186 Recommendation 1.5.8

Consider a comprehensive programme of aerobic and moderate progressive resistance activity combined with cognitive behavioural techniques for fatigue in people with MS with moderately impaired mobility (an EDSS[23] score of greater than or equal to 4).

MS symptom management and rehabilitation – Mobility or fatigue

NICE CG186 Recommendation 1.5.11 (key priority for implementation)

Consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat people with MS who have mobility problems and/or fatigue.

MS symptom management and rehabilitation - Treatment programmes for mobility and/or fatigue

NICE CG186 Recommendation 1.5.13

Encourage people with MS to keep exercising after treatment programmes end for longer term benefits (see Behaviour change: individual approaches NICE public health guideline 49).

NICE CG186 Recommendation 1.5.14

Help the person with MS continue to exercise, for example by referring them to exercise referral schemes.

Annual review

Comprehensive review

NICE CG186 Recommendation 1.6.1

Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year.

NICE CG186 Recommendation 1.6.2

Ensure the comprehensive review is carried out by healthcare professionals with expertise in MS and its complications. Involve different healthcare professionals with expertise in specific areas of the review if needed.

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[23] Expanded Disability Status Scale.

NICE CG186 Recommendation 1.6.3

Tailor the comprehensive review to the needs of the person with MS assessing:

- MS symptoms:
  - mobility and balance including falls
  - need for mobility aids including wheelchair assessment
  - use of arms and hands
  - muscle spasms and stiffness
  - tremor
  - bladder (see Urinary incontinence in neurological disease NICE clinical
  - guideline 148), bowel (see Faecal incontinence NICE clinical guideline 49)
  - and sexual function
  - sensory symptoms and pain
  - speech and swallowing (see Nutrition support in adults NICE clinical guideline 32)
  - vision
  - cognitive symptoms
  - fatigue
  - depression (see Depression in adults with chronic physical health problems
  - NICE clinical guideline 91) and anxiety (see Generalised anxiety disorder and
  - panic disorder NICE clinical guideline 113)
  - sleep
  - respiratory function.
- MS disease course:
  - relapses in last year.
- General health:

  - weight
  - smoking, alcohol and recreational drugs
  - exercise
  - access to routine health screening and contraception
  - care of other chronic conditions.
- Social activity and participation:
  - family and social circumstances
  - driving and access to transport
  - employment
  - access to daily activities and leisure.
- Care and carers:
  - personal care needs
  - social care needs
  - access to adaptations and equipment at home.

NICE CG186 Recommendation 1.6.4

Refer any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed.

NICE CG186 Recommendation 1.6.5

Ensure people with MS are offered a medication review in line with Medicines adherence (NICE clinical guideline 76).

NICE CG186 Recommendation 1.6.9

Discuss the care provided by carers and care workers as part of the person's care plan. Ensure carers know about their right to a local authority carer's assessment and how to apply for one.

Relapse and exacerbation

Treating acute relapse of MS with steroids

NICE CG186 Recommendation 1.7.1

Develop local guidance and pathways for timely treatment of relapses of MS. Ensure follow-up is included in the guidance and pathway.

NICE CG186 Recommendation 1.7.2

Non-specialists should discuss a person's diagnosis of relapse and whether to offer steroids with a healthcare professional with expertise in MS because not all relapses need treating with steroids.

Recognising a relapse

NICE CG186 Recommendation 1.7.3

Diagnose a relapse of MS if the person:

- develops new symptoms **or**
- has worsening of existing symptoms

and these last for more than 24 hours in the absence of infection or any other cause after a stable period of at least 1 month.

NICE CG186 Recommendation 1.7.4

Before diagnosing a relapse of MS:

- rule out infection – particularly urinary tract and respiratory infections **and**
- discriminate between the relapse and fluctuations in disease or progression.

NICE CG186 Recommendation 1.7.5

Assess and offer treatment for relapses of MS, that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms.

NICE CG186 Recommendation 1.7.6

Do not routinely diagnose a relapse of MS if symptoms are present for more than 3 months.

Treating a relapse

NICE CG186 Recommendation 1.7.7 (key priority for implementation)

Offer treatment for relapse of MS with oral methylprednisolone 0.5 g daily for 5 days.

NICE CG186 Recommendation 1.7.8

Consider intravenous methylprednisolone 1 g daily for 3–5 days as an alternative for people with MS:

- in whom oral steroids have failed or not been tolerated **or**
- who need admitting to hospital for a severe relapse or monitoring of medical or psychological conditions such as diabetes or depression.

NICE CG186 Recommendation 1.7.9

Do not prescribe steroids at lower doses than methylprednisolone 0.5 g daily for 5 days to treat an acute relapse of MS.

NICE CG186 Recommendation 1.7.10

Do not give people with MS a supply of steroids to self-administer at home for future relapses.

4.4.3 Current UK practice

Exercise

An MS Society survey[24] found that 53% (n=2,532) of people with MS in England that needed support so that they could keep physically active had not received any. Unmet need also increased with increasing support needs: 46% (n=835) of people with MS who require occasional assistance do not receive the support they need to be physically active (Total number of respondents=1805). This increases to 64% (n=626) for people with MS who require constant assistance (Total number of respondents=978).

Annual review

35% (n=400) of MS patients who responded to a survey of patients' experiences of health and social care in long-term neurological conditions in England[25] reported not having had a review with a specialist in the last year.

2013–14 Hospital Episode Statistics data shows that multiple sclerosis was responsible for 46,584 episodes of admitted patient care and accounted for 53,554 occupied bed days. Of the 44,335 finished admission episodes for MS, 2,453 (6%) admissions were emergency admissions.

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[24] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

[25] Peters M, Fitzpatrick R, Doll H et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of Health Services Research and Policy January 2013 vol. 18 no. 1 28-33.

Relapse and exacerbation

An MS Society survey[26] reports that 31% of respondents in England sometimes, 11% rarely and 10% or never found it easy to see health care professionals when they needed to.

Responses from people with MS to the national audit of services for people with multiple sclerosis 2011[27] show that:

- 73% of respondents with MS thought that they could be seen by a specialist neurologist if needed
- Only 36% thought they could be seen by a specialist rehabilitation service if needed
- 72% felt able to make contact directly with someone in the specialist neurology service about a new problem
- Only 30% felt they could contact someone in the specialist neurological rehabilitation service about a new problem

Responses from NHS organisations to the same national audit showed that:

- Only 33% of general practitioners were aware of co-ordinated care pathways between primary and secondary care
- 45% of GPs said that people with MS are able to self-refer back to a specialist neurological service and 31% to a rehabilitation service
- About one third of community trusts provide specialist neurological rehabilitation
- 20% of trusts do not provide any inpatient or outpatient neurological rehabilitation services.

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[26] Multiple Sclerosis Society (2013) A lottery of treatment and care – MS services across the UK and Technical Report.

[27] Royal College of Physicians (2011) The national audit of services for people with multiple sclerosis 2011.

4.5 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 30 April 2015.

Vitamin D

A stakeholder suggested that GPs should test vitamin D levels and supplement them and that the effects of higher levels of vitamin D be investigated. NICE guideline CG186 recommendation 1.4.6 recommends talking to a person with MS who is thinking about pregnancy about the use of vitamin D before conception and during pregnancy, and recommendation 1.8.1 states that vitamin D should not be offered solely for the purpose of treating MS. The guideline does not recommend the use of vitamin D to treat MS.

Use of MRI for diagnosis and monitoring

Stakeholders suggested using MRI scans for the initial diagnosis of MS as well as for ongoing disease monitoring. NICE guideline CG186 recommendation 1.1.5 says “Do not diagnose MS on the basis of MRI findings alone”. Using MRI scans for monitoring is not contained within the development source (NICE CG186).

Respiratory abnormalities

A stakeholder highlighted diagnosis of lung function impairment and respiratory abnormality, referral to a respiratory physician and treatment of respiratory failure. While the development source (NICE CG186) mentions assessing respiratory function as part of a comprehensive review (recommendation 1.6.3), and ruling out respiratory infections before diagnosing a relapse (1.7.4), it does not cover diagnosing abnormalities or treatment.

Record treatment rates

A stakeholder recommended recording active treatment rates for people with MS. This area is not contained within the development source (NICE CG186) but could be covered in the measures rather than as a statement.

Research and evidence appraisal suggestions

A stakeholder made suggestions for areas for further research and evidence appraisal, such as support needs of people with MS, sleep and fatigue management and prevention of contractures. NICE quality standards do not review or re-appraise the underlying primary evidence base.

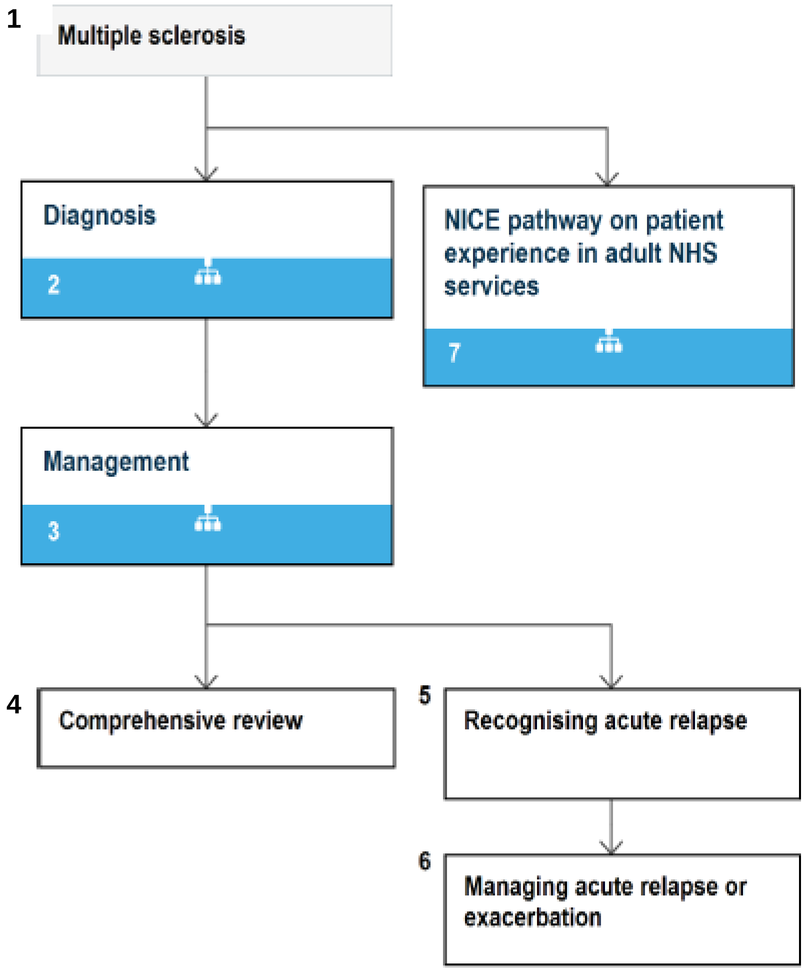
Disease-modifying treatments

Stakeholders discussed access to disease-modifying treatments and one stakeholder requested consistency of language in different guidance regarding patients who are eligible to take them. The development source (NICE CG186) does not address the use of disease-modifying treatments as there are NICE technology appraisals about them. Quality standards do not draw on technology appraisals as development sources.

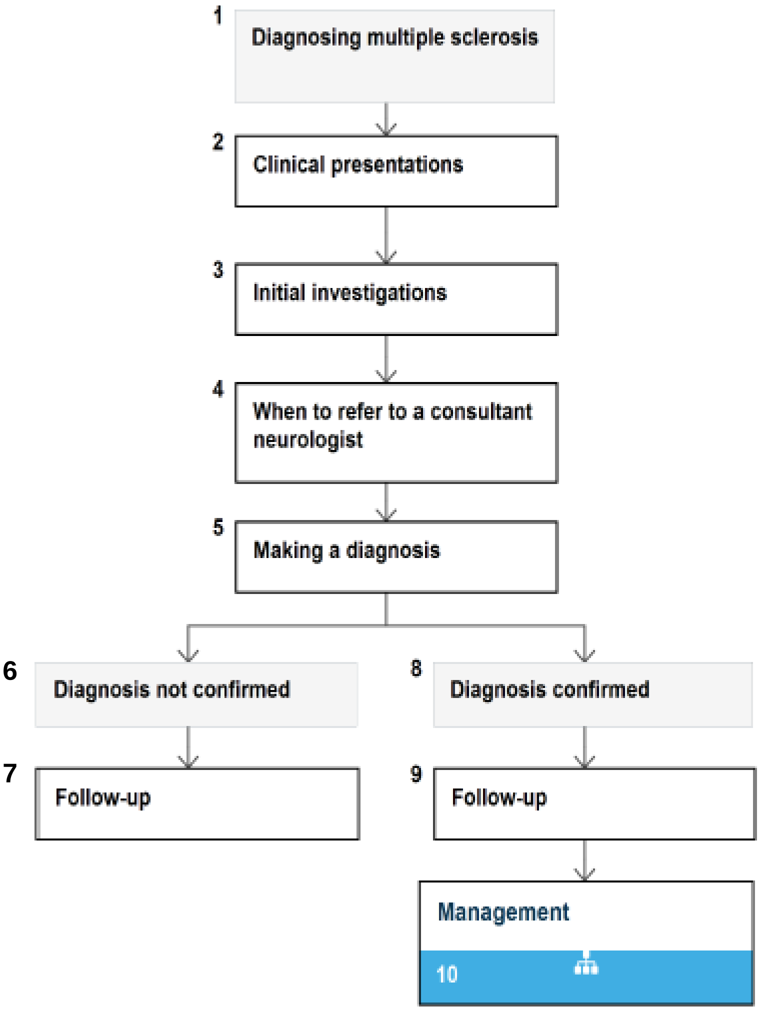
Appendix 1: Multiple sclerosis care pathways

Taken from NICE Multiple sclerosis pathway

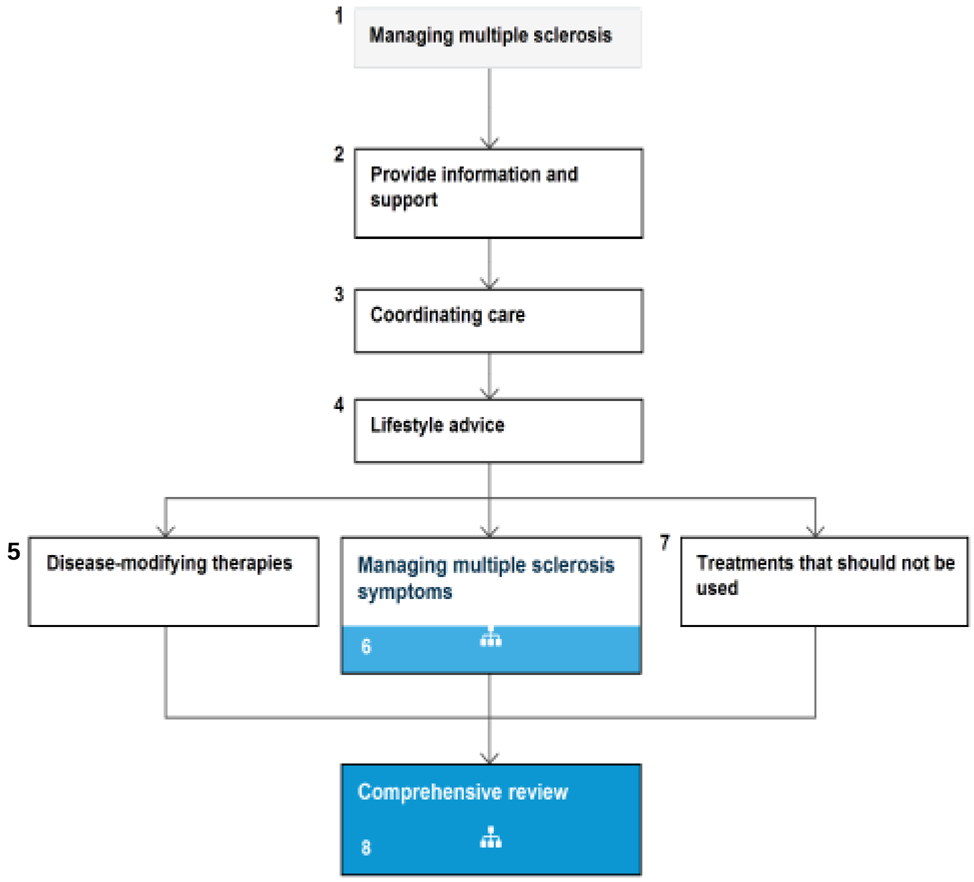
Pathway 1: Multiple sclerosis overview



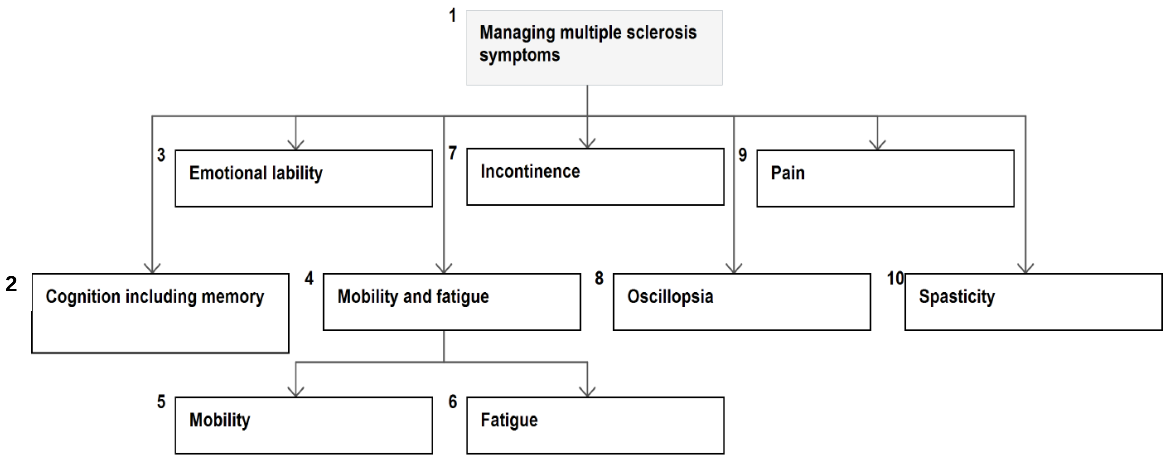
Pathway 2: Diagnosing multiple sclerosis



Pathway 3: Managing multiple sclerosis



Pathway 4: Managing multiple sclerosis symptoms



Appendix 2: Key priorities for implementation (CG186)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Diagnosing MS

- Do not diagnose MS on the basis of MRI findings alone. [1.1.5]
- Refer people suspected of having MS to a consultant neurologist. Speak to the consultant neurologist if you think a person needs to be seen urgently. [1.1.6]
- Only a consultant neurologist should make the diagnosis of MS on the basis of established up-to-date criteria, such as the revised 2010 McDonald criteria, after:
  - assessing that episodes are consistent with an inflammatory process
  - excluding alternative diagnoses
  - establishing that lesions have developed at different times and are in different
  - anatomical locations for a diagnosis of relapsing–remitting MS
  - establishing progressive neurological deterioration over 1 year or more for a diagnosis
  - of primary progressive MS. **[1.1.7]**

Information and support

- The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written information at the time of diagnosis. This should include, but not be limited to, 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. [1.2.2]

  - Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis. **[1.2.4]**

Coordination of care

- Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including:
- consultant neurologists
- MS nurses
- physiotherapists and occupational therapists
- speech and language therapists, psychologists, dietitians, social care and continence specialists
- GPs. **[1.3.1]**

MS symptom management and rehabilitation

- Consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat people with MS who have mobility problems and/or fatigue. **[1.5.11]**

Treating acute relapse of MS with steroids

- Offer treatment for relapse of MS with oral methylprednisolone 0.5 g daily for 5 days. **[1.7.7]**

Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Section 4.1: Diagnosing MS					
001	Association of British Neurologists	Key area for quality improvement 1	A person who is reasonably suspected of having MS by their primary care doctor should be entitled to timely access to a diagnostic service able to offer a prompt diagnosis of MS based on the NICE CG. The aim is to facilitate an early diagnosis of the condition.	MS can be a difficult condition to diagnose with varied symptoms and criteria which require specialist referral to a neurologist by the primary care doctor. Not only is it desirable for a person with MS to receive an early accurate diagnosis from a suitably skilled healthcare professional but also there is evidence that in some people this may improve prognosis by facilitating earlier intervention with appropriate disease modifying therapy (DMT).	Evidence from a recent patient experience survey of around 1,600 people with MS undertaken by the Neurological Alliance found significant variation and possible delay [1]. 25% (n=407) of people with MS had to see a GP 5 or more times before they were referred to a consultant neurologist, whilst a further 23% (n=378) had to see a GP 3 or 4 times. 35% (n=547) of people with MS had to wait more than 12 months to see a neurologist, whilst a further 16% (n=256) had to wait between 6-12 months.

					[1] Neurological Alliance – Invisible patients report: revealing the state of neurology services (2015) http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report
002	Biogen Idec Limited	Earlier diagnosis of MS without delays in the referral pathway.	Early diagnosis leads to earlier treatment for those with MS and the removal of long periods of uncertainty for those who do not have MS.	Referral times from GP to General Neurologist or specialist MS neurologist are long. This process is exacerbated by the practice of General Neurologists discharging patients back to GPs for onward referral to specialist centres. Direct General Neurologist referral to specialist MS neurologists would lower the number of patients 'lost' to the system and significantly improve referral times for others.	39.8% of respondents waited more than 12 months from when they first noticed their symptoms to seeing a neurological specialist. Neurological Alliance – The Invisible Patients. http://www.neural.org.uk/
			Better referral pathways and better information for GPs and Opthalmologists would help achieve this.	GPs need further education and assistance in recognising symptoms of MS and have clear guidance on criteria for referral to a neurologist.	The importance of prioritising a rapid and accurate diagnosis was clearly stated in the 2005 National Service Framework for Long-term Conditions, recognising the importance of early diagnosis "to reduce neurological damage, slow down the rate of disease progression, increase survival rates and improve the person's quality of life."

			Lack of expertise contributes to long times from first contact to diagnosis and may contribute to progress of the disease through lack of disease modifying intervention.	An individual GP will very rarely see a patient present with MS or suspected MS and consequently has little experience in this area. Specialist MS services should actively seek engagement with GPs on the topic of MS.	https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions 31.5% (n=2,140) of respondents had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist. 39.8% (n=2,357) of respondents waited more than 12 months from when they first noticed their symptoms to seeing a neurological specialist. *Neurological Alliance – The Invisible Patients.*
				Some patients will first present at Opthalmology clinics and receive a diagnosis of optic neuritis. Opthalmologists should have guidance on MS and optic neuritis and clear criteria for referral to a specialised MS clinical specialist.	

003	Essex Centre for Neurological Sciences	Early diagnosis of MS	Patients expect a timely and correct diagnosis of MS with clear management goal posts. An early, accurate and efficient access of MS and segregation of non-MS patients is important	There is evidence that diagnosis of MS is often delayed, or suspected but not confirmed in patients for unacceptably long periods when patients have little or no access to clinical and nursing support. Clinical pathway for rapid access to a diagnostic MS service is necessary after first clinical episodes of optic neuritis, brainstem or spinal cord demyelination confirmed by an optometrist, ophthalmologist or a general physician in primary care setting.	Please see below
004	MS Society	Fast, accurate and tactful diagnosis: rapid referral from GP to consultant neurologist	The NICE clinical guideline for MS recommends that if someone with MS is presenting with MS-like symptoms, they should be referred to a consultant neurologist for examination. Diagnosis should be established on the basis of the McDonald criteria (2010) and not on the basis of an MRI alone. **Why is this important?**	Evidence from a recent patient experience survey of around 1,600 people with MS undertaken by the Neurological Alliance found significant variation in people with MS' experience of diagnosis. 25% (n=407) of people with MS had to see a GP 5 or more times regarding the health problems caused by their condition before they were referred to a consultant neurologist, whilst a further 23% (n=378) had to see a GP 3 or 4 times (total respondents=1628).	**Evidence of the importance of early treatment with Disease Modifying Therapies** Goodin DS et al. Cause of death in MS: long-term follow-up of a randomised cohort, 21 years after the start of the pivotal IFNβ-1b study. BMJ Open. 2012 Nov 30;2(6). pii: e001972 http://www.ncbi.nlm.nih.gov/pubmed/23204140

			MS can be difficult to diagnose. Symptoms fluctuate and vary in nature and severity from person to person. Waiting for a diagnosis can be a stressful and bewildering time – it's important that diagnosis is therefore done as quickly, accurately and tactfully as possible to minimise anxiety. This would also facilitate the initiation of appropriate management and treatment. There is increasing evidence that early treatment of relapsing remitting MS (RRMS) with a disease modifying therapy (DMT) improves long term outcomes for people with MS. Fast, accurate diagnosis enables an earlier conversation between patient and neurologist regarding treatment options for all forms of MS	35% (n=547) of people with MS had to wait more than 12 months to see a neurologist, whilst a further 16% (n=256) had to wait between 6-12 months (total respondents=1560) **These statistics demonstrate significant barriers in primary care to receiving an MS diagnosis. It is crucial that the quality standards seek to address this by providing credible, up to date information and support for GPs to refer confidently and appropriately to a consultant neurologist when an MS diagnosis seems likely.** 21% (n=320) of people with MS felt the way they were told about their diagnosis was not done appropriately at all (total respondents=1560), whilst 22% (n=341) of people with MS felt it should have been done a bit more appropriately.	Cocco et al. Influence of treatments in multiple sclerosis disability: A cohort study. Mult Scler. 2014 Sep 25. pii: 1352458514546788 http://www.ncbi.nlm.nih.gov/pubmed/25257611 **Evidence regarding people with MS' experiences of diagnosis**

005			Access to diagnosis by a consultant neurologist is recommended within NICE guidance. Diagnosis early is essential, to reduce anxiety and ensure people are able to come to terms with a chronic long-term condition. It is also essential so that those people with Clinically Isolated Syndrome or multiple sclerosis who meet prescribing criteria gain access to appropriate disease modifying therapy, which in turn is recognised to have long-term	The way a person receives their diagnosis can have a profound effect on how they manage the condition and go on to access treatment and support. 43% of the people surveyed feel this aspect of diagnosis needs to be improved. **The quality standards must seek to improve the sensitivity with which diagnosis is communicated and the support available.**	Neurological Alliance (2015) – Patient experience survey http://www.neural.org.uk/store/assets/files/491/original/Neurological_Patient_Experience_Survey_final_14_January_2015_.xls
	Multiple Sclerosis Trust	Referrals to a consultant neurologist for people suspected of having MS, including urgent referrals.		Many people with MS report delays, sometimes significant delays, in being referred to a consultant neurologist who can make a diagnosis of MS. This is an issue not confined to MS: the Neurological Alliance's *Invisible Patient* report demonstrates that 31% of people with a neurological condition had to visit their GP five times or more before being referred to a consultant neurologist, and nearly 40% had to wait more than 12 months from symptom onset to seeing a consultant neurologist. Early and accurate diagnosis is also humane, since multiple sclerosis is most commonly diagnosed in people of working age between 20-40 years, who will need to make choices and decisions about treatment and management and about life issues such as work, family, financial decisions etc.	Neurological Alliance (2015). The invisible patients:revealing the state of neurology services; http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf Association of British Neurologists. Revised (2009) Guidelines for Prescribing in Multiple Sclerosis.

			benefits in reducing the rate of relapses and the disability that some relapses bring with them. These criteria are described by the ABN prescribing guidelines and NHS England's clinical commissioning policy on disease modifying drug therapy.	There are two issues here. The primary one is getting GPs to recognise possible MS or CIS symptoms when they present in the consulting room, and making suitable referrals quickly. Therefore a key area for quality improvement and a metric will be the number of times someone had to present to their GP before getting referred to a consultant neurologist. A separate but related issue is that most people with MS benefit from being diagnosed by a neurologist with a special interest in MS. This is for a number of reasons, but a primary the MS specialist neurologist is more likely to recognise	http://www.mstrust.org.uk/competencies/downloads/abn_ms_guidelines_2009_final.pdf NHS England (2014). Clinical Commissioning Policy: Disease Modifying Therapies for Patients with Multiple Sclerosis. http://www.england.nhs.uk/wp-content/uploads/2013/10/d04-p-b.pdf
006	Salford Royal NHS Foundation Trust	DIAGNOSIS	MS can be difficult to diagnose, with variation of symptoms that are variable from patient to patient. Time to diagnosis is also variable which often	Evidence from a recent patient experience survey of around 1,600 people with MS undertaken by the Neurological Alliance found significant variation in people with MS' experience of diagnosis.	Neurological Alliance – Invisible patients report: revealing the state of neurology services (2015)

			impacts upon the patient's journey and future care. With the advent of early treatment, diagnosis is a crucial component of the pathway to get right.	25% (n=407) of people with MS had to see a GP 5 or more times regarding the health problems caused by their condition before they were referred to a consultant neurologist, whilst a further 23% (n=378) had to see a GP 3 or 4 times (total respondents=1628). 35% (n=547) of people with MS had to wait more than 12 months to see a neurologist, whilst a further 16% (n=256) had to wait between 6-12 months (total respondents=1560) 22% (n=341) of people with MS felt the way they were told about their diagnosis should have been done a bit more appropriately, whilst 21% (n=320) said it was not done appropriately at all (total respondents=1560) The way a person receives their diagnosis can have a profound effect on how they manage the condition and go on to access treatment and support. 43% of the people surveyed feel this aspect of diagnosis needs to be improved. The quality standards must seek to address this as part of their quality standard on diagnosis.	http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report
007	SCM 1	Only a consultant neurologist should make the diagnosis of MS on the basis of established up to date criteria, such as the revised 2010 McDonald criteria. Do not diagnose MS on the basis of MRI			

		findings alone.			
Section 4.2: Providing information and support					
008	Association of British Neurologists	Key area for quality improvement 2	A person receiving a new diagnosis of MS should receive comprehensive written and oral information and follow-up by a healthcare professional specialising in MS within 6 weeks of the diagnosis and contact details of their MS specialist nurse (where one exists) at time of diagnosis.	The diagnosis of MS is a life changing event for the person and can be associated with physical impairment, depression and other mental health disorders, loss of employment and significant impact on the person's whole family. The overall consequences can be devastating. The MS specialist nurse has a key role in providing information, supporting the person and wider family and helping those affected access available resources and services to lessen the impact of the condition. It is important that the person with MS is made aware of this resource and put into contact with them at the earliest opportunity.	The NICE clinical guideline (CG 186) recommends that the consultant neurologist should provide comprehensive written and oral information for the people with MS, their family & carers at diagnosis and there should be a follow up appointment at 6 weeks with a health care professional with an expertise in MS. An MS Society survey of ~8,500 people with MS in England found that: 71% of people with MS felt they had received sufficient information relating to their MS whilst 56% felt they had received enough information from health care professionals about

					drugs available to support the treatment of your MS. This suggests that a significant minority of people with MS are currently not receiving information related to their condition. MS Society (2013). A lottery of treatment and care – MS Services across England at the UK. http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/UK-ms-lottery.pdf
009	Association of British Neurologists	Key area for quality improvement 3	A person with a diagnosis of MS should have a named care coordinator (usually a MS specialist nurse) and have the opportunity to have a personalised care plan agreed by patient/carer and the care coordinator and a yearly review either by a neurologist or other healthcare professional with specialism in MS.	People with MS can develop a wide variety of symptoms both physical and non-physical. Often a number of healthcare professionals are required for optimal care. To ensure the person with MS is able to access all those professionals in a coordinated and timely manner requires careful coordination of care. Good communication between the person with MS and their carers/family and the various healthcare professionals is also vital.	Evidence from a recent patient experience survey undertaken by the Neurological Alliance found that:

				A named care coordinator (usually the person's MS specialist nurse where one exists) is necessary to provide seamless care acting as a route of communication between the person with MS and all healthcare professionals involved in that person's care at any particular time. MS is a long term condition associated with unpredictable exacerbations. The development of a personalised care plan between the person with MS and their family and the care coordinator with the opportunity to regularly review this at least on a yearly basis is necessary to enable the person with MS to participate in their care and identify areas where intervention may be required to prevent acute crises that may precipitate unplanned admissions.	Only 50% of people with MS felt that the different people treating and caring for them work well together effectively most or all of the time (total number of respondents=1457). This indicates that the treatment is not as well integrated, co-ordinated or responsive as it could be. Additionally, it found that 74% of respondents stated that they were not offered a care plan. http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report The NICE Clinical Guideline (CG 186) recommends that care should be delivered by a multi-disciplinary team (MDT) and that one team member should act as

					the contact point to coordinate care.
010	Biogen Idec Limited	There needs to be close integration of care at all levels of the NHS (primary, secondary and tertiary services) with social care.	MS affect people of all types and treatment and care needs vary considerably between different individuals. The importance of tailoring treatment and care to the individual needs of the patient is paramount, with a failure to access specialist care at the right time potentially leading to poorer outcomes for people with neurological conditions and putting pressure on other parts of the health and social care system. Provision of individual care plans on discharge is important to inform patients of their management plan, ongoing care and monitoring of drugs and set clear criteria for what they can expect from primary, secondary and tertiary services - particularly in relation to referral back to a specialist service.	Care plans empower patients to improve their self-management and ensure appropriate monitoring and review. They can also educate patients when to seek specialist intervention if their condition deteriorates. Currently few patients are offered care plans and in many areas clear integrated care pathways are lacking.	The traditional divide between primary care, community services, and hospitals - largely unaltered since the birth of the NHS - is increasingly a

			Integrated care pathways are also important in this key area	Commissioners have a lack of information on which to evaluate what is a good MS service and hence commission services that will be of high quality and to construct good integrated care pathways. There are examples of excellent local registries that record the required data but these are fragmented and there is a clear need for a common national register of MS patients and their treatment.	barrier to the personalised and coordinated health services patients need. *NHS Five Year Forward View.* http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
					In a survey of neurological patients, over two-thirds of survey respondents (71.5%, n=4,603) were not offered a care plan to help manage their condition. *Neurological Alliance – The Invisible Patients.* The right for patients to be offered a plan is enshrined in the NHS Constitution. ‘The NHS also commits to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge)’

					NHS Constitution March 2013 https://www.gov.uk/government/publications/the-nhs-constitution-for-england *Association of British Neurologists: Acute Neurology services survey 2014* Quality Standards, Statement 9 – Upon discharge, transfer of care information, including a management plan, is sent immediately to a named GP, as well as printed information for the patient. http://www.theabn.org/news/abn-acute-neurology-2014.html
011	Biogen Idec Limited	All MS patients should have access to an MS Specialist Nurse (MSSNs)	MSSNs take a leading role in ensuring patients get the best care possible. Studies have shown that specialist nurses are both clinically and cost effective. The direct and indirect benefits of specialist nursing roles can include reducing referral times, the length of hospital stays and preventing unplanned readmissions.	MSSN posts have already been lost and some specialist nurses are being asked to work outside their specialty to cover staff shortages in general clinical settings. The MS Trust in a recent survey identified a clear shortfall of MS specialist nurses of between 126 and 214 whole time equivalent posts across the UK.	A report by the Royal College of Nursing (RCN) has highlighted the contribution made by specialist nurses. In the Northamptonshire PCT, an MS specialist nurse saved £65,773 by treating 34 patients at home rather than in hospital and also freed up secondary care neurology appointments

					by half, saving £16,402. Specialist nurses: Changing lives, saving money. The Royal College of Nursing. http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf Shortfall of MS nurse posts. The MS Trust: MS specialist nursing in the UK - 2014 http://www.mstrust.org.uk/downloads/mssn-survey-report-2014.pdf
012	Essex Centre for Neurological Sciences	Long term care of MS patients	Comprehensive long term care support of MS patients is presently lacking due to a disjointed approach and separation of responsibilities between primary, secondary and social care services across the country.	Ideal care for MS patients should reach beyond hospital clinics and specialist treatment centres into individual homes, workplaces and social life. There should be named care provider and home support team for chronic progressive MS with provision for end-of-life care planning.	Quality Standards for MS Service.pdf

013	MS Society	Tailored information provision and management plan	The NICE clinical guideline recommends that the consultant neurologist should provide comprehensive written and oral information for the people with MS, their family & carers at diagnosis. The information should explain the condition, MS treatment (DMTs and symptom management), local support groups and services and DVLA, employment and social care information. There should be a follow up appointment at 6 weeks with a health care professional with an expertise in MS. Information should continue to be offered even if it is refused initially. People with MS and their family members or carers should develop a management plan with health and care professionals, this should be initiated by the health care professional but take into account the goals and preferences of the person with MS and their family. The management plan should include who to contact should their symptoms change. Information should be provided on an ongoing basis.	Research conducted by the MS Society and the Neurological Alliance into people with MS' experiences of information provision and care planning show significant variation across the country.	**Evidence regarding people with MS' experiences of information provision:**

			Why is this important?	In terms of quality of information provision, an MS Society survey of ~8,500 people with MS in England found that:	MS Society (2013). A lottery of treatment and care – technical report http://www.mssociety.org.uk/sites/default/files/Documents/Research/A%20lottery%20of%20treatment%20and%20care%20-%20technical%20report.pdf
			Comprehensive, tailored information provision and a care management plan are the foundations for people with MS to manage their condition effectively. People with MS have complex information needs. They have to be able to make informed decisions for both the short and long term. Their family and carers are also faced with uncertainty about the future and are likely to require information and support. The exact level and type of information needs to be tailored around a number of factors such as the time since diagnosis, the nature of diagnosis, disease progression, and the person receiving the information.	Only 56% (n=3,096) of people with MS felt they had received enough information from health care professionals about drugs available to support the treatment of their MS (total number or respondents=5510).	**Evidence of people with MS' experiences of care planning**
			Being diagnosed with a long term, progressive condition like MS can be extremely	71% of people with MS felt they had received sufficient information relating to their MS (total number of	Neurological Alliance (2015) – Patient experience survey

			challenging and people's initial reaction may not be to seek information and support – it's important that this is continued to be offered at the six week follow up and beyond to ensure they make informed decisions about their condition. A consultation with a specialist can be stressful and is constrained by time so its important materials are provided that summarises the dialogue, resulting actions and provides further information that can be considered afterward Information provision should be complemented by the creation of a management plan for a person with MS. The management plan should be developed in dialogue with a person with MS and their family is crucial to supporting effective self-management; facilitating self-referral, minimising hospital admissions and maintaining quality of life. It should evolve with a person's condition and look to be integrated with social	respondents=6366). These statistics show that the majority of people are receiving information but steps need to be taken to improve the quality and appropriateness of this, particularly in relation to treatments. Treatment can have a profound effect on the prognosis and quality of life. However, to initiate a long term treatment, with potential side effects, can be a difficult and complex decision to make. It is important people have the right information and support for them to engage in dialogue with their specialist to make the most appropriate decision. The same MS Society survey found that when asked 'How often did your health or social care professionals ask what is important to you when helping you to manage your MS?' 36% (n=3,081) replied never and a further 17% (n=1,440) replied rarely. This is extremely worrying as people's clinical, emotional and social needs may be being neglected; leaving people with MS unable to manage their condition and lives in the way that best suits them.	http://www.neural.org.uk/store/assets/files/491/original/Neurological_Patient_Experience_Survey_final_14_January_2015_.xls

			care services as these needs arise. Whilst information provision and care planning should begin with the consultant neurologist, subsequent information and support regarding such as local voluntary sector support services, welfare benefits, social care and exercise classes may be better provided from a range of sources such an MS nurse, patient organisations (like the MS Society, MS Therapy Centres or MS Trust) or at NHS Choices. However, it is crucial the initial information given by a consultant neurologist is comprehensive and enable people with MS to seek further comprehensive information following the consultation.	The findings correlate with the findings of the recent Neurological Alliance survey that people with MS are rarely offered a care plan to help manage their needs. 74% (n=1159) respondents stated that they were not offered a care plan (total number of respondents=1573). **Improving the range and quality of information provision and creating a management plan as close to diagnosis as possible would support people to make informed decisions about their treatment and care and self-manage**	

				effectively. A quality standard focusing on these two aspects would drive up the quality of services.	
014	Multiple Sclerosis Trust	Everyone to be offered information and support at diagnosis and on a regular basis thereafter, even if it has been declined previously. "The consultant neurologist should ensure that people with MS and with their agreement their family members of carers are offered oral and written information at the time of diagnosis". "Review information, support and social care needs regularly. Continue to offer information and support to people with MS even if this has been declined previously."	Information provision at diagnosis has been shown to be vital – and often lacking - by MS Trust research and by a recent Cochrane review. It is vital to enable the individual to adjust to the new diagnosis, and then to subsequent challenges as they arise in the course of this lifelong condition. The MS Trust study identified the need for information to aid adjustment to the diagnosis and to come from a trusted source, but also that it needs to be supported with expert input from specialists.	There is no metric for measuring whether people with MS are provided with written information at diagnosis or at later stages of their condition, and this seems to be dependent on the individual health professionals involved. Anecdotally, the MS Trust continues to hear stories from individuals who were not offered information at diagnosis or who were offered information but no support in how to interpret and manage that information at times of key decision making, eg choosing a disease modifying therapy.	MS Trust research: The information needs of the newly diagnosed. Way Ahead 2012;16(4):6-7 http://www.mstrust.org.uk/professionals/information/wayahead/articles/16042012_03.jsp Köpke S, Solari A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. Cochrane Database Syst Rev. 2014 Apr 21;4.

			A Cochrane review of information provision for people with multiple sclerosis found that the emotional burden on people with MS at diagnosis was high, and emphasised the need for careful monitoring and management of mood symptoms (chiefly anxiety). Information provision improved patients' knowledge of their condition, the achievement of 'informed choice', and satisfaction with the diagnosis communication. The House of Care model identifies that engaged, informed individuals and carers are more able to deal with the issues that living with a long-term condition throws at them. This is a finding replicated by new research into Patient Activation, where involving people actively in managing their health is more likely to reduce health inequalities and deliver improved outcomes, better quality care and lower costs	The Guideline recommends that the neurologist is offering written information at diagnosis, which we believe should be quality assured information such as the MS Trust's *Making sense of MS*. There is no recommendation in the Guidance about who should be offering information and support beyond diagnosis, but it makes sense that this should be the MS specialist nurse if available, or other health professional with specialist expertise in MS. A key consideration at this point is the inequitable provision of MS specialist nurses across England, with unsustainable caseloads in some areas. We are also concerned that people with MS who were diagnosed some time ago may not be known to services, and a key area for quality improvement is identifying these individuals so that information and support is available to them.	Solari A[1].Effective communication at the point of multiple sclerosis diagnosis. Multiple Sclerosis. 2014 Apr;20(4):397-402. Hibbard J, Gilburt H.(2014) Supporting people to manage their health:an introduction to patient activation. London: King's Fund. http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: building the House of Care. London: King's Fund.

					http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480
015	Multiple Sclerosis Trust	"Offer the person with MS an appropriate single point of contact to coordinate care and help them access services"	An appropriate single point of contact for people with MS has been recognised as important in NICE Guidance. The House of Care model for long-term conditions recognises person-centred coordinated care as central to encouraging self-management and improving outcomes. For people with MS, particularly in crisis, having a single point of contact is a significant leap forward in improving self management and patient activation.	There is no agreed model for the single point of contact, but a reasonable assumption might be an MS specialist nurse or an MS specialist care coordinator where one exists. One key area for quality improvement would be identifying who might work as a single point of contact in a given locality, and what form that contact could take. Part of the metric for measuring quality improvement must be expected time of response/actual time of response, and outcomes of that response.	Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480 House of Care http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/house-of-care/house-care-mod/

			People with MS with a significant deterioration in symptoms will present anywhere they think can help them, eg GP/A&E/urgent care centres. There is a risk that without specialist input, health professionals will assume the person is in relapse, whereas symptom deterioration may be caused by infection, comorbidities as well as relapse. A single point of specialist contact that can triage such experiences should reduce NHS wastage in unnecessary appointment and prescriptions.	There are two practical issues that will need to be resolved with this model: First, MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable. Offering these nurses as a single point of contact to people with MS risks burnout among professionals without significant increases in capacity Third, work in progress by the MS Trust as part of the Generating Evidence in MS Services project indicates that there are many people with MS who are not known to services. People with MS who were diagnosed some time ago, were seen by neurology services and then discharged, may be lost to the specialist service but	

				still in need of specialist help. Identifying them and offering them a single point of contact must form part of this step for quality improvement.	
016	Novartis Pharmaceuticals (UK) Ltd	Access to Specialist Nurse Resource.	Every patient with MS should be under the care of a Specialist Neurologist and Specialist Nurse. Coming to terms with a diagnosis of MS as well as navigating the complex treatment decisions that need to be made requires time and expertise. A team specialising in MS is best placed to do this.	Helping newly diagnosed patients through the process of adjustment and decision making in the early days is complex and time consuming. The decision regarding disease modifying treatments (DMTs) needs to be undertaken with an MS Specialist Consultant or Nurse. There are 10 licenced DMTs with different forms of delivery and monitoring that need to be matched to the individuals' abilities, motivation and lifestyle.	Multiple sclerosis: management of multiple sclerosis in primary and secondary care: https://www.nice.org.uk/guidance/cg186 (accessed 15th March 2015)
017	Roche Products Ltd	Each patient should have a Personalised Care Plan and be provided with full supporting information for families	Every patient and their family should be provided with clear contact information, including a named specialist multiple sclerosis nurse at first diagnosis and for when the disease worsens e.g. further relapse.	The clinical objective and principal benefit to patient is to delay progression of the disease.	NICE Guidance on Multiple Sclerosis Oct 2014

			A recent Cochrane Review showed this to be both beneficial to the patient and often lacking. It is important that people with MS experiencing disease relapses or possible drug-related side effects are able to obtain advice from the MS specialist service rapidly, in order to prevent any further	A recent report into Patient Activation by the Kings Fund highlights that “Patient activation scores have been robustly demonstrated to predict a number of health behaviours. They are closely linked to clinical outcomes, the costs of health care and patients’ ratings of their experience. Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation, and to report higher levels of satisfaction with services.	“A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include consultant neurologists (doctors specialising in the brain and nervous system), MS nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, dieticians, social care providers and specialists to help with bladder and bowel problems, as well as your GP. All these people should work together to care for you. You should be given the name and contact details for one of these people, so that you can make contact with the team if you have any questions.” Kopke S, Solari A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. Cochrane Database Systs Rev. 2014 April 21;4.

			nerve damage incurring. Delayed progression and reduced relapses offer significant benefits to multiple sclerosis patients and their families		The Kings Fund. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf
018	Roche Products Ltd	Every patient should have a single point of contact into the multidisciplinary team to co-ordinate their care	As recognised in the guideline, individual patient needs place varying demands on nurse time but every patient requires some specialist nurse care and support for effective management to enable the patient to remain active, engaged and as well as possible and to encourage self-management and to reduce acute hospital admissions	Patients can lead relatively normal productive lives with adequate specialist nurse support in a community setting. A recent report by the MS Trust recommends an optimal staffing level of 300 patients per whole time equivalent specialist nurse.	Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. www.mstrust.org 2009 – 10 HES data shows that multiple sclerosis was responsible for 26,804 episodes of admitted patient care and accounted for 86,014 occupied bed days imposing a significant cost to the NHS.

019	Royal College of Nursing	Impact of MS nurses	The impact of MS nurses in the healthcare community and value for money.	Demonstrating quality of care that saves the local health economy money but puts the patient at the centre of its care.	Published articles, RCN, MS Trust and MS Society
020	Royal College of Nursing	Access to Multiple Disciplinary Team particularly Sclerosis (MS) Specialist Nurses	There is currently variation of access to the expertise of the multiple disciplinary teams including access to MS nurse specialists. *“Based on a sustainable caseload of 358 people with MS per whole time specialist nurse, there is currently a shortfall of 62 MSSNs across the UK, with significant shortfalls in England and Scotland” (MS Trust 2014).* With Multiple Sclerosis Nurse Specialists’ caseloads being exceptionally high across UK, in some areas despite there being adequate provision, some people are travelling a significant distance to access services. It is estimated that a further eighty or more MS nurses are required to ensure fair access for all.	Currently access to Multiple Disciplinary Team (MDT), including specialist MS nurses is variable depends on where one lives leading to variation of service and quality of care. In particular there is lack of access to psychology. This service is crucial for people with MS who are dealing with low mood, anxiety and cognitive problems. Very few patients have access to this service. We would like a standard on access to the MDT including specialist Multiple Sclerosis Nurse and who the MDT should consist of as a minimum and can be accessed in a timely manner.	MS Trust publications on value of MS Nursing etc.: MS Specialist Nursing in the UK 2014: The case for equitable provision Nov-14 Royal College of Nursing (2013): Innovative and empowering project helps show the value of nursing
021	Salford Royal NHS Foundation Trust	INFORMATION & SUPPORT	Information needs to be comprehensive & tailored to individual patient’s needs and requirements. The ability to make informed decisions is paramount in the provision of information. The provision of information is not a one of	Research conducted by the MS Society and the Neurological Alliance into people with MS’ experiences of information provision and care planning show significant variation across the country.	MS Society (2013). A lottery of treatment and care – MS Services across England at the UK. http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/

			event; it is an ongoing need by the patient & their family to help negotiate their MS journey		UK-ms-lottery.pdf
			NICE Guideline on Patient Experience in Adult NHS Services (DH 2012) Identifies information giving and shared decision making as enablers for active participation in care	In terms of quality of information provision, an MS Society survey of ~8,500 people with MS in England found that:	Neurological Alliance (2015). Invisible patients report: revealing the state of neurology services (2015) http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report
				71% of people with MS felt they had received sufficient information relating to their MS (total number of respondents=6366).	Association of British Neurologists. Revised (2009) Guidelines for Prescribing in Multiple Sclerosis.
				56% (n=3,096) of people with MS felt they had received enough information from health care professionals about drugs available to support the treatment of your MS (total number or respondents=5510).	http://www.mstrust.org.uk/competencies/downloads/abn_ms_guidelines_2009_final.pdf
				The same MS Society survey found that when asked 'How often did your health or social care professionals ask what is important to you when helping you to manage your MS?' 36% (n=3,081) replied never and a further 17% (n=1,440) replied rarely.	Hibbard J, Gilburt H.(2014) Supporting people to manage their health: an introduction to patient activation. London: King's Fund. http://www.kingsfund.org.uk/publications/supporting-people-manage-their-

				Improving the information provision and creating a care plan as close to diagnosis as possible would support people to make informed decisions about their treatment and care and self-manage effectively. The Kings Fund have also identified the importance of information provision in improving the quality of shared decision-making and patient activation. The ABN recognise this contribution to safety and quality in their Prescribing Guidelines “MS specialist nurses play an important role in managing symptoms as well as providing information and reassurance to patients on treatment during and between clinic attendances”. A quality standard which identified this would ensure consistency of approach and support at the crucial time.	health
022	SCM 1	The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written			

		information at the time of diagnosis.			
023	SCM 1	Offer the person with MS a face to face follow up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis.			
024	SCM 2	Information at time of diagnosis	Giving people diagnosed with MS information at the time of diagnosis is a recommendation in the NICE guidelines. Evidence from patient forums and the MS Society helpline shows that there is considerable variation in practice, Leaving a patient in “Limboland” with a diagnosis but no further information is unacceptable. Currently only some consultants expect the MS nurse to give the patient information when they meet a few weeks later, others give a very limited amount of information.	It is simple and measurable to give patients a defined set of information at diagnosis. Most of it is available through the literature already published by charities. This should include 1) Phone number for MS nurse or MDT lead 2) Charity helpline numbers 3) Details of the type of MS diagnosed 4) Information listing the most common MS symptoms (UTI, fatigue …) 5) Information on recognising a relapse	

025	SCM 2	Single point of contact	The guidelines specify people with MS have access to a single point of contact who has specialist knowledge of MS (typically an MS Nurse). Evidence from patient forums and the MS Society helpline shows that in practice there is considerable variation in practice in how well or if this happens at all.	This is key for the welfare of patients. Many do not contact their MS nurse because they know that the response will tae days if it happens at all. In consequence they use A&E or ignore symptoms until they become more serious resulting in greater costs. The quality standard needs to specify 1) That all people with a diagnosis have access using self-referral 2) If an answering machine is used or an email address provided that there is a response from an MS specialist within 1 working day of contact being made.	
026	United Kingdom Multiple Sclerosis Specialist Nurse Association	**Information giving** The consultant neurologist should ensure that people with MS and, with their agreement, their family members or carers are offered oral and written information at the time of diagnosis.	NICE Guideline on Patient Experience in Adult NHS Services (DH 2012) Identifies information giving and shared decision making as enablers for active participation in care. Providing high quality information in accessible format contributes to the NHS Outcomes Framework Domain 2 Enhancing quality of life for people with long term conditions by enabling them to understand the implications of their diagnosis and make decisions and plans for the future.	Information around treatment options is particularly important from the outset as giving patients accurate information on the expectations of treatment including the evidence of efficacy and risk of side effects or harms is not only empowering for the patient, it also reduces risk and improves compliance. This information is usually given by the MS specialist nurse. The ABN recognise this contribution to safety and quality in their Prescribing Guidelines	Association of British Neurologists. Revised (2009) Guidelines for Prescribing in Multiple Sclerosis.

		Review information, support and social care needs regularly. Continue to offer information and support to people with MS even if this has been declined previously.”	It also enhances the autonomy of people living with MS by enabling them to participate in shared, informed decision making	“MS specialist nurses play an important role in managing symptoms as well as providing information and reassurance to patients on treatment during and between clinic attendances”. The Kings Fund have also identified the importance of information provision in improving the quality of shared decision-making and patient activation. This support is particularly valuable at time of diagnosis when emotions are volatile and stress is increased by a lack of clarity or confusion.	http://www.mstrust.org.uk/competencies/downloads/abn_ms_guidelines_2009_final.pdf Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480 Hibbard J, Gilburt H.(2014) Supporting people to manage their health: an introduction to patient activation. London: King’s Fund. http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health

				The MS Specialist nurse is best placed to assess the information needs and offer the continuity of support that information giving provides. However it is important to recognise that the increasing number of DMTs and the demands of monitoring the impact of these is inevitably limiting the time available for those who are not taking DMTs. This is especially true where the case load is already large and capacity diminished. Consideration of these issues will be required in developing this quality standard.	Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: building the House of Care. London: King's Fund. http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions Köpke S, Solari A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. Cochrane Database Systematic Review. 2014
027	United Kingdom Multiple Sclerosis Specialist Nurse Association	**Single Point of Contact**	There is evidence that a single point of contact to coordinate care is preferred by patients and improves access to expertise.	Although the guidelines do not specify a service model it is acknowledged that in order to be safe and effective this role needs to be undertaken by a clinician with specialist knowledge and expertise in MS management. This should include; knowledge of the disease process and how this is likely to impact on the individual; experience in guiding access to appropriate therapeutic and rehabilitative interventions; an understanding of the increasing and complex range of disease	Quality Standard for Non-urgent Neurological Conditions Statement 4 Association of British Neurologists

				modifying therapies (DMT); as well as case management skills to ensure good communication and coordination of effort.	
		Offer the person with MS an appropriate single point of contact to coordinate care and help them access services.	The full Clinical Guideline states, “The GDG considered that co-ordination of care was best seen from a patient perspective. The evidence and GDG experience indicated that people with MS want a point of contact, ideally someone with knowledge of them and of MS, and for timely communication to occur between the professionals involved in their care. …. due to the complexity and low prevalence of MS, every person with the disease should be able to access healthcare professionals who are knowledgeable.” The Association of British Neurologists Quality Statement 4 states that, “Patients with Long Term Neurological Conditions will have a named point of contact for re-accessing	Patient surveys carried out by the MS Society and the Neurological Alliance have indicated that improving access to and coordination of care is an area of patient experience that could be significantly improved. The NSF for Long Term Neurological Conditions identified a single point of contact as part of Quality Requirement 1. A report assessing progress against the NSF commented that “Where a specialist nurse existed, they were often cited as the single point of contact for all issues” MS Specialist Nurses or Clinicians are ideally placed to fulfil the care coordinator role. Working in both hospital and primary care settings they provide a pivotal role in coordinating many services currently and often function as a bridge between	ABN 2014 http://www.theabn.org Association of British Neurologists. Revised (2009) Guidelines for Prescribing in Multiple Sclerosis.

			the service”	specialist prescribing centres and generic community services.	
			The ABN have also identified that more aggressive DMTs have the potential for serious harm. This will be highlighted in the review of Treatment Guidelines for MS to be published later this year. It is therefore important that the person providing ongoing support understands the significance of reported symptoms and acts accordingly.	However at present access to this expertise is not equitable across the United Kingdom and there are areas where MS Specialist Nurses are available but access to them is constrained by the demands of their work plan and case load. The provision of a single point of contact without consideration of an individual’s case load will not necessarily lead to more equitable provision.	http://www.mstrust.org.uk/competencies/downloads/abn_ms_guidelines_2009_final.pdf
				The quality improvement in this area therefore, needs to consider not only who should undertake this role in each locality but also if the individual acting in this capacity has reasonable capacity to perform it. Evidence from the GEMSS project indicates there is a considerable variance in the way that services have been set up so that some 28% of people with MS (nearly 30,000) live in areas where MS Specialist Nurse caseload are more than twice the level that is sustainable.	Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: building the House of Care. London: King’s Fund. http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions

					Neurological Alliance (2015). The invisible patients: revealing the state of neurology services; http://www.neural.org.uk Quality Requirement 1 NSF Long Term Neurological Conditions (DH 2005) Halfway through are we halfway there?: A mid-term review of the NSF for Long Term Neurological Conditions (Neurological Commissioning Support 2010) Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480
Section 4.3: Coordination of care					

028	Association of British Neurologists	Key area for quality improvement 5	A person with MS should have timely referral to multi-disciplinary services including community neurological rehabilitation teams. The named care coordinator for the person with MS would facilitate this and ensure clear and prompt communication.	MS is a complex long-term condition with varied symptoms which can fluctuate over time but in most people deterioration and progression is inevitable and can be irreversible [1]. DMTs are only suitable for people with MS who have regular relapses as defined by NICE criteria and although they have value in reducing relapse and MRI activity they do not generally address ongoing symptoms such as mobility problems and fatigue. Additionally MS has a huge impact not only for the person with the condition but also for family/carer and can affect all aspects of life including employment, marriage and overall quality of life. Hence during the lifetime of someone with MS a large and varied number of health professionals are required to address all these issues. Mobility is the most common symptom affecting people with MS [2] and access to community rehabilitation is often the only treatment option and also can help with other common symptoms including spasticity and balance. [1] C Confavreux, et al. Natural history of multiple sclerosis: a unifying concept. Brain 2006; 129:606-16.	The NICE clinical guideline (CG 186) recommends that people with MS consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat mobility problems and/or fatigue, two of the most common symptoms associated with MS [1]. Both the 2008 and 2011 Royal College of Physicians MS audit reports [2,3] highlight concerns people with MS have regarding access to rehabailitation services and equipment. In a MS Society survey 43% of people with MS who require support to be physically active did not receive it. Further 31% of people who need to see a physiotherapist are unable to do so [4].

				[2]https://www.rcplondon.ac.uk/sites/default/files/ms-audit-2008-summary-report_1.pdf	In a recent Neurological Alliance report 54% (n=786) of people with MS experienced problems or delays in accessing the treatment to help manage their condition [5]. Additionally although people with MS generally appreciated the skill and value of individual healthcare professionals only 50% felt that the different people treating and caring for them work well together effectively most or all of the time. This would seem to emphasise the importance of the role of a named care coordinator [5]. [1]http://www.nice.org.uk/guidance/cg8. [2]https://www.rcplondon.ac.uk/sites/default/files/ms-audit-2008-summary-report_1.pdf [3]https://www.rcplondon.ac.uk/sites/default/files/ms_audit_executive_summary_2011_1.pdf

029	Biogen Idec Limited	There needs to be close integration of care at all levels of the NHS (primary, secondary and tertiary services) with social care.	MS affect people of all types and treatment and care needs vary considerably between different individuals. The importance of tailoring treatment and care to the individual needs of the patient is paramount, with a failure to access specialist care at the right time potentially leading to poorer outcomes for people with neurological conditions and putting pressure on other parts of the health and social care system. Provision of individual care plans on discharge is important to inform patients of their management plan, ongoing care and monitoring of drugs and set clear criteria for what they can expect from primary, secondary	Care plans empower patients to improve their self-management and ensure appropriate monitoring and review. They can also educate patients when to seek specialist intervention if their condition deteriorates. Currently few patients are offered care plans and in many areas clear integrated care pathways are lacking.	[4] MS Society. A lottery of treatment and care – MS Services across England at the UK, 2013 http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/UK-ms-lottery.pdf [5] http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report The traditional divide between primary care, community services, and hospitals - largely unaltered since the birth of the NHS - is increasingly a

			and tertiary services - particularly in relation to referral back to a specialist service.		
			Integrated care pathways are also important in this key area	Commissioners have a lack of information on which to evaluate what is a good MS service and hence commission services that will be of high quality and to construct good integrated care pathways. There are examples of excellent local registries that record the required data but these are fragmented and there is a clear need for a common national register of MS patients and their treatment.	barrier to the personalised and coordinated health services patients need. *NHS Five Year Forward View.* http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
					In a survey of neurological patients, over two-thirds of survey respondents (71.5%, n=4,603) were not offered a care plan to help manage their condition. *Neurological Alliance – The Invisible Patients.* The right for patients to be offered a plan is enshrined in the NHS Constitution. ‘The NHS also commits to involve

					you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge)’ NHS Constitution March 2013 https://www.gov.uk/government/publications/the-nhs-constitution-for-england *Association of British Neurologists: Acute Neurology services survey 2014* Quality Standards, Statement 9 – Upon discharge, transfer of care information, including a management plan, is sent immediately to a named GP, as well as printed information for the patient. http://www.theabn.org/news/abn-acute-neurology-2014.html
030	Essex Centre for Neurological Sciences	Access to a designated clinical service for Multiple Sclerosis (MS)	There is evidence that access to a multi-disciplinary and comprehensive service supports care of patients more effectively and meets the expectation of patients	Ease of access to a multi-disciplinary MS clinic within an acceptable time period in England is highly variable and patchy at present; it is a key area of quality improvement	Please see below

031	Essex Centre for Neurological Sciences	Effective management of MS	Patients with MS require a multi-disciplinary approach to managing their conditions in partnership between the primary and secondary care	Patients with acutely relapses should be fast-tracked, and all patients require appropriate management of their symptoms to improve quality of life and self-care abilities.	Please see below
032	Essex Centre for Neurological Sciences	Long term care of MS patients	Comprehensive long term care support of MS patients is presently lacking due to a disjointed approach and separation of responsibilities between primary, secondary and social care services across the country.	Ideal care for MS patients should reach beyond hospital clinics and specialist treatment centres into individual homes, workplaces and social life. There should be named care provider and home support team for chronic progressive MS with provision for end-of-life care planning.	Quality Standards for MS Service.pdf
033	MS Society	Care coordination: MS nurse as the named care-coordinator within a	The guideline recommends that care should be delivered by a multi-disciplinary team (MDT). Depending on a person's needs, the team could include: consultant neurologists, MS nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dieticians, social care and continence specialists and GPs. One team member should act as the contact point for the team and coordinate care for the person with MS. If a person's symptoms change, they can approach the contact person for a referral to the necessary service.	The MDT and care coordinator should provide a responsive and holistic package of care for people with MS. However we know that access to treatment, care and support is variable across the country.	**Evidence supporting the role of the MS nurses as care coordinator**

		multi-disciplinary team of MS specialists			
			Why is this important?	In terms of access to specialists, an MS Society survey of ~8,500 people with MS in England found that:	MS Society (2011) Experiences of people using MS specialist nurse services http://www.mssociety.org.uk/sites/default/files/Documents/Campaigns%20resources/MS%20Specialist%20nurses%20final%202011.pdf
			People with MS are faced with an array of symptoms that may arise unpredictably and suddenly. Hence their physical, emotional and social needs may frequently require the action of more than one category of health professional at any particular time or support from the voluntary sector or social care services. Provision of care should therefore be adequately co-ordinated to allow it to be timely, appropriate and comprehensive. Given the right mix of knowledge and skills, and the trust of other members of the team, a single point of contact facilitates fast and appropriate referrals. MS nurses are particularly suited to the role of care coordinator owing to	21% rarely (n=905) or never (n=832) find it easy to see specialist (neurologist and MS nurse), 31% (n=2,590) sometimes find it easy (total number of respondents=8,471).	

			their knowledge of the impact of the condition, accessibility to people with MS and knowledge of health care systems referral processes to enable effective referral to other members of the MDT Access to MS specialists (MS Specialist neurologist, neuro-physiotherapist specialising in MS, MS nurse etc) helps ensure people with MS receive the best care and treatment across the duration of their life. For example, research by the MS Society shows that those who have access to an MS nurse or neurologist are more than twice as likely to be taking a DMT, emphasising how crucial access to specialists is to taking a DMT.	30% (n=1,148) of people with MS who have needed to see a continence advisor have been unable to do so (total number of respondents=3,874). 50% (n=1,666) of people with MS who have required support for mood or emotional issues from their local health services felt they did not receive enough support (total number of respondents=3355) Evidence from a recent patient experience survey undertaken by the Neurological Alliance found that:	MS Trust (2012) Defining the value of MS specialists nurses http://www.mstrust.org.uk/shop/product.jsp?prodid=401 Forbes A et al. (2003) Impact of clinical nurse specialists in multiple sclerosis--synthesis of the evidence J.Adv Nursing 42442-62 http://www.ncbi.nlm.nih.gov/pubmed/12752865 Johnson J et al Smith P & Goldstone L MS research Trust and Southbank University (2001) Evaluation of MS Specialist Nurses

				54% (n=786) of people with MS experienced problems or delays in accessing the treatment to help manage their condition (total number of respondents=1457) Only 50% (n=727) of people with MS felt that the different people treating and caring for them work well together effectively most or all of the time (total number of respondents=1457). This indicates that the treatment is not as well integrated, co-ordinated or responsive as it could be. **Better care coordination should facilitate self-referral and improve access to treatment and care for people with MS. An MS nurse is perfectly suited to the role care coordinator. The rest of the MDT should be made up of MS specialists such as an MS specialist neurologist and neuro-physiotherapist. To ensure consistency across the country, a quality standard should be developed stating that people with MS should have an MS nurse as care coordinator within an MDT of MS specialists.**	**Evidence regarding access to specialists:** MS Society (2013). A lottery of treatment and care – technical report http://www.mssociety.org.uk/sites/default/files/Documents/Research/A%20lottery%20of%20treatment%20and%20care%20-%20technical%20report.pdf Neurological Alliance (2015) – Patient experience survey http://www.neural.org.uk/store/assets/files/491/original/Neurological_Patient_Experience_Survey_final_14_January_2015_.xls
034	Multiple Sclerosis Trust	Care for people with MS using a coordinated multidisciplinary team approach.	Access to the multidisciplinary team for people with MS is recommended within NICE guidance.	But access to specialists who can provide that care is limited.	Association of British Neurologists, Royal College of Physicians (2011). Local adult neurology services for

					the next decade. Report of a working party.
			Multidisciplinary input is known to be vital to deal with the complex and inter-related symptoms of MS and other neurological conditions, especially those that are not susceptible to medical intervention alone, such as mobility and dexterity problems, spasticity, pain, cognitive symptoms and speech and swallowing symptoms.	Research undertaken by the Association of British Neurologists indicates that the UK has around less than a third of the European average of consultant neurologists per head of the population. In 2011, there were 285 UK consultant neurologists, or approximately 1:115,000 of the UK population.	https://www.rcplondon.ac.uk/publications/local-adult-neurology-services-next-decade
		"Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS, including consultant neurologists, neurologist, MS nurses, physiotherapists and occupational therapists, speech and language therapists,	For people with MS, access to MS specialists, as part of a wider multidisciplinary team, means having support to feel in control of the many symptoms of MS. It means being prepared for potential problems or changes and knowing how to prevent crises. It means being able to receive the expert support to recover from set-backs and to adapt to new circumstances.	MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable.	Mynors G, Bowen A. MS specialist nursing in the UK 2014: the case for equitable provision. MS Trust: Letchworth Garden City. http://www.mstrust.org.uk/shop/product.jsp?prodid=480

		pscyhologists, dietitians, social care and continence specialists; GPs.”	Access to MS specialists in neuro-rehabilitation is becoming more difficult but is key to maintaining and promoting function in people with mild to significant disability, particularly in common MS symptoms such as spasticity, pain, mobility, cognition, dexterity, speech and swallowing and other issues. Input from a range of therapists and other specialists is essential to ensure a coordinated approach to these symptoms which may be interrelated; for example, untreated spasticity can cause pain, mobility problems, sleep disorders and infections.	The small descriptive study into NHS provision of physiotherapy led by Markwick found “that the majority of the free text comments on MS services were negative (55%). Physiotherapy provision was rated the most negative of NHS services (38%), with the primary complaints being lack of information about services and excessive waiting times for appointments. This study has revealed that NHS physiotherapy provision is not meeting the needs of PwMS.”	Markwick R[1], Singleton C, Conduit J. The perceptions of people with multiple sclerosis about the NHS provision of physiotherapy services. Disability Rehabilitation 2014;36(2) :131-5
			MS specialists are also vital in aiding health promotion, such helping people with MS to stay active, eat healthily and prevent secondary complications of MS such as pressure ulcers, urinary tract infections. MS specialists aid the individual to make choices about care and treatment that suit each person’s unique circumstances.	While there is less detailed information about the other members of the multidisciplinary team, a recent report by the MND Association has found that there are not currently enough speech and language therapists to meet the needs of people with MND, a considerably smaller population than that of people with MS.	All-Party Parliamentary Group on MND. *Condemned to silence*: inquiry into access to communication support for people with MND. London: 2014.

	Much of this is recognised in the NICE Guideline's recommendations around symptom management, particularly	Access to neuro-specialists working in rehabilitation is key to ensuring optimal outcomes for people with MS and other neurological conditions. Improving access to neuro-specialist therapists working in community settings has long been an aim of the National Clinical Director for Neurosciences, David Bateman – for example, in the Neurological Alliance's *Navigating neurology services* report - but so far with limited success, and despite NHS England's work to improve rehabilitation services, for example through its Rehabilitation Delivery Board. Work in progress by the MS Trust indicates that specialist neuro-therapist teams, particularly in community settings, are under pressure to take on more general caseloads. As a result skills are being lost and services are finding caseloads less and less manageable. We are also aware that continence services are not always available and that neuro-psychologist and dietitian services are very rare. While some people with MS may benefit from general psychology services, in some areas even initiatives such as IAPT (Improving Access to Psychological Therapies) are not available to individuals presenting with an MS diagnosis.	Neurological Alliance. Navigating neurology services:helping strategic clinical networks to be a success story. London; NA. 2013.

				Overall, we would suggest a metric for quality improvement that measures the number of MS teams which involve or have access to the whole range of healthcare professionals outlined in the Guideline, including measurement of how many of these services are specialist. As part of that metric, we might like to see the range of services on offer, eg patient education in the form of 'getting to grips' and symptom management courses; and symptom specific management such as cognitive assessments; fatigue management courses; exercise classes.	
035	Roche Products Ltd	Earlier patient relapses should trigger immediate re-assessment by specialist MS team	Access to the multidisciplinary team for people with MS is recommended within NICE Guidance Patient reviews at 18 month intervals have been reported and access to specialists who can provide care is limited	Significant irreversible disease progression can occur between the re-assessments 2009 – 10 HES data shows that multiple sclerosis was responsible for 26,804 episodes of admitted patient care and accounted for 86,014 occupied bed days imposing a significant cost to the NHS	See above references Association of British Neurologists, Royal College of Physicians (2011). Local adult neurology services for the next decade. Report of a working party. www.rcplondon.ac.uk/publications/local-adult-neurology-services-next-decade. HSCIC HES data report on Multiple Sclerosis.
036	Royal College of Nursing	Access to Multiple Disciplinary Team particularly Sclerosis	There is currently variation of access to the expertise of the multiple disciplinary teams	Currently access to Multiple Disciplinary Team (MDT), including specialist MS nurses is variable depends on where one	MS Trust publications on value of MS Nursing etc.:

		(MS) Specialist Nurses	including access to MS nurse specialists. *“Based on a sustainable caseload of 358 people with MS per whole time specialist nurse, there is currently a shortfall of 62 MSSNs across the UK, with significant shortfalls in England and Scotland” (MS Trust 2014).* With Multiple Sclerosis Nurse Specialists’ caseloads being exceptionally high across UK, in some areas despite there being adequate provision, some people are travelling a significant distance to access services. It is estimated that a further eighty or more MS nurses are required to ensure fair access for all.	lives leading to variation of service and quality of care. In particular there is lack of access to psychology. This service is crucial for people with MS who are dealing with low mood, anxiety and cognitive problems. Very few patients have access to this service. We would like a standard on access to the MDT including specialist Multiple Sclerosis Nurse and who the MDT should consist of as a minimum and can be accessed in a timely manner.	MS Specialist Nursing in the UK 2014: The case for equitable provision Nov-14 Royal College of Nursing (2013): Innovative and empowering project helps show the value of nursing
037	Salford Royal NHS Foundation Trust	ACCESS TO MULTIDISCIPLINARY TEAM Care for people with MS using a coordinated multidisciplinary	Clarity about the organisation of care and how it is co-ordinated and delivered was considered a high priority by the Guideline Development Group: “The GDG considered that while it might be possible to define a core multi-disciplinary team of people who are involved in	Access to multidisciplinary neurological specialists for ongoing long term management or rehabilitation is variable and inequitable across the country, and even within local areas. A worrying trend is the reported dilution of specialist therapists’ expertise as a result of merging their services with generic teams. In addition there is inequitable access to key members of an MDT.	NSF Long Term Neurological Conditions (DH 2005) Statement 6 Quality Standard for Non-urgent Neurological Conditions ABN 2014 www.theabn.org

		approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS.	patient care e.g. a neurologist, MS nurse, physiotherapist and occupational therapist, individual patients might have more need of management from other health care professionals such as continence nurse, a rehabilitation physician, a speech and language therapist or a psychologist, or from social care. A multi-disciplinary team approach should encompass all these perspectives as well as those of patient and family." The NSF for Long Term Neurological Conditions also highlighted the importance of an MDT approach to ongoing support in the community as well as specific rehabilitation interventions as seen in Quality Requirement 1 and 5.	A Consultant in Rehabilitation Medicine is a key member of the multidisciplinary team and is able to provide management of specific issues such as spasticity, vocational advice as well as providing a holistic overview in complex advanced presentations. In many areas they are also the gatekeepers for specialist rehabilitation either as an inpatient or an outpatient. Cochrane systematic reviews provide strong evidence of the short term effectiveness of multidisciplinary rehabilitation in improving ability to undertake activities of daily living and increased societal participation.	Defining the value of Allied Health Professionals with expertise in MS: Supporting evidence and recommendations for Commissioners and Practitioners. K. Dix and H. green MS Trust Nov 2013 Recommendations on Rehabilitation Services for Persons with MS in Europe (EMSP 2012) http://www.emsp.org/attachments/article/184/Recommendations%20on%20Rehabilitation%20Services%20for%20Persons%20with%20Multiple%20Sclero~.pdf

038	SCM 1	Care for people with MS using a coordinated multidisciplinary approach.			Khan F, Turner–Stokes L, Ng L, Kilpatrick T, Multidisciplinary Rehabilitation for adults with Multiple Sclerosis. Cochrane Database Systematic Review 2005 Medical Rehabilitation in 2011 and beyond: Report of a Working Party RCP and BSRM Nov 2010
039	SCM 2	Co-ordination of care	The guidelines specify people with MS have access to a co-ordinated multidisciplinary team that specialises in MS. Evidence from patient forums neurological strategy development groups and the MS Society Helpline shows that there is considerable variation in practice,	Currently many patients do not have access ir are not aware of their MDT. In consequence they use A&E or their GPs which places a greater cost burden on the NHS and provides a poorer standard of care for them. A measurable quality standard is simple to define and implement. The guidelines list the skills that the MDT need to have so the standard should both measure whether MS people have access and whether the MDT has all the skills specified	

040	United Kingdom Multiple Sclerosis Specialist Nurse Association	**Multidisciplinary team care and access to rehabilitation** Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS.	Clarity about the organisation of care and how it is co-ordinated and delivered was considered a high priority by the Guideline Development Group: “The GDG considered that while it might be possible to define a core multi-disciplinary team of people who are involved in patient care e.g. a neurologist, MS nurse, physiotherapist and occupational therapist, individual patients might have more need of management from other health care professionals such as continence nurse, a rehabilitation physician, a speech and language therapist or a psychologist, or from social	Access to multidisciplinary neurological specialists for ongoing long term management or rehabilitation is variable and inequitable across the country. Some areas have excellent, established specialist services while others have a more generic focus on short term interventions that is not always accessible or useful for people living with MS. A worrying trend is the reported dilution of specialist therapists’ expertise as a result of merging their services with generic teams. In addition there is inequitable access to key members of an MDT. For example successive reports have highlighted the limited access to psychological therapies in the community. Although this has been in part addressed by the IAPT initiative there is still considerable difficulty in accessing neuro psychology for the assessment and management of cognitive impairment, a significant confounding issue when setting up rehabilitation programmes or developing person centred management for individuals living with MS. A Consultant in Rehabilitation Medicine is a key member of the multidisciplinary team and is able to provide management of specific issues such as spasticity, vocational advice as well as providing a holistic overview in complex advanced presentations. In many areas they are also the gatekeepers for specialist rehabilitation either as an inpatient or an outpatient.	NSF Long Term Neurological Conditions (DH 2005) Statement 6 Quality Standard for Non-urgent Neurological Conditions ABN 2014 www.theabn.org Defining the value of Allied Health Professionals with expertise in MS: Supporting evidence and recommendations for Commissioners and Practitioners. K. Dix and H. green MS Trust Nov

			care. A multi-disciplinary team approach should encompass all these perspectives as well as those of patient and family.” The NSF for Long Term Neurological Conditions also highlighted the importance of an MDT approach to ongoing support in the community as well as specific rehabilitation interventions as seen in Quality Requirement 1 and 5. This topic area has coherence with Domains 2 and 3 of the NHS England Outcomes Framework	Cochrane systematic reviews provide strong evidence of the short term effectiveness of multidisciplinary rehabilitation in improving ability to undertake activities of daily living and increased societal participation.	2013 Recommendations on Rehabilitation Services for Persons with MS in Europe (EMSP 2012) http://www.emsp.org/attachments/article/184/Recommendations%20on%20Rehabilitation%20Services%20for%20Persons%20with%20Multiple%20Sclero~.pdf Khan F, Turner–Stokes L, Ng L, Kilpatrick T, Multidisciplinary Rehabilitation for adults with Multiple Sclerosis. Cochrane Database Systematic Review 2005 Medical Rehabilitation in 2011 and beyond: Report of a Working Party RCP and BSRM Nov 2010
Section 4.4: Management, rehabilitation and relapse					

041	Association of British Neurologists	Key area for quality improvement 3	A person with a diagnosis of MS should have a named care coordinator (usually a MS specialist nurse) and have the opportunity to have a personalised care plan agreed by patient/carer and the care coordinator and a yearly review either by a neurologist or other healthcare professional with specialism in MS.	People with MS can develop a wide variety of symptoms both physical and non-physical. Often a number of healthcare professionals are required for optimal care. To ensure the person with MS is able to access all those professionals in a coordinated and timely manner requires careful coordination of care. Good communication between the person with MS and their carers/family and the various healthcare professionals is also vital. A named care coordinator (usually the person's MS specialist nurse where one exists) is necessary to provide seamless care acting as a route of communication between the person with MS and all healthcare professionals involved in that person's care at any particular time.	Evidence from a recent patient experience survey undertaken by the Neurological Alliance found that: Only 50% of people with MS felt that the different people treating and caring for them work well together effectively most or all of the time (total number of respondents=1457). This indicates that the treatment is not as well integrated, co-ordinated or responsive as it could be. Additionally, it found that 74% of respondents stated that they were not offered a care plan.

				MS is a long term condition associated with unpredictable exacerbations. The development of a personalised care plan between the person with MS and their family and the care coordinator with the opportunity to regularly review this at least on a yearly basis is necessary to enable the person with MS to participate in their care and identify areas where intervention may be required to prevent acute crises that may precipitate unplanned admissions.	http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report The NICE Clinical Guideline (CG 186) recommends that care should be delivered by a multi-disciplinary team (MDT) and that one team member should act as the contact point to coordinate care.
042	MS Society	Supporting physical activity	The clinical guideline recommends that people with MS consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat mobility problems and/or fatigue, two of the most common symptoms associated with MS.	MS Society research shows that:	**Evidence regarding access to support to be physically active and physiotherapy**

			It is important that patients with MS be encouraged to participate in exercise for the general health benefits associated with this and that they could be reassured that exercise would not result in deterioration in MS. The type and frequency of exercise should be appropriate to general health and abilities of the patient and also be accessible in timing and location around other commitments such as work and family. Fatigue management programmes such as FACETs and access to neuro-physiotherapy support people with MS to be physically. Whilst access to NHS/public health funded schemes is crucial, there is a strong role for the voluntary sector in providing some of this support.	43% (n=2,532) of people with MS who require support to be physically active did not receive it (total number of respondents=4,773).	MS Society (2013). A lottery of treatment and care – technical report http://www.mssociety.org.uk/sites/default/files/Documents/Research/A%20lottery%20of%20treatment%20and%20care%20-%20technical%20report.pdf
			For mobility	The more assistance someone requires with their MS, the less likely they are to have support to remain physically active. 46% (n=835) of people with MS who require occasional assistance do not receive the support they need to be physically active (Total number of respondents=1805). This increases to 64% (n=626) for people with MS who require constant assistance do not receive the support they need to be physically active (Total number of respondents=978).	**Evidence regarding physical activity programmes for MS**

			The clinical guideline states that reduced mobility is one of the most common problems in MS and 85% of people with MS report a gait disturbance as their main complaint. Gait is a complex function and many of the symptoms of MS, such as fatigue, weakness, spasticity and ataxia can impact on its quality. One of the main contributors to poor gait is muscle weakness which may be primary (for example, because of the disease process) or secondary (as a result of deconditioning). The latter is common as people with MS are known to reduce their activity levels soon after diagnosis. Allowing people to regain and then maintain maximal strength is important so that they can perform their usual tasks and remain independent for as long as possible; also providing the core strength to offer greater resistance to other conditions which would require NHS care.	**A quality standard needs to be developed to support people with MS to exercise. Support should come in a variety of forms such as targeted exercise classes and cognitive behavioural techniques used in fatigue management programmes such as FACETS. Support should be delivered across public (NHS & local authority) and voluntary sectors. It should be tailored to peoples' need and held at times and locations accessible to people with MS. Provision of transport may be necessary.**	Saxton, J et al (2013) Pragmatic exercise intervention for people with multiple sclerosis (ExIMS Trial): Study protocol for a randomised controlled

			For fatigue The clinical guideline states that excessive fatigue may affect up to 80% of people with MS. The level of fatigue can be overwhelming, and is usually out of proportion to prior activity levels. Such fatigue may be a direct effect of the disease process on the central nervous system, or may be secondary to weakness, stiffness, tremor, disturbed sleep or depression. Some medications may have a beneficial effect on MS fatigue, but they do not help all people and may also have adverse effects. Non-pharmacological methods such as exercise may therefore also be useful to help manage this disabling symptom.	31% (n=1,688) of people who need to see a physiotherapist are unable to do so. Total number of respondents=5,495). This has a significant knock on impact on whether people are supported to be physically active. Of the people receiving physiotherapy, 61% (n=1,818) of people are receiving the support they need to be physically active. Of the people not receiving physiotherapy but who require it, 17% (n=240) of people are receiving the support they need to be physically active. **Routine access to neuro-physiotherapists, facilitated by the care coordinator within the context of the care plan, is therefore an essential quality standard to support the uptake of exercise programmes. A quality standard needs to be developed to ensure access to neuro-physiotherapists as needed.**	trial pp. 205-211 http://www.contemporaryclinicaltrials.com/article/S1551-7144%2812%2900238-8/abstract

				Physical activity as an organisational priority for the MS Society and we would welcome to work with NICE and other colleagues to develop and deliver best practice in this area through our Models of Excellence programme. Please contact us for further details.	Thomas et al (2013) A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis http://dx.doi.org/10.1136/jnnp-2012-303816
043	MS Society	Comprehensive annual review	The guideline recommends that most people with MS should have at least one comprehensive review per year. The review should be undertaken by a health care professional with specialism in MS and coordinate the input of other members of the MDT as necessary to address particular symptoms or needs. It should look at all symptoms, relapses experienced, social care needs and the needs of carers.	Access to the MDT is fundamental to receiving a comprehensive annual review. However, we know that people with MS's access to professionals is variable. An MS Society survey of ~8,500 people with MS in England found that:	The guideline recommends that most people with MS should have at least one comprehensive review per year. The review should be undertaken by a health care professional with specialism in MS and coordinate the input of other members of the MDT as necessary to address particular symptoms or needs. It should look at all symptoms, relapses experienced, social care needs and the needs of carers.

			Why is this important? A comprehensive annual review for people with MS helps ensure clinical oversight of a person’s condition and that care and treatment packages are tailored accordingly. The treatment landscape is constantly evolving. For example, three new Disease Modifying Therapies (DMTs) have been approved by NICE for use on the NHS in the past 18 months. To ensure that peoples’ treatment and care packages evolve with these developments as well as their own changing needs, it is essential they have a formal review with the relevant professionals to access the most suitable treatment and care. It is crucial that the resulting treatment and care is delivered in a timely way, be that accessing a DMT or being referred to another member of the MDT.	21% rarely (n=905) or never (n=832) find it easy to see specialist (neurologist or MS nurse), 31% (n=2,590) sometimes find it easy (total number of respondents=8,471). The shape of these conversations is worrying with 36% (n=3,081) of people with MS replying ‘never’ and a further 17% (n=1,440) replying ‘rarely’ when asked ‘How often did your health or social care professionals ask what is important to you when helping you to manage your MS?’ This worry is compounded by the findings of the recent Neurological Alliance survey that people with MS are rarely offered of a care plan to help manage their needs. 74% (n=1159) respondents stating that they were not offered a care plan (total number of respondents=1573).	**Why is this important?** A comprehensive annual review for people with MS helps ensure clinical oversight of a person’s condition and that care and treatment packages are tailored accordingly. The treatment landscape is constantly evolving. For example, three new Disease Modifying Therapies (DMTs) have been approved by NICE for use on the NHS in the past 18 months. To ensure that peoples’ treatment and care packages evolve with these developments as well as their own changing needs, it is essential they have a formal review with the relevant professionals to access the most suitable treatment and care. It is crucial that the resulting treatment and care is delivered in a timely way, be that accessing a DMT or being referred to

				A quality standard must be included to ensure that every person with MS receives at least one comprehensive review with a health care professional with specialism in MS per year. With the review covering all needs, including the social and emotional needs of the person with MS and their carer/family, support may be better accessed from social care services and the voluntary sector. Referrals should be made as appropriate. Any changes in the care, support or treatment required should be reflected in the person's management plan. For people with RRMS, the annual review is an important opportunity to review whether the person with MS is taking a DMT. We know that access to DMTs in the UK is extremely low. Six out of 10 eligible people do not take DMTs and the UK is ranked 25 out of 27 European countries on the proportion using DMTs; only Poland and Romania doing worse. **A conversation regarding DMTs should be addressed explicitly as part of the quality standard on the annual review.**	another member of the MDT.

044				An additional related concern is that the UK lags behind the rest of Europe in terms of number of neurologists per patient population: for every neurologist in the UK, Germany & Spain have six and Italy has eight[1]. This may have an impact on the ability of people with MS to access an annual review with their specialist. Specialists are already stretched for capacity. To deliver the standards of care outlined in the guideline will require increased NHS investment in specialists. This should be addressed as part of the quality standards.	
	Multiple Sclerosis Trust	Annual review. “Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year. Ensure the comprehensive review is carried out by healthcare professionals with expertise in MS and	An annual review including medication review is recommended within the NICE Guidance for MS. The requirement for an annual medication review for people with long-term conditions forms part of the Medicines Optimisation NICE clinical guideline (2015). At the moment, people with MS who receive disease modifying drug therapy are monitored normally several times a year (depending on the treatment), in the course of which most of the issues considered within an annual review will be discussed.	At the moment there is no requirement for a comprehensive annual review. Consequently people with MS may be offered an annual appointment with an MS specialist health professional or they may not, but there is no consistency across the country. Each MS service follows its own protocols. We believe the metric for measurement should include: who conducts the annual review; whether it happens annually; what is monitored in the review; and what happens as a result, including monitoring other health inputs and outcomes over the following year.	NICE. Multiple sclerosis. Management of multiple sclerosis in primary and secondary care (2014). Clinical Guideline 186, pp515-516 NICE Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015).NG 5. http://www.nice.org.uk/guidance/ng5

		its complications. Involve different healthcare professionals in different aspects of the review if needed.” “Refer any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed”	However, people with MS who are not on disease modifying drug therapy may be discharged from MS specialist services and then go years without seeing healthcare professionals with expertise in MS; very often they may only become known to services again once they are in crisis.	The following practical issues will need to be considered around implementation: First, people with MS who were diagnosed some years ago may long have been discharged from neurology services and may not be known to MS specialists. These people might particularly benefit from annual reviews which might prevent too many additional complications developing. A number of these patients are likely to be ageing and developing comorbidities which need to be identified, managed and treated before they develop into crises.	Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480

				Second, there are questions over who has sufficient expertise in MS to deliver the annual review. MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable. As discussed in previous items, specialist neuro-therapists are coming under threat. Therefore, if, as we suspect, there are many people with MS who are not known to services, this is likely to exacerbate existing capacity issues. Third, the Guideline Development Group's discussions around the annual review, which indicate that the GDG suggested a framework for general items to be considered within an annual review. The MS Trust considers that this is an area that will benefit from further work, in particular in relation to symptoms that benefit from specialist assessment and management.	
045	Novartis Pharmaceuticals (UK) Ltd	Standardised access to relapse assessment and treatment.	Clinical relapse is a marker of disease activity in multiple sclerosis and can present in a number of forms. Current pathways and timelines for management of relapse have developed based on local resource levels but there is no consistency between centres as	Time to assessment, assessment methods and reporting of relapses varies greatly from centre to centre. Defining standards that address this could make a significant impact on the long term outcomes of patients with MS if relapses are assessed and treatments initiated and changed in appropriate patients in a timely manner.	Multiple sclerosis: management of multiple sclerosis in primary and secondary care: https://www.nice.org.uk/guidance/cg186 (accessed 17th March 2015)

			to what constitutes best practice in relapse management.		
046	Roche Products Ltd	Ensuring that patients are fully re-assessed regularly at least every 12 months	Significant irreversible disease progression can occur between re-assessments From the MS clinical guideline "Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year" A recent report into Patient Activation by the Kings Fund highlights that "Patient activation scores have been robustly demonstrated to predict a number of health behaviours. They are closely linked to clinical outcomes, the costs of health care and patients' ratings of their experience. Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of	Delayed progression and reduced relapses offer significant benefits to multiple sclerosis patients and their families. This may also have significant benefits in terms of cost savings across health and social care for the NHS, as accumulated disability cannot be reversed.	Paper: Early clinical predictors and progression of irreversible disability in MS. Confaureux et al Brain 2003 126:4:770-782. The Kings Fund. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf Social consequences of multiple sclerosis: early pension and temporary unemployment—a historical prospective cohort study Claudia Christina Hilt Pfleger et al Multiple Sclerosis 2010 16(1) 121–126

			hospitalisation, and to report higher levels of satisfaction with services. The requirement for an annual medication review for people with long term conditions is included in the Medicines Optimisation clinical guideline (2015)		NICE Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015) NG 5. www.nice.org.uk/guidance/ng5
047	Royal College of Nursing	Relapse management for multiple sclerosis	To consolidate good practice throughout the country in light of the growing number of disease modifying treatments available and access to them in a timely/appropriate manner.	Treatment for multiple sclerosis varies across services and from primary and secondary care.	Identify best practice examples already known by NICE Multiple Sclerosis Guideline CG186, RCN innovation reports: Generating evidence in Multiple Sclerosis Service (GEMSS), other published work.
048	Salford Royal NHS Foundation Trust	ANNUAL REVIEW	To provide an equitable service to all people with MS independent of type or time with the disease	A comprehensive annual review for people with MS helps ensure clinical diligence of a person's condition and that care and treatment packages are personal to that patient.	MS Society. A lottery of treatment and care – MS Services across England at the UK, 2013 http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/UK-ms-lottery.pdf

		For all people with MS by a healthcare professional who has an expertise in MS care. The review needs to be comprehensive, incorporating an MDT approach.	All should have an annual review to include: medication review, symptomatic review, health promotion & self-management strategies etc.	Self-management support and the development of collaborative relationships is at the heart of service delivery in the quality driven “House of Care” approach to managing long term conditions. It is also consistent with the drive for patients to gain far greater control of their own care evident in the Five Year Forward Review In a MS society report, when asked about access to professionals the replies were 21% rarely (n=905) or never (n=832) find it easy to see specialist, 31% (n=2,590) sometimes find it easy (total number of respondents=8,471).36% (n=3,081) of people with MS replying ‘never’ and a further 17% (n=1,440) replying ‘rarely’ when asked ‘How often did your health or social care professionals ask what is important to you when helping you to manage your MS?’ Indicating a proactive approach to review is required rather than reactive.	
049	Salford Royal NHS Foundation Trust	RELAPSE MANAGEMENT PATHWAY:	One of the commonest features of MS is relapse, with the number of relapses per annum estimated to be between 8 & 10.000 UK.	85% or more of patients with MS will experience a relapse; these can range from mild, to moderate to severe that impact upon the patient’s activities of daily living and the timeframe for recovery is variable as is the degree of recovery. Whatever the impact of the relapse on that individual, it serves as an indicator that there is some degree of on-going inflammation within the central nervous system (Hutchinson, 2012).	Hutchinson M. There is no such thing as a mild MS relapse. The mild relapse is an Anglo-Saxon delusion – Commentary.Multiple Sclerosis Journal. 2012; 18(7)930-931.

		Development of local protocol & pathway: to include: patient triage/ review & follow up	Variation in practice across the UK	A large proportion of MS nurses work is dealing with part or the entire relapse management pathway.	Burton JM, O'Connor PW, Hohol M, et al. Oral versus intravenous steroids for treatment of relapses in multiple sclerosis.Cochrane Database Syst Rev. 2009;3:CD006921.14.
			Potential for unplanned hospital admissions if no relapse management pathway identified in MS services	Specialist skills are needed to determine whether it is a relapse or pseudo relapse/ or another aetiology. This assessment is an indicator for a patient's ability to commence or escalate DMT.	J Craig, C A Young, M Ennis, G Baker,
			Variation in specialist community or inpatient rehabilitation during or after a relapse; which has been found to reduce the impact of disability but is not always available.	This is becoming increasingly important with the advent of new MS therapies with increasing side effects.	M Boggild 2003
					A randomised controlled trial comparing rehabilitation against standard therapy in multiple sclerosis patients receiving intravenous steroid treatment
					J Neurol Neurosurg Psychiatry 2003;74:9 1225-1230 doi:10.1136/jnnp.74.9.1225
					MS Society: Prevalence of MS, www.mssociety.org.uk/m

					s-resources/ms-society-briefing-uk-prevalence-study(accessed 16TH March 2015).
050	SCM 2	Comprehensive review	The guidelines specify an annual review by the multidisciplinary team (subject to agreement with the patient). This helps identify if there I any slow change in the condition which is especially important as the patient may have cognition problems and not recognise deterioration in themselves. Evidence from patient forums and the MS Society helpline shows that this does not currently happen in many cases.	The annual review by the MDT of everyone with MS will help identify any slow change in the condition. It will also allow the team to suggest changes in treatment based on up-to-date information. There are a lot of new therapies and medications available which may be missed once people have been diagnosed. A quality standard is simple to implement and measure and will save costs from A&E and in-patient care, it will also ensure that patients get the best treatment and advice.	
051	United Kingdom Multiple Sclerosis Specialist Nurse Association	**Annual Comprehensive review**	People with progressive forms of MS are not amenable to disease modifying therapies and consequently are likely to have less regular contact from Specialist Neurological Services.	An Annual review carried out by a clinician with the appropriate level of clinical expertise in MS would ensure that individuals who are vulnerable (as a result of psychological, cognitive, physiological or sociocultural disadvantage) are not overlooked if they are discharged by specialist centres or neurology outpatient clinics. It would provide an opportunity to review polypharmacy and complex care arrangements and assess the need for further intervention in a proactive way.	NICE Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015).NG 5. http://www.nice.org.uk/guidance/ng5

		Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year. Ensure the comprehensive review is carried out by healthcare professionals with expertise in MS and its complications. Involve different healthcare professionals with expertise in specific areas of the review if needed.	However these individuals do benefit from symptomatic treatments and impairment management strategies. These approaches combined with proactive support to maximise self- management have a significant impact on the level of disability experienced as well as reducing the level of care required in the community. It fulfils the NHS Outcomes Framework Domain1	Regular review would also provide an opportunity to support those who are not suitable for DMTs but are not yet requiring the help of other services. Timely support for these individuals could improve quality of life and long term health outcomes by providing information, education and advice. It may also enable them to stay in work. Self-management support and the development of collaborative relationships is at the heart of service delivery in the quality driven “House of Care” approach to managing long term conditions. It is also consistent with the drive for patients to gain far greater control of their own care evident in the Five Year Forward Review. An Annual review would offer the opportunity for all people living with MS to be consulted and assisted to draw up a management or care plan. 74%(n+1159) of respondents in a recent Neurological Alliance Survey stated they were not offered a care plan. Currently there is no national standard for regular review if the patient is not receiving	Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: building the House of Care. London: King’s Fund. http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions Five Year Forward View NHS England 2014

				DMTs. An annual review would ensure a more equitable and accessible service for the MS population as a whole.	http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf Invisible Patients Report: Revealing the state of Neurology services. Neurological Alliance 2015 http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf
052	United Kingdom Multiple Sclerosis Specialist Nurse Association	**Relapse or exacerbation of MS pathway and management**	It has been estimated that 8000 to 10,000 MS relapses will occur each year in the UK, which place a burden on individual patients and the NHS. The primary treatment of acute relapses is with corticosteroids, using a variety of different dosing regimens with both intravenous and oral administration.	85% of people diagnosed with MS will have Relapsing Remitting MS (RRMS) Disease Modifying Therapies are used to reduce the number and severity of these relapses. This slows the course of disease progression and reduces the accumulated level of impairment with the attendant burden of disability.	J Craig, C A Young, M Ennis, G Baker, M Boggild 2003 A randomised controlled trial comparing rehabilitation against standard therapy in multiple sclerosis patients receiving intravenous steroid treatment

		Develop local guidance and pathways for timely treatment of relapses of MS. Ensure follow-up is included in the guidance and pathway. Non-specialists should discuss a person's diagnosis of relapse and whether to offer steroids with a healthcare professional with expertise in MS because not all relapses need treating with steroids.	There is large variation in practice around the UK. Poor management of individuals can result in hospital admission with high personal costs and a detrimental impact on the health economy as a whole. Access to specialist community or inpatient rehabilitation during or after a relapse has been found to reduce the impact of disability but is not always available.	The importance of recognising the difference between an MS relapse and general ill health or infection needs to be disseminated throughout primary care and the development of local pathways would facilitate this and provide a safer and more supportive local service for individuals living with MS Accurate assessment of the number and severity of relapses can be a useful determinant of the efficacy of the DMT and may signal the need to try a different type of medication. Experiencing a relapse is frightening and often gives rise to a loss of confidence with uncertainty about the future. Providing a clear pathway removes some of the uncertainty and ensures that clinicians provide responsive timely interventions to shorten recovery time. Accurate feedback to specialist prescribing centres as a result of the pathway would improve the quality of decision making for on-going management.	J Neurol Neurosurg Psychiatry 2003;74:9 1225-1230 doi:10.1136/jnnp.74.9.1225
Section 4.7: Additional areas					
053	HQT Diagnostics	General Practitioners to test and supplement Vitamin D	Higher levels of Vitamin D have been shown to help prevent & treat Multiple Sclerosis	Patients with Multiple Sclerosis often self-treat with Vitamin D.	www.vitamindwiki.com/Overview+MS+and+vitamin+D

		25(OH)D to be between 100-150 nmol/L		This will enable the General Practitioner to include Vitamin D measurement and supplementation within the overall medical treatment.	www.grassrootshealth.net/media/download/scientists_call_to_daction_020113.pdf
054	HQT Diagnostics	Investigate effects of Vitamin D 25(OH)D between 150-375 nmol/L	Experimental treatment in Brazil has shown good results	One Brazilian doctor is adjusting the dose of Vitamin D to achieve blood levels of 25(OH)D of 375 nmol/L and achieving good results This is not a mono-therapy and must be integrated with other treatments.	http://vitamindwiki.com/tiki-index.php?page_id=5155
055	Biogen Idec Limited	Availability and routine use of MRI scanning facilities for initial diagnosis and ongoing disease management	Modern diagnostic practice for both initial diagnosis of MS and ongoing assessment of the progression of the disease includes detailed consideration of MRI data.	MRI access is now available at all specialist neurology centres and most other centres but there is increasing pressure on services. The ABN recommends that acute neurology services should have access to MRI 24 hrs a day, seven days a week. However, in its survey MRI was only available at all times in 30% of centres. Reduced services may lead to prioritisation of acute need and a subsequent pressure on MRI availability fpr initial diagnosis and ongoing management of MS. MRI capacity must be available to meet all demands for both routine and acute activity.	Statement 5 - Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (CT and MRI) where indicated. *ABN Acute Neurology services survey 2014.*

056	Novartis Pharmaceuticals (UK) Ltd	MRI for MS disease activity monitoring.	New MRI lesions can be a more sensitive measure of inflammatory disease than clinical relapses. Although MRI is used widely for diagnosis of MS it is infrequently utilised in the UK as a surveillance measure to assess treatment response.	A method with greater sensitivity would be appropriate to measure disease activity alongside assessment of clinical relapse. As an example, literature review has demonstrated that patients with MRI evidence of poor response to IFN-β treatment based on MRI criteria had significantly increased risk of both future relapses and progression. Evidence suggests that recognising MRI activity may allow more timely assessment of disease progression than assessment on the basis of clinical assessment alone.	Assessing treatment response to interferon-β: is there a role for MRI? Dobson et al; Neurology. 2014 Jan 21;82(3):248-54
057	Roche Products Ltd	Re-assessments should include MRI scans, including routine reviews before relapse	Plaque formation and brain volume can be monitored effectively through MRI scan	Disease progression should drive therapy management choices because the principal aims of therapy are to prevent progression, prevent formation of plaques and reduced brain volume.	Predicting clinical progression in MS with magnetic resonance disease severity scale. Bakshi et al Arch. Neurol. Nov 2008; 65(11) 1449 – 53. Neurol Neurosurg Psychiatry. 2001 Mar;70(3):390-3. **Assessing the risk of early multiple sclerosis in patients with clinically isolated syndromes: the role of a follow up MRI.** Brex PAMiszkiel KAO'Riordan JIPlant GTMoseley IFThompson AJ Miller DH

058	Association for Respiratory Technology & Physiology (ARTP) (and support by British Thoracic Society)	Diagnosis of lung function impairment and referral to respiratory physician/specialist	There are a variety of respiratory abnormalities in MS including restriction, respiratory muscle impairment, respiratory failure and reduced exercise capacity	While few MS patients develop ventilatory failure to the extent that they need non-invasive ventilation (NIV) the respiratory muscle weakness may affect cough. For this standard will NICE look at evidence for the number of patients that this may be applicable to or do ARTP & British Thoracic Society need to provide this evidence?	Chapter 20, G.J. Gibson Clinical Tests of respiratory Function, 3rd Edition Hodder Arnold, 2009, London
059	Association for Respiratory Technology & Physiology (ARTP) (and support by British Thoracic Society)	Initiation of non-invasive ventilation when respiratory failure occurs.	The current guideline doesn't mention MS patients ever requiring respiratory support. Although numbers are small	Could the NICE MND guidelines be used where there are trigger measurements for muscle strength to initiate NIV. This is referenced and has an evidence base so could use is already published in NICE Guidelines without lots of original evidence searching. We suggest that if recurrent infections are >2/year they should have spirometry and if Vital Capacity is reduced then this should trigger muscle strength, cough peak flow, blood gases and overnight oximetry oximetry.	See NICE Motor Neurone Disease Guidelines 2010 (currently under revision)
060	Association for Respiratory Technology & Physiology (ARTP) (and support by British Thoracic Society)	Use of lower limit of normal for FEV1, FVC and FEV1/FVC ratio should be used to determine abnormality and not "percent of predicted" or a "fixed ratio" for FEV1/FVC using the widely accepted Global Lung Initiative Spirometry Reference values	Percent of predicted underestimates abnormality in the young and overestimates abnormality in the elderly. The use of a "fixed ratio" FEV1/FVC also classifies elderly people as having some obstructive defect when in fact they are normal for their age. Restrictive defects caused my MS may be "masked" using this approach. The GLI Reference values are the best reference range from age three to 95 years and are	By using correct methods for diagnosing abnormality, it will be easier to classify the degree of respiratory impairment used elsewhere in the guideline. This standard is being recommended in other NICE guidelines involving respiratory impairment.	Quanjer PH, Stanojevic S, Cole TJ et al. and the ERS Global Lung Function Initiative. Multi-ethnic reference values for spirometry for the 3-95 years age range: the Global Lung Function 2012 equations. Eur Respir J 2012; 40: 1324-1343. Miller MR, Quanjer PH, Swanney MP, Ruppel G,

			more relevant that previous published values		Enright PL. Interpreting lung function data using 80% predicted and fixed thresholds misclassifies more than 20% of patients. Chest 2011; 139; 52-59. Quanjer PH, Pretto JJ, Brazzale DJ, Boros PW. Grading the severity of airways obstruction: new wine in new bottles. Eur Respir J 2014; 43(2): 505-512.
061	Roche Products Ltd	Recording active treatment rates for those patients with a diagnosis of multiple sclerosis	There is good evidence that having patients whose disease is well controlled can drive quality of life improvements for multiple sclerosis patients. UK active treatment rates are lower than neighbouring EU countries	A significant proportion of patients can live for many years of potentially useful productive life, including family life~~.~~ The availability of high efficacy, disease modifying therapies offers significant quality of life and economic benefits when used appropriately	MS symptoms are mostly seen between the ages of 20 and 40, with women being twice as likely to develop MS as men. MS is the most common neurological condition in young adults and affects approx. 100,000 people in the UK. From NHS Choices, Multiple Sclerosis www.nhs.uk/Conditions/Multiple-sclerosis https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216249/dh_117977.pdf

062	College of Occupational Therapists Specialist Section - Neurological Practice	COTSS-NP would welcome additional qualitative research evidence, particularly in relation to understanding the information, education and support needs of people with MS, their families and carers.	People with MS are often affected in young adult-hood, and their ability to maintain their health will make a difference to their long-term health and the welfare of their families. We need a better understanding of what the person with MS feels would help, and that of their families.	National Audit Office report on Services for People with Neuro Conditions 2011 suggests that implementation of the NSF for Long Term Conditions (LTC) has been poor and commissioners have not been held to account in how funds were spent for people with neuro conditions. As funding as not increased for people with neuro conditions this may demonstrate that support structures for people with MS have not improved significantly since the NSF was produced.	http://www.nao.org.uk/wp-content/uploads/2011/12/10121586.pdf A knowledgeable patient is more likely to take care of him or herself well (Ennis et al., 2006) Education gives one control over disability (Cardol, DeJong and Ward, 2002)
063	College of Occupational Therapists Specialist Section - Neurological Practice	We would welcome research to show that sleep and fatigue management, and management of cognitive problems, are being addressed.	There is evidence that OT can help with the management of fatigue, sleep and cognitive problems in people with MS. Fatigue in particular is often a “hidden” symptom, and can be one of the most disabling symptoms if not managed well.	The funding of OT services is currently insufficient to meet the demand. There needs to be a greater understanding by commissioners, of the importance of OT in delivering fatigue, sleep and cognitive management for people with neuro conditions.	(Mathiowetz and Busch, 2006, Mathiowetz et al., 2001, Mathiowetz et al., 2007, Mathiowetz et al., 2005, Finlayson, 2005, Finlayson et al., 2011)
064	College of Occupational Therapists Specialist Section - Neurological Practice	COTSS-NP would be keen to see an appraisal of the current evidence in relation to the maintenance of leisure, work or self-care abilities in PwMS.	People with MS are often in young adult-hood, and it has been shown that keeping an active lifestyle (such as maintaining leisure, work and self-care skills) can lengthen the period of time the person can remain independent.	Occupational Therapists are ideally placed to support/enable independence in self-care productivity and leisure, but commissioners are slow to realise this. An increase in the numbers of OTs in neuro services would have a beneficial effect on how well and for how long PwMS can maintain their independence, and therefore reduce the need for financial and supportive assistance from the health and social services.	Self management is a way to reduce any secondary physical complications of chronic illness (Motl et al., 2006)

065	College of Occupational Therapists Specialist Section - Neurological Practice	COTSS-NP would be keen to see an appraisal of the current evidence in relation to postural management and the prevention of complications in MS.	People with MS normally have a standard life expectancy, and therefore any postural problems that develop will cause huge issues later in the disease course. These may include flexor contractions of the legs that can prevent the person being seated in a wheelchair, and deformities of the spine that restrict breathing.	Clinicians need to know what can be done to seating at an early stage, to prevent unnecessary complications at a later stage.	
066	College of Occupational Therapists Specialist Section - Neurological Practice	COTSS-NP would be keen to see an appraisal of the current evidence in relation to the prevention and management of contractures in MS.	If PwMS develop contractures it can cause huge difficulties maintaining the person's preferred lifestyle, and makes care in the end stages very difficult for carers	Clinicians need to know how to manage limbs early, to avoid contractures in PwMS where there is muscle weakness and increased muscle tone, and once contractures have occurred, how to ameliorate these	
067	Association of British Neurologists	Key area for quality improvement 4	A person with MS who would qualify for a disease modifying therapy (DMT) as per NICE guidelines should have timely access to a neurological service able to prescribe the full range of NICE approved DMTs appropriately and with the required monitoring.	All of the licensed DMTs in MS – ß-interferons, glatiramer acetate, fingolimod, teriflunomide, dimethyl fumarate, natalizumab, and alemtuzumab – reduce relapse rate and MRI lesion accumulation in relapsing-remitting MS, to varying extents [1]. Each drug has its own characteristics and individual patients who may be eligible by NICE criteria should have access to the right drug for them (after discussion with their neurologist and also MS specialist nurse and family if required) in a timely manner to avoid continuing disease activity whilst not on a DMT. There is some evidence that early relapse activity is relevant to long term	The ABN Revised (2009) Association of British Neurologists' guidelines for prescribing in multiple sclerosis [1] recommends the usage of ß-interferons, glatiramer acetate and natalizumab in eligible people with RR MS whilst fingolimod [2], teriflunomide [3], dimethylfumarate [4] and alemtuzumab [5] have received positive NICE technological appraisals

				disability [2]. Each individual drug has monitoring and safety requirements and hence any neurologist prescribing such DMTs should have the ability and capacity to safely prescribe and monitor each drug prescribed to minimise risk to the patient. [1] Rice CM. Disease modification in multiple sclerosis: an update. Pract Neurol. 2014 Feb;14(1):6-13. [2] Scalfari A, Neuhaus A, Daumer M, Deluca GC, Muraro PA, Ebers GC. Early relapses, onset of progression, and late outcome in multiple sclerosis. JAMA neurology. 2013 Feb;70(2):214-22.	since 2009 for people with relapsing-remitting MS depending on disease activity. However despite these guidelines access to DMTs is low with six out of ten eligible people not taking DMTs [6]. Access to neurologists with MS expertise appears to be an important factor with DMT prescribing being more than twice as likely in comparison to non-specialist services [6]. [1]http://www.theabn.org/media/docs/ABN%20publications/ABN_MS_Guidelines_2009_Final(1).pdf [2] https://www.nice.org.uk/guidance/ta254 [3]

068	Biogen Idec Limited	Earlier access for clinically eligible patients who wish to access Disease Modifying Therapies (DMTs) through specialist MS treatment services.	There is good evidence that early treatment with DMTs can have a beneficial effect on outcomes for patients, reducing the accumulation of disability and improving QoL.	Accumulating disability is a major factor in limiting patients QoL, increasing their demand upon health and social services and limiting their ability to contribute to national budgets through remaining in work. Disease Modifying Therapies (DMTs) are generally only available through specialist centres and are the mainstay of disease modifying treatment for MS, as opposed to therapies for symptomatic control, which are available on a wider basis.	https://www.nice.org.uk/guidance/ta303 [4]http://www.nice.org.uk/guidance/ta320/resources/guidance-dimethyl-fumarate-for-treating-relapsingremitting-multiple-sclerosis-pdf [5] https://www.nice.org.uk/guidance/ta312 [6] MS Society. A lottery of treatment and care – MS Services across England at the UK, 2013 http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/UK-ms-lottery.pdf Those with access to an MS nurse or neurologist are more than twice as likely to be taking a Disease Modifying Therapy (DMT). MS Society 'A lottery of treatment and care - MS services across the UK' http://mslottery.mssociety.org.uk/download-report/
069	Essex Centre	Access to appropriate	Eligible MS patients should have	Early treatment may reduce disease-	Please see below

	for Neurological Sciences	Disease Modifying Therapy	timely access to an agreed and NHS England commissioned disease and symptom modifying therapies	related functional impairment and improve quality of life.	
070	Novartis Pharmaceuticals (UK) Ltd	Uptake of Disease Modifying Treatments in line with NHS England Policy.	There has been a significant increase in the number of treatment options available to clinicians and patients for the treatment of MS. Tailoring the right treatment to the right patient is important to achieve to ensure that patients are treated effectively without exposing them to unnecessary risk.	Uptake rates of first line treatments in England remain some of the lowest in Europe. This lack of urgency to treat and the regional variability in uptake of newer treatments suggests that MS patients are being under treated in England. Addressing this issue may substantially reduce disease burden for patients with MS.	A lottery of treatment and care: MS services across Scotland and the UK: http://mslottery.mssociety.org.uk/wp-content/uploads/2013/04/Scotland-ms-lottery.pdf (accessed 17th March 2015)
071	Novartis Pharmaceuticals (UK) Ltd	Consistency of descriptors of RRMS patients between NICE STAs, clinical guidelines and clinical standards to avoid confusion with patient eligibility for disease modifying therapy (DMT)	The field of MS is complex and patients exist in a number of subgroups of RRMS, SPMS and PPMS. Licencing by the EMA and subsequent NHS England Guidance and NICE STAs have allowed prescription of DMTs in subtypes of RRMS patients based on efficacy and cost-effectiveness in these groups.	Consistency of language between NICE STAs, NHS England guidance, clinical guidelines and clinical standards will provide greater clarity on the patients that will most benefit from individual DMTs.	Multiple sclerosis: management of multiple sclerosis in primary and secondary care: https://www.nice.org.uk/guidance/cg186 (accessed 17th March 2015) Individual technology appraisals for individual DMTs Clinical Commissioning Policy: Disease Modifying Therapies for Patients with Multiple Sclerosis (MS), May 2014, Reference: NHS ENGLAND/ D04/P/b

None

072	British Thoracic Society	The British Thoracic Society supports the comments submitted by the Association for Respiratory Technology and Physiology (ARTP) for this consultation.
073	RCP	RCP wishes to endorse the response of the ABN on the above consultation. I would be grateful if you could confirm receipt