NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Multiple sclerosis

Date of Quality Standards Advisory Committee post-consultation meeting:
29 September 2015

2 Introduction

The draft quality standard for Multiple sclerosis was made available on the NICE website for a 4-week public consultation period between 8 July and 5 August. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 22 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

3. For each quality statement what do you think could be done to support improvement and help overcome barriers?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Stakeholders were broadly in support of the areas prioritised for statements but suggested that further development of wording is needed to improve impact and outcomes.
- Some stakeholders highlighted additional areas of quality improvement that could be considered for inclusion in the quality standard.

- There was concern that the terminology 'healthcare professional with expertise in MS' does not adequately support the role of specialist staff such as MS neurologist, MS specialist nurse, or neuro-specialist allied health professionals, as organisations could employ staff who are experienced but do not have specialist knowledge.
- GPs play an important role in providing care to people with multiple sclerosis, so it is important to highlight the need for excellent communication between secondary and primary care.

Consultation comments on data collection

- There is currently wide variation in data collection and IT systems and commissioners and professionals will need to support improvement in order to collect the data required. Specific issues include:
  - Current clinical information systems only record individual episodes of care and therefore there is a need to develop a caseload database in every area in order to measure the impact of services and interventions. It is important that IT systems support integrated data collection for people with MS that is accessible to GPs, neurologists, specialist nurses and social care. There is currently no outpatient diagnostic coding for multiple sclerosis.
  - Prevalence data for multiple sclerosis is currently unknown for a local area and it was suggested that the care.data collection should be developed to support this. It was also suggested that there should be a national register of people with multiple sclerosis.
  - There is a need to undertake routine patient surveys with people with multiple sclerosis to measure outcomes and experience.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults with MS are supported by the consultant neurologist at the time of diagnosis to understand the condition, its progression and the ways it can be managed.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Statement:
  - There was support for this statement but some confusion as stakeholders felt it included two concepts – diagnosis by a consultant neurologist (also suggested as an additional statement) and information and support at the time of diagnosis.
  - Several stakeholders suggested that the statement should refer to a consultant neurologist with a specialist interest in multiple sclerosis and a multi-disciplinary team. One stakeholder, however, indicated that most patients are likely to be diagnosed by a general neurologist who may not be the best person to give this support and information. It was suggested that in these circumstances statement 2 on follow-up after diagnosis is more important.
  - It was suggested that the statement wording should be amended to 'to understand MS and the ways it can be managed and treated' in order to highlight the importance of disease-modifying therapies. It would be difficult to give information about the progression of the condition at this stage as this is unpredictable for each person.
  - It was suggested that the statement should include the development of a management plan (also suggested as an additional statement).
- Measures:
  - There was confirmation that patient experience measures are important for this statement and it was suggested that additional measures could be included to identify if the information and support provided is helpful.
- Definitions:
  - It was suggested that the definition of support needs further clarification. Support should be personalised and should include:
    - joint discussion of treatment options in order to support patient choice
    - supporting the person with multiple sclerosis to understand and interpret information, and
    - providing emotional support.

  - The definition of support should be flexible as some consultant neurologists provide a regional service and therefore it would be difficult for them to have all the information about local services and support groups to hand.
- Equality and diversity considerations
  - It would be useful to identify the requirements of the Accessible Information Standard to clarify the equality and diversity considerations.

5.2 Draft statement 2

Adults with MS are offered a follow‑up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Statement:
  - Several stakeholders indicated that the statement should be more specific about which healthcare professionals should carry out the follow-up consultation i.e. a specialist MS neurologist and/or MS specialist nurse.
  - There were several comments about the 6 week timescale. Some suggested a shorter time period for follow-up. It was also felt that it will be important to clarify when the 6 week time period begins as there can be delays in referral letters from specialists to community based MS specialist nurses, and some referrals have to be made via the GP rather than directly.
  - It is important to highlight that adequate referral pathways should be in place to support the 6 week timescale as these do vary.
- Rationale:
  - In the rationale 'This means that they have time to adjust to their diagnosis' should be re-worded to reflect that adjustment is a process that happens over a period of time rather than a single event.
- Measures:
  - A patient satisfaction measure should be included.
- Audience descriptors:

  - Poor administrative support to neurologists and MS nurses can lead to delays in follow-up. Ensuring adequate administrative support could be included in the provider audience descriptor.
- Definitions:
  - There was a suggestion that more information is needed on what will be included in the follow-up consultation.
- Equality and diversity considerations:
  - The equality and diversity considerations should clarify that a person with MS should not be discharged and sent back to the GP for a further referral if they miss an appointment due to cognitive problems.

5.3 Draft statement 3

Adults with MS have a single point of contact to co-ordinate access to care from multi-disciplinary services.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Statement:
  - There was general support for this statement although some stakeholders felt an additional statement will also be needed to ensure access to the co-ordinated multi-disciplinary services that the person with MS may need (including communication with GPs)
  - Changes to the statement wording were suggested as follows:
    - Adults with MS will be provided with a single point of contact to access specialist advice and case management.
    - Adults with MS should have a named individual or team who takes responsibility for ensuring delivery of a multidisciplinary management plan.
- Measures:
  - The denominator for the process measure ‘the number of adults with MS’ is generally not available in local areas and may need to be replaced with ‘the number of adults on the service caseload’.

  - It was suggested that an additional process measure on responsiveness of the co-ordinator following contact by the person with MS is needed e.g. within 2 days.
  - Satisfaction with co-ordination of care may be due to factors other than having a co-ordinator and so may not be an appropriate outcome measure.
  - Unplanned admissions should be included as an outcome measure.
- Audience descriptors
  - Commissioners should ensure there is sufficient capacity so that co-ordinators can meet demand and that referral pathways are in place for onward referrals.
  - Does the provider audience descriptor accurately identify the role of GPs?
- Definitions:
  - It is important to clarify who the single point of contact could be e.g. MS specialist nurse, and that it should be a named healthcare professional with expertise in MS rather than a telephone/email/online service or a GP.
  - It was suggested that the definition of multi-disciplinary services should specify the minimum requirements. Some stakeholders indicated this should include ongoing access to MS specialists. It was also suggested that the definition should include orthotists, a consultant in rehabilitation medicine, and a urological consultant with a special interest in neurology.

5.4 Draft statement 4

Adults with MS who have a relapse are offered treatment as soon as possible but within 14 days of the onset of symptoms.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Rationale:
  - It is important to identify that diagnosis of relapse is important information that will help to optimise ongoing management with disease-modifying therapies.
- Statement:
  - The recommendation that supports this statement includes assessment and treatment following relapse. Stakeholders suggested that the focus of the

  statement should be on assessment as this is the most important area for quality improvement to ensure there is no delay in diagnosis. There is a need for a comprehensive assessment to be carried out by a specialist to give access to the full range of therapeutic interventions, and review other needs including social care. It will be important to identify an appropriate timescale for the assessment of relapse.
  - Stakeholders indicated that the statement should focus on all those with acute deteriorating symptoms in order to capture the breadth of need of people with different forms of MS, not just relapse-remitting MS. All those who experience a sudden exacerbation of symptoms will require urgent assessment.
  - It was suggested that 14 days is too long and instead advice should be provided within 48 hours and treatment within 7 days.
  - The timescale should be linked to first contact with services rather than the onset of symptoms because the person with MS may delay in contacting services immediately.
  - This statement may increase demand for urgent MRI scans when these services are already under considerable pressure. Stakeholders suggested that it would therefore be helpful if the statement could be more specific about when an MRI scan is or isn’t needed.
- Measures:
  - Separate measures for different components of treatment should be considered.
  - A patient satisfaction measure about the relapse assessment service should be added as a measure.
  - It is important to highlight that unplanned admissions data will not be able to identify only those admitted due to relapse.
- Audience descriptors:
  - Does the provider audience descriptor accurately identify the role of GPs?
  - The patient audience descriptor should indicate that what should happen in the event of a relapse should be included in the person’s management plan.
- Definitions:

  - It was suggested that treatment should be defined and include a review of medical and therapy needs including treatment with disease-modifying therapies and rehabilitation.

5.5 Draft statement 5

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

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Statement:
  - There was general support for this statement although one stakeholder suggested a more flexible approach is needed that is responsive to individual needs. The course of MS is variable and having a comprehensive review at least once a year may not always be appropriate.
  - Some stakeholders suggested that the statement should identify a multidisciplinary team review.
- Measures:
  - The denominator for the process measure ‘the number of adults with MS’ is generally not available in local areas and may need to be replaced with ‘the number of adults on the service caseload’.
  - Would it be useful to include a structure measure to assess arrangements to identify all people with MS in the local area who should have an annual review?
  - It was suggested that a patient satisfaction measure to assess whether their needs were met by their review should be included.
  - Unplanned admissions data is a relevant outcome measure.
- Audience descriptors:
  - It is important to identify that commissioners should ensure there is sufficient capacity to undertake comprehensive reviews.
- Definitions:
  - It was suggested that a more specific definition of a comprehensive review is needed to support audit in a clinical setting. Specifically, it is important to clarify

  if the comprehensive review should include an MRI scan to support review of disease-modifying therapies. It was suggested that a standardised template for the content of the review is needed.
  - It was recommended that the definition of a healthcare professional with expertise in MS should include a rehabilitation medicine specialist.
- Equality and diversity considerations
  - It was suggested that the comprehensive review may need to be held in community settings or the patient's home in order to ensure equity of access.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

Additional statement suggested	**Status**
• Personalised care/management plan	This was considered at the first meeting as part of a broader priority to provide ongoing responsive support including regular review of support needs. A specific statement on a personalised care/management plan was not discussed.
• Access to a MS specialist nurse	This was discussed at the first meeting and it was agreed it would be included within a statement focussed on providing ongoing responsive support with a description of the roles of different professionals.
• Disease-modifying therapies (DMTs) – Access for eligible people with MS – Monitoring the response to disease-modifying therapies (DMTs) – pharmacovigilance	Access to DMTs was discussed at the first meeting but not prioritised for a statement because NICE technology appraisals specify that access is mandatory. It was agreed that treatment with DMTs would be included within the statement on ongoing responsive support. Monitoring of DMTs was not specifically discussed at the first meeting.
• Support to be physically active	This was discussed at the first meeting

	but it was agreed that it should not be progressed as a separate statement but should be included within other statements on ongoing support from a multidisciplinary team.
• Referral to a consultant neurologist for diagnosis – waiting time from referral to consultant led care – waiting time from first appointment to diagnosis	This area was considered but not prioritised at the first Committee meeting. • Time from presentation of symptoms to referral may not influence outcomes. It is reasonable for there to be a number of primary care consultations before a referral for possible MS. There is no specific waiting time identified in CG186. • The Committee felt that waiting time for support once a diagnosis is established was more important than when diagnosis is uncertain. This was addressed by draft statement 2.
• Access to symptomatic treatments and neuro-rehabilitation	This area was not identified by the prioritisation exercise and was not discussed at the first meeting.
• Mental health assessment and review – annual review by consultant neuropsychiatrist	This area was not identified by the prioritisation exercise and was not discussed at the first meeting.
• End-of-life care	This area was not discussed at the first meeting but is covered by a separate quality standard on end of life care.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	MacGregor Healthcare Limited	General	MacGregor Healthcare Limited supports this MS Quality standard.
	The Royal College of Radiologists	General	The RCR would like to emphasise that although the draft includes a reference to the diagnosis of Multiple Sclerosis in its title, it contains very little detail relating to the process of diagnosis, including imaging and specifically MRI. MRI services are currently under great pressure at the moment and any steps to increase MRI utilisation would have major resource implications.
	The MS Trust	General	To develop our response, the MS Trust surveyed people with MS (PwMS) and health professionals registered on our database. The surveys were open for one week from 21st to 28th July. We received responses from 166 PwMS and 79 health professionals including MS specialist nurses, neuro-specialist AHPs, neurologists, and neuro-rehabilitation specialists. In 2012 the MS Trust published Defining the Value of MS Specialist Nurses, which found strong anecdotal evidence for the value of the MS nursing role. However, robust data on impact and cost effectiveness were lacking as nurses were not collecting evaluation data due to a lack of time, tools and evaluation skills. The Generating Evidence in MS Services project (GEMSS) was designed to address this by supporting the evaluation over one year of 16 MS teams supporting nearly 13,000 PwMS. The approach included identifying general Quality Indicators and tools for data collection on activity, caseload and outcomes. The final report of the GEMSS project will be published in November 2015. However, a number of early findings are highly relevant and we will reference them throughout our response. We will make a copy of the full report available to NICE on publication. Other sources of evidence used for our response include the MS Trust reports MS Specialist Nursing in the UK 2014: The case for equitable provision (November 2014) and Modelling Sustainable Caseloads for MS Specialist Nurses (November 2014). We have structured our response by outlining the additional quality statements we wish to see included, then highlighting some general issues with data collection before addressing each proposed quality statement in detail.

---

[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			The MS Trust was pleased to see many of the areas we raised in our earlier consultation submission reflected in the draft quality standards. We are broadly in support of the statement areas included, although think that the wording of a number of the individual statements needs to be revised to more accurately reflect the intended outcomes. We have provided detailed comments on each statement as part of our response.
	Multiple Sclerosis Society	General	Established in 1953 and with over 38,000 members and 290 branches, the MS Society is the UK's largest charity for people affected by multiple sclerosis (MS) and the largest not-for-profit funder of MS research in the UK. There are over 100,000 people with MS in the UK and, with 50 new people diagnosed every week, it is one of the most common neurological conditions affecting young adults. We are committed to bringing high quality standards of health and social care within reach of everyone affected by MS. The MS Society welcomes the opportunity to offer comments on the draft quality standards for MS. We hope that our comments will be helpful. This consultation response was informed by dialogue with a range of health social care professionals with a special interest in MS, people with MS and MS Society employees. We broadly welcome the suggested quality statements but have recommended amendments for each to enhance their impact. We have also suggested a further two quality statements in areas where there is evidence of signification variation in clinical practice. We urge NICE to make the amendments and include the suggested statements in their final standards
	Department of Health	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
	UKMSSNA	General	**Overall Impression** We welcome the development of standards to drive up the quality of services for people living with MS and acknowledge the considerable work that has been undertaken to incorporate the views of the stakeholders who contributed to the topic engagement process. In trying to capture the key topic areas some of the Quality Statements have combined elements identified as important for improvement by including them in the rationale or sometimes in the description. We would like all the elements to be clearly set out within the quality statements as it is the combination of these elements that will bring about quality improvements (see the specific comments related to each statement)
	UKMSSNA	General	**MS Specialist Nurses** We are disappointed that throughout the document the term "Healthcare professional with expertise in MS" is used to describe roles that are currently undertaken by MS Specialist Nurses. This role evolved to support people living with MS in recognition of the complexity of both the condition and its management. MS Specialist Nurses play a vital role in MS care by helping patients to manage their symptoms and medication, and by co-ordinating the multidisciplinary

ID	Stakeholder	Statement number	Comments[1]
			services they need. They provide information and advice to people with MS at diagnosis and every stage of the disease, initiate and monitor treatment, provide psychological support, and co-ordinate their care packages They also save the NHS money by helping patients to self-manage their condition, which keeps them out of hospital. They reduce waiting times, free up consultant appointments for other patients, reduce patient treatment drop-out rates, and educate both patients and other health and social care professionals. A comparison of MS nurse roles in European countries concluded that the MS nurse role in the UK was “perhaps the most advanced in Europe”. (Royal College of Nursing Specialist Nurse Report, 2010). They are involved in both the early diagnosis and the later complex management of the disease as well as facilitating palliative care. This provides a relationship of continuity and trust that is invaluable to people living with MS who have to cope with uncertainty and change. There is a great deal of evidence from patient surveys and questionnaires that people living with MS find the role to be the most supportive. We are concerned that by using the word “expertise” there is an opportunity for organisations to employ individuals with experience but little specialist knowledge.(Clinicians with insufficient specialist knowledge may miss important clues relating to the progress of the disease or attribute all symptoms to MS when other treatable co- morbidities are present.)This would dilute specialist services and drive down quality. We would therefore suggest that the following wording be used: MS Specialist Neurologist, MS Specialist Nurse or MS Specialist AHP. As part of the GEMSS (Generating Evidence in Multiple Sclerosis Services) project the MS Trust produced a report demonstrating that the provision of MS specialist nursing in the UK is highly variable with some services struggling to support large caseloads. (MS Specialist Nursing in the UK 2014: The case for equitable provision 2014) Explicit reference to these posts in the Quality Standard would encourage commissioners and providers to review local capacity and ensure that every person with MS had access to an MS Specialist Nurse with the capacity to deliver a quality service.
	Salford Royal NHS Foundation Trust	General	We fully support the development of quality standards to help to continue to support and ultimately improve services for people with multiple sclerosis. The five QS, we feel cover the important aspects of how services for pwms should be configured but in their final wording there needs to be clear distinctions as within each QS there are a number of important elements. Whilst we fully endorse the statement that within the varying QS, it is a “healthcare professional with expertise in MS” who sees the patient, we remain disappointed that the QS and indeed, the NICE Guidance itself has not identified the MS specialist nurse or MS specialist therapist as this person, as these are the people already carrying out most of the work identified within the QS. The statement “healthcare professional with expertise in MS” is open to interpretation and as such will, in our view, lead to a wide variation in care for pwms and does nothing to drive the specialism forward. One of our concerns is for some services to be able to collect the data/evidence in order to show compliance with the

ID	Stakeholder	Statement number	Comments[1]
			QS. Again there is a wide variation in data collection/ IT systems to support this data; whilst we agree with the importance of the data it needs to be supported at all levels in terms of personnel, time and IT. With the NHS moving towards a paper light organisation this can be seen as an opportunity to develop such systems to support MS services. We would recommended that more guidance is sort from the GEMSS project (Generating Evidence in Multiple Sclerosis Services); MS Trust
	University Hospital Birmingham	General	There is a need to develop these standards to ensure all PWMS have access to appropriate services.
	British Medical Association	General – briefing paper	4.1.3 'Current UK Practice', p. 10 - We agree that it is important to receive timely diagnosis, support and treatment of Multiple Sclerosis (MS). However, we believe it should be acknowledged in the guideline that symptoms of MS are intermittent and non-specific. GPs see many such patients, the majority of whom do not have MS, and this difficulty should be recognised in the quality standards.
	British Medical Association	General – briefing paper	'Information at the time of Diagnosis', pp.13-14 - It is stated in the quality standard that patients should be offered a face-to-face follow-up within six weeks of diagnosis to allow the information to sink in and for them and their families to formulate questions. During this time, the first point of contact for anxious patients and their families will most likely be their GP, therefore it is crucial that comprehensive and prompt communication systems are in place.
	British Medical Association	General – briefing paper	4.2.3 'Current UK practice', p. 15 - We welcome the attempts of the guideline to improve the patient's experience regarding ongoing information and support, which would also make easier for GPs to provide better support. There is scope for a departmental organisation in secondary care to help towards that direction.
	British Medical Association	General – briefing paper	4.3.3. 'Current UK practice', p. 20 - According to the Neurological Alliance survey results quoted in the briefing paper, GPs are by far the most contacted health professionals by patients with MS. Since this evidence support the fact that it is GPs who are caring for patients with MS most of the time, more resources should be provided to primary care, to ensure that the standards set by the guidance are met. It is acknowledged in the guidance that patients with MS need multidisciplinary, patient centred, integrated care. At the same time, the provided statistical data show that care is mainly delivered within a primary care setting, hence there is a need to set excellent communication pathways between secondary and primary care, with phone numbers being shared and the provision of adequate resources.
	British Medical Association	Introduction	We welcome the emphasis given on a person-centred, integrated approach to providing services as fundamental to delivering high quality care to adults with MS.
	Royal College of Psychiatrists	Introduction	The quality standard should include an additional outcomes statement about improving "access to mental health services".
	Royal College of Nursing	Introduction	*Why the standard is needed:* No need to state 10 -15% of 100 people with multiple sclerosis (MS), suggest it should read 'either 10 -15% or 10-15 of 100 people'.
	NHS England (&	Questions for	An area that is neglected in this and other statements is access to disease-modifying therapies (DMTs) and the

ID	Stakeholder	Statement number	Comments[1]
	Association of British Neurologists)	consultation – Question 1	monitoring of the response to these treatments. We acknowledge that defining and implementing quality standards to assess access to DMTs will not be simple, but the proportion of people with relapsing MS on first- or second-line disease modifying therapies would provide valuable information about access to NICE-approved therapies and the proactive management of relapsing MS. We recommend that should include a statement about pharmacovigilance. Quality metrics measuring access, or lack of access, to DMTs would help address healthcare inequities across the NHS.
	NHS England (& Association of British Neurologists)	Questions for consultation – Question 1	MS is a chronic disease and the service needs of people with MS vary depending on the stage of the disease they are at. With regard to service needs MS can be divided down into five stages: (1) diagnostic, (2) minimal impairment, (3) moderate impairment, (4) severe impairment and (5) terminal stages. At present three out of five the quality statements (1, 2 and 4) refer to management in the diagnostic or early/relapsing stages of the disease. The other two statements (3 and 5) are not stage specific but need to be defined more clearly to allow them to become measurable. The ABN would urge NICE to include some quality standards that focus on the services for people with more severe impairments and in the terminal phase of the disease, in particular access to symptomatic treatments, neuro-rehabilitation and end-of-life care.
	NHS England (& Association of British Neurologists)	Questions for consultation – Question 1	Additional statement - patients should be referred to a MDT with necessary neurology competences.
	The MS Trust	Questions for consultation – Question 1	While we broadly support the draft quality standard there are a number of areas we think must be added. In our original submission to NICE we proposed two quality statements that have not been included in the draft quality standard. These are: adults suspected of having MS are referred quickly to a consultant neurologist who can make a diagnosis, and; adults with MS are cared for using a co-ordinated multi-disciplinary team approach involving a range of professionals with expertise in managing in MS who can best meet the needs of the person with MS. In our surveys we added these two statements to the five proposed by NICE, and asked people to rank the seven statements in order of preference. There was very little difference in the overall ranking of each statement meaning that all the statements were equally important to both people with MS and health professionals. We would therefore encourage NICE to include more than five quality statements rather than set an arbitrary bar to the number of statements that can be included. The quality standard offers an opportunity to clarify certain aspects of the recommendations in the Clinical Guideline, and the MS Trust would welcome the clarification of service standards in three additional areas. Specifically, we would like to include three additional quality statements. In priority order these are: • Every person with MS should have continuous access to an MS specialist nurse with an acceptable caseload; • Adults with MS are cared for using a co-ordinated multi-disciplinary team approach involving a range of

ID	Stakeholder	Statement number	Comments[1]
			professionals with expertise in managing in MS who can best meet the needs of the person with MS; • Adults suspected of having MS are referred to a consultant neurologist within two months who can make a diagnosis.
	The MS Trust	Questions for consultation – Question 1	Additional Quality Statement Every person with MS has continuous access to an MSSN service with a sustainable caseload**.** Rationale MS specialist nurses are highly valued by and trusted by PwMS, and will be instrumental in ensuring that the overall quality standard is achieved. However, not every PwMS has access to an MSSN and many services are overstretched. The quality standard offers an opportunity for further clarification of the Clinical Guideline, and the MS Trust would encourage NICE to take this opportunity by including an additional quality statement that every PwMS should have continuous access to an MSSN with a sustainable caseload. The MS Trust report Modelling Sustainable Caseloads for MS Specialist Nurses found that the maximum sustainable caseload is 358 per full-time MSSN working across the whole disease trajectory and delivering a service based on a specified job plan. The MS Trust report The Case for Equitable Provision found that, in England, less than one-third of PwMS live in areas where the MSSN service has a sustainable caseload, and a similar proportion live in areas with more than double the sustainable caseload. Early indications from the GEMSS data show there are significant differences between and within Strategic Health Authorities, with the increase in MS specialist nurse FTEs needed to reach a sustainable caseload ranging from 0% to 348%. Data to be published in the final report of the MS Trust GEMSS project clearly shows the value that PwMS place on their MSSN. The GEMSS data shows that MSSNs are the most consulted professional about MS. 78% of GEMSS patient survey respondents (n= 1,254) had consulted their MS nurse at least once in the past year. The next most consulted professions were neurologist and GP, with around half having contacted these health professionals within the last year. When asked what, if any, difference the MSSN service made to them over the past year, respondents reported on a number of benefits from a list of options. The most frequently reported benefits were information and education on MS, advice on physical symptoms on MS, emotional support, and advising on medications. The GEMSS data therefore provides evidence that these are the domains that MS specialist nurses are routinely covering. Furthermore, PwMS rely on their MS nurse for this kind of support and advice. Asked what they would have done if they hadn't had access to an MSSN, the impact on other NHS services is clear: PwMS reported that without access to an MSSN they would have seen their GP and/or neurologist more. PwMS need the services of an MS

ID	Stakeholder	Statement number	Comments[1]
			nurse, they prefer to contact their MS nurse, and they overwhelmingly have trust and confidence in their MS nurse (with over 95% of GEMSS survey respondents agreeing). This is supported by respondents to the MS Trust survey on the quality standard. When asked who the most helpful health professionals are in helping you to learn about MS, over 95% picked the two core roles of MS neurologist and MS specialist nurse, with more than half of these ranking their MS nurse as their first preference. PwMS also had a strong preference for their MSSN to co-ordinate the care they need. The role of MSSNs in implementing and achieving the quality standard is considered crucial by health professionals as well as PwMS. Health professionals responding to our survey on the quality standard thought that the MSSN is the best-placed health professional to carry out the 6-week follow up appointment, act as the single point of contact, and conduct the annual review. Even where the quality standard allows for local variation to reflect the needs of the individual person with MS (e.g. in who is best placed to co-ordinate care or conduct the annual review), in practice it is likely to be the MS nurse who carries out these functions in areas where there is a specialist nurse service. The quality standard therefore needs to seize the opportunity to clarify the Clinical Guideline by setting an aspiration that every PwMS should have access to an MS nurse with a sustainable caseload. Having continuous access to an MSSN is also crucial in ensuring that information provision and support is not a one-off at diagnosis, but an ongoing process. MS is a lifelong condition and people’s information needs will change throughout the course of their condition. Information and support therefore needs to be available on a regular basis. Ensuring that every person with MS has continuous access to an MS specialist nurse will help to address this issue. <u>Quality measures</u> • Evidence of local arrangements to ensure that adults with MS have access to an MSSN with a sustainable caseload; • Number of PwMS per FTE MSSN; • % of PwMS who know how to contact their MSSN; • We recommend including a number of patient satisfaction measures on the quality and responsiveness of the service within a regular patient survey programme.
	The MS Trust	Questions for consultation – Question 1	<u>Additional Quality Statement</u> Adults with MS are cared for using a co-ordinated multi-disciplinary team approach involving a range of professionals who can best meet the needs of the person with MS and who have expertise in managing MS. <u>Rationale</u>

ID	Stakeholder	Statement number	Comments[1]
			While we recognise that quality statement 3 makes reference to the multi-disciplinary team we think this issue warrants being separated out from the single point of contact. The two issues have a different focus and will need to be measured by different metrics. The principle of care being provided by a multi-disciplinary team with expertise in MS is extremely important to both PwMS and health professionals. Although there was no major variation in the ranking of the quality statements in our survey responses, access to a multi-disciplinary team was ranked first by people with MS and second by health professionals. There is clear evidence that access to specialists who can provide the care that people with MS need is limited. Research undertaken by the ABN indicates that the UK has less than a third of the European average of consultant neurologists per head of the population. MS Trust research also shows that access to MS specialist nurse is highly variable, as set out above. A recent study by the MS Trust, Parkinsons UK and the MND Association (awaiting publication) also shows that neuro-specialist AHPs are under pressure to take on more general caseloads and face the threat of services being reduced or downgraded. In our survey on the proposed quality statements, PwMS did not rank generalist options highly in any of the questions apart from co-ordination of care, where 18% picked their GP as one of a maximum of two choices. (For comparison, 89% picked MS specialist nurse and 48% picked MS neurologist.) The quality standard would be a welcome opportunity to clarify the fundamental importance of a range of specialist services for PwMS, including neuro-specialist AHPs and neuro-rehabilitation specialists. The supporting detail for this quality statement should define what is meant by a ‘multi-disciplinary service’ and by ‘expertise in managing MS’. In Scotland, Quality Standard 14 states that ‘an effective and comprehensive specialist multiple sclerosis service is available across all NHS boards’. The minimum components of a specialist service are defined as a consultant who specialises in the diagnosis and management of MS, and an MS clinical nurse. A range of other healthcare professionals with experience and training in neurological conditions are recognised as offering additional input. http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf The MS Trust considers that the only appropriate roles that meet the criteria of ‘expertise in managing MS’ are: MS neurologists, MS specialist nurses, and neuro-specialist AHPs (including neuro-rehabilitation specialists). It is important to capture this to ensure that PwMS are supported by health professionals with appropriate expertise and experience, but also as there might be a shift in emphasis in use of the MDT at different points in the disease trajectory. For example, someone with RRMS who is taking DMDs may require more regular access to their MS nurse for blood monitoring. However, someone with SPMS may benefit from greater access to neuro-specialist AHPs.

ID	Stakeholder	Statement number	Comments[1]
			Quality measures We recommend including the following quality measures: • Evidence of local arrangements to provide a multi-disciplinary team involving a range of professionals who have expertise in managing MS (Services to describe the makeup of their team and the services available); • % of MS teams which involve or have access to the whole range of healthcare professionals outlined in the definition; • Patient satisfaction measure on satisfaction with the range of specialists available to be included as part of a routine patient survey programme.
	The MS Trust	Questions for consultation – Question 1	Additional Quality Statement Adults suspected of having MS are referred to a consultant neurologist within two months who can make a diagnosis. Rationale Many PwMS report delays, sometimes significant delays, in being referred to a consultant neurologist who can make a diagnosis of MS. This is an issue affecting neurology services more generally: the Neurological Alliance's Invisible Patients report highlighted that 31% of people with a neurological condition had to visit their GP five or more times before being referred to a consultant neurologist, and more than 40% had to wait more than 12 months from symptom onset to seeing a consultant neurologist. Access to diagnosis by a consultant neurologist is recommended within NICE guidance. Diagnosis early is essential to reduce anxiety (and its impact on wider health services) 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 MS who meet prescribing criteria gain access to appropriate DMDs which, in turn, is recognised to have long-term benefits in reducing the rate of relapses and the disability 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. Furthermore, there is a growing strength of evidence and consensus around the benefit of early treatment, especially for RRMS. The Association of British Neurologists' (ABN) revised prescribing guideline for the treatment of RRMS recognises that disease modifying treatments - of which eleven are now licensed in the UK - have a significant impact on relapsing MS. Delays in diagnosis mean delays in starting treatment. Although there was no major variation in the ranking of the quality statements in our survey responses, quick referral to a consultant neurologist for people suspected of having MS was ranked first by health professionals and second by PwMS.

ID	Stakeholder	Statement number	Comments[1]
			We agree that this quality statement should specify a consultant neurologist. Although we would welcome every person suspected of having MS being assessed and diagnosed by a consultant neurologist with expertise in MS, we believe it is more important that people are diagnosed quickly and are then supported by appropriate specialist services. We think that specifying an MS neurologist here could lead to longer delays in diagnosis in practice. One of the consequences of this approach is that systems need to be put in place to make referrals between consultant neurologists and specialist MS services quicker and easier. In many cases a general neurologist cannot directly refer a person newly diagnosed with MS to specialist services but must request the GP makes a new referral. Eliminating unnecessary steps in the process will be one of the levers to help achieve this quality statement. Quality measures We recognise that one of the key barriers to a quality statement on this issue is finding the right metric. Early symptoms of MS can present in many different ways, and differentiating between symptoms that could mean the onset of MS and similar symptoms that do not is a challenge for primary care. We acknowledge the concern over possible over-referral and agree this should be avoided. However, given the case for diagnosis as early as possible, and the experience of significant delay reported by many PwMS, this is a priority area for service improvement. The recent National Audit Office review of the Public Accounts Committee Inquiry found that neurology outpatient waiting times have increased since 2008 while for the NHS as a whole waiting times have remained stable. The development of waiting time targets in other conditions such as cancer shows that a challenging target can stimulate improvement. Given the growing evidence around the benefits of early treatment (which can only begin after diagnosis) we think the national outpatient target of 18 weeks is too long for a person suspected of having MS to wait. The national cancer target is for no more than two months between the date the hospital receives an urgent GP referral for suspected cancer and starting treatment. We suggest adopting a similar approach here, but for the target to relate to the start of consultant-led care rather than starting treatment. We would suggest the following quality measure: • % of adults suspected of having MS who are seen by a consultant neurologist within two months of being referred by their GP.
	Multiple Sclerosis Society	Questions for consultation – Question 1	**Suggested quality statement** – Adults with suspected MS receive timely and appropriate referral to a consultant neurologist for diagnosis. **Comment:** Timely, accurate diagnosis enables an earlier conversation between patient and neurologist regarding treatment options for all forms of MS. There is increasing evidence that early treatment of relapsing forms of MS (RRMS) with a disease modifying therapy (DMT) improves long term outcomes for people with MS.

ID	Stakeholder	Statement number	Comments[1]
			However, 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). 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) Recommendation: These statistics demonstrate significant barriers in primary care to receiving an MS diagnosis, a matter the quality standards should seek to address through adding the following quality statement: Adults with suspected MS receive timely and appropriate referral to a consultant neurologist for diagnosis. 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 **Data collection:** This statement is measurable in a variety of ways. Data should be collected from locally administered surveys of patient experience. This should include questions on early symptoms, patient and clinicians actions in response to symptoms and time from first symptoms until diagnosis. **Improvements/overcoming barriers:** With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services. This should help improve referral pathways between primary care and consultant neurologists. This should be coupled with a stronger emphasis on MS in GP training and public and voluntary sector awareness raising campaigns regarding early symptoms of MS and treatments.
	Multiple Sclerosis Society	Questions for consultation – Question 1	**Suggested quality statement** – Adults with MS are supported to be physical active. **Comment:** The clinical guideline recommends that people with MS consider supervised exercise programmes

ID	Stakeholder	Statement number	Comments[1]
			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 there are issues accessing appropriate 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). 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). A quality statement should 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' needs and held at times and locations accessible to people with MS. Provision of transport may be necessary. **Data collection:** This statement is measurable in a variety of ways. Data should be collected from locally administered surveys of patient experience. Data should be collected regarding the availability of exercise and fatigue management classes in the local area. **Improvements/overcoming barriers**: With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services to support physical activity.
	Novartis Pharmaceuticals UK	Questions for consultation – Question 1	Whilst we welcome the steps being taken to publish quality standards for MS, we believe that the current set of five statements lack ambition and is a missed opportunity for addressing the more extensive challenges posed for those living with MS. As you note in your draft consultation, MS can lead to a high level of disability with considerable personal, social and economic consequences. People with MS may live for many years after diagnosis with significant impact on their ability to work, as well as an adverse and often highly debilitating effect on their quality of life and that of their families. Given the wide ranging consequences of MS for patients, their carers and for society, we would recommend that this opportunity is to taken to extend this consultation to also include the following areas,

ID	Stakeholder	Statement number	Comments[1]
			which could all have a significant impact on improving the diagnosis and management of MS. 1. **Recognition of the importance of specialist nurses**. All five quality statements would be strengthened by the recognition of the role played by specialist nurses in the diagnosis, referral, care and review of patients with MS. The guidelines should clearly state that a MSSN contact is required. Specialist nurses are best equipped to ensure patients receive the right treatment at the right time and are supported in managing their long term condition. In particular, we believe that a greater recognition and use of specialist nurses could lead to improvements in emergency hospital admissions (which we note is a proposed outcome of this review). In one Trust alone, the Hospital Episodes Statistics (HES) for primary and secondary diagnosis of MS during 2010/11 and 2011/12 were analysed and this identified over £95k of admissions due to people with MS receiving inpatient treatment for urinary tract infections. We believe ensuring patients have access to a MS specialist nurse would drive measurable improvements in all three areas defined by this consultation – patient safety, patient experience and clinical effectiveness. 2. **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 to disease modifying therapy. We would welcome an addition to quality statement 5 to include an annual MRI scan as part of the comprehensive review proposal. This may not be appropriate in all cases e.g. where a patient reaches a stage of disease where they are not on therapy but should be a consideration for patients with relapsing MS where a number of treatments are available. We believe this would drive measurable improvements in all three areas defined by this consultation – patient safety, patient experience and clinical effectiveness. 3. **Uptake of Disease Modifying Treatments in line with NHS England Policy**. There is no mention in this consultation of the role of DMTs in helping patients manage their condition or the need for a review of Disease Modifying Treatment (DMT) if a patient experiences a relapse. 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 ensuring that patients are treated effectively without exposing them to unnecessary risk. However, 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. We would welcome a quality statement on the uptake of DMTs to help reverse this trend. We believe this would drive measurable improvements in all three areas defined by this consultation – patient safety, patient experience and clinical effectiveness. 4. **Consistency of descriptors of RRMS patients between NICE STAs, clinical guidelines and clinical standards**. Again, a quality statement around the consistency of descriptors would help to avoid confusion with patient eligibility for disease modifying therapy. In turn this would support one of the proposed outcomes - to improve patient experience of the diagnostic process and support. The field of MS is complex and patients exist in a number

ID	Stakeholder	Statement number	Comments[1]
			of subgroups of RRMS, SPMS and PPMS. Licensing by the EMA and subsequent NHS England Guidance and NICE STAs has enabled prescription of DMTs in subtypes of RRMS patients based on efficacy and cost-effectiveness in these groups. We believe consistency of language between NICE STAs, NHS England guidance, clinical guidelines and quality standards will provide greater clarity on identifying patients who will most benefit from individual DMTs. We believe this would drive measurable improvements in all three areas defined by this consultation – patient safety, patient experience and clinical effectiveness and would also make improvements easier to measure through audit, particularly with the forthcoming introduction of Bluetec.
	Merck Serono Ltd	Questions for consultation – Question 1	Merck Serono are in support of all five statements, with only a perceivable gap in measurement of symptom identification and referral to a Neurologist by primary care. The majority of multiple sclerosis patients present acutely to emergency departments with altered levels of consciousness, falls, headaches and infection. This presentation often repeats several times before a diagnosis is made by a Neurologist. Patients in this situation should be immediately transferred to a Neurology service for appropriate tests and possible diagnosis. Further education of non-specialist multiple sclerosis services could prevent acute emergency presentations and support immediate transfer to Neurology depts.. The current NHSE Neurosciences Service Specifications states: *Specialised neurological centres will be a resource for education and training for non specialised neurology services within their area.* *Specialised services will need to work with Strategic Clinical Networks (SCNs) to develop appropriate care pathways and models of care that deliver care close to home, meet national standards and audit requirements. They should use innovative technologies to enable those living remote from neurology centres to receive the same care as those living close by and enable advancement of future care through research and enhanced training.*
	Royal College of Psychiatrists	Questions for consultation – Question 1	List of quality statements Additional statement is required to address mental health in view of increased rates of affective disorder, anxiety and suicide in this long-term neurological condition. Adults with MS should have an annual review of their mental health by a consultant neuropsychiatrist. Additional statement is required to address cognitive function in view of Quality statement 1: Support at diagnosis Equality and diversity considerations (p10). Adults with MS should have access to neuropsychology for baseline cognitive screening at point of diagnosis and

ID	Stakeholder	Statement number	Comments[1]
			subsequently as required to track the cognitive impact of MS.
	Roche Products Limited	Questions for consultation – Question 1	The National Audit Office has again highlighted that only a small proportion of people with a long-term neurological problem have a written care plan or have been offered one. 1 Over three years ago, the Committee of Public Accounts recommended a national quality outcome measure regarding personal care plans. 2 NICE CG186 includes the recommendation that people with MS and their family members or carers have a management plan that includes who to contact if their symptoms change significantly. 3 We would suggest that a quality statement would drive improvement in this area and would be consistent with NICE Quality Standards for other long-term conditions (dementia, diabetes) e.g. *Adults with MS have an assessment and an ongoing personalised care plan agreed across health and social care that identifies a named care coordinator and addresses their individual needs* 1 Comptroller and Auditor General, Services for people with neurological conditions: progress review, Session 2015-16, HC 301, National Audit Office, July 2015. 2 HC Committee of Public Accounts, *Services for people with neurological conditions*, Seventy-second Report of Session 2010-2012, HC 1759, March 2012. 3 NICE, *Multiple sclerosis: management of multiple sclerosis in primary and secondary care*, CG186, October 2014.
	Royal College of General Practitioners	Questions for consultation – Question 1	The RCGP welcomes these quality statements about the care of people with multiple sclerosis (MS) and their families and carers. Many people with MS need to make extensive use of primary and secondary health care, and social services. In 2004 the RCP and the Chartered Society of Physiotherapists published MULTIPLE SCLEROSIS -National clinical guideline for diagnosis and management in primary and secondary care. Their recommendations included 1. Rapid diagnosis Once a patient has experienced symptoms suggestive of MS, a rapid diagnosis is needed. This ensures that any required treatments are started, and reduces anxiety and uncertainty. We recommend that an individual who is suspected of having MS should be referred to a specialist neurology service and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time). 2. Seamless services People with MS often have complex problems requiring input from many different groups both within and outside the NHS. Many find that bureaucracy and border disputes lead to stress and delays in even the simplest of actions. Current policies should lessen this, but still we recommend that every health commissioning organisation should

ID	Stakeholder	Statement number	Comments[1]
			ensure that all organisations in a local health area agree and publish protocols for sharing and transferring responsibility for and information about people with MS, so as to make the service seamless from the individual's perspective. We recommend that these protocols are publicly available and that the timescales involved are audited to ensure that unnecessary delays do not occur. 3. A responsive service People with MS can experience one or more of a wide variety of symptoms and difficulties. Each person's needs are unique, and a flexible response is required from the NHS. We recommend that all services and service personnel within the health care sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively in all decisions and actions. In other words, services should be patient centered. A patient-led system of audit can help address some of the difficulties in monitoring this. 4. Sensitive but thorough problem assessment The great variety of possible problems that people with MS may have can make it difficult for health care professionals to detect all relevant changes. We have recommended that health service professionals in regular contact with people with MS, should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control. The main text of the guideline details the various problems that a person with MS may have and appropriate ways of treating these problems. 5. Self-referral after discharge There is no predictable pattern or progress of the condition in any individual with MS, but problems may arise quickly at any time. Some people therefore have routine appointments 'to keep in touch', which is wasteful and perpetuates a dependent approach, while many others 'fall out' of the system until a crisis occurs. We have strongly recommended that every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate. This recommendation should mean that each specialist service (neurology, and neurological rehabilitation) has in place a mechanism for accepting and responding to direct contact by someone. In addition the MS Society has recommended that people with MS get regular reviews with an MS specialist and receive multidisciplinary care from a team of healthcare professionals. These teams should include neurologists, MS nurses, GPs, speech and language therapists, occupational therapists and physiotherapists.

ID	Stakeholder	Statement number	Comments[1]
			The current quality statements that need amendment to: Include a statement about rapid diagnosis within audited time. Statement 3 to include self referral after discharge Statement 5 is amended to include a multidisciplinary team review
	Teva UK Limited	Questions for consultation – Question 1	GP referral to Consultant not addressed - GP referral pathways are required to ensure prompt referral. Education in Primary Care around signs and symptoms of Multiple Sclerosis also required for timely referral to a specialist. Need for individualised, multi-disciplinary care plans which are linked to a standard, in order to reduce geographical variations and inequalities in care, and to optimise the quality of care.
	Genzyme Therapeutics (a Sanofi company)	Questions for consultation – Question 1	We think these standards have omitted a key area for improving quality. We would suggest that a quality standard to monitor the use of disease monitoring treatments (DMT) is included. The rationale for this is that, as highlighted by the MS Society Report “A lottery of treatment and care – MS Services across the UK” (April 2013), only 4 out of 10 patients eligible for DMT receive it and this proportion is the lowest amongst European countries with the exception of Poland and Romania. Such treatments have a valuable contribution to make to MS relapse prevention and reducing disability progression. The wording of the standard we would suggest should be “Statement 6. It should be reported whether adults with MS eligible for DMT receive it. The metric we would suggest for measuring this quality standard is proportion of patients with relapsing remitting multiple sclerosis (RRMS) who receive a DMT with a numerator of patients receiving a DMT and a denominator of patients with RRMS.
	The MS Trust	Questions for consultation – Question 2	In our view, the metrics for many of the quality statements need more careful articulation. However, as well as thinking about the specific, auditable metrics, we would encourage NICE to think globally about the systems and structures that are needed to enable data collection. Three things need to be in place: - local caseload databases in every MS service; - an understanding of wider prevalence of MS locally. Currently do not know the denominator for number of people with MS. To enable this care.data needs to move ahead; - Regular patient surveys with a sample caseload, to include a subset of newly diagnosed. Specific barriers to data collection include:

ID	Stakeholder	Statement number	Comments[1]
			Episodic versus caseload approach GEMSS project working with 16 teams found that, in many cases, data collection is poor. Clinical information systems do not support a caseload approach, they record individual episodes of care rather than the overall package of care provided to people on a caseload. MS teams need to have access to database systems that enable them to look at their caseload as a whole and track what is happening in individual cases. Every area needs a caseload database, and every person newly diagnosed with MS must be recorded on the database. Without this longer-term tracking as opposed to an episodic approach it will be impossible to measure the difference that services and interventions make to outcomes for people with MS and the impact on other outcome indicators, e.g. hospital admissions. **Outpatient coding** It can be difficult to identify the caseload because of outpatient coding. There is no outpatient diagnostic coding for MS. Not everyone is seen in a clinic that is coded as an MS clinic; it might be coded as a neurology clinic. **Prevalence data** We simply often do not know how many people with MS live in a specific area, especially if they have not been in contact with services for a long time. This lack of accurate prevalence data limits potential use of national data (e.g. HES data on emergency admissions). Joining up of data held by GP practices is essential to understanding the prevalence of MS within a local population. This will require initiatives like care.data to make progress quickly. Accurate prevalence data is also required to help identify everyone with MS in a given area so that they can be recorded on the local caseload database and offered appropriate services. **Patient survey programme** The quality statements will require a number of patient satisfaction measures. In order to collect objective data a regular patient survey programme will need to be implemented in each local area. MS teams need to implement a routine patient survey programme, including a subset of newly diagnosed (within 12 months). The MS Trust offers a patient survey service, based on the patient surveys conducted as part of our GEMSS programme which have provided data from over 12,000 people with MS.
	Multiple Sclerosis Society	Questions for consultation – Question 2	To improve MS services, the quality standards need to be readily auditable. There are certain systemic barriers to doing this that we urge NICE to address. For example, we know that the prevalence of MS in a local area, the denominator of many of the quality statements, is often not known. There is no outpatient code for MS, making setting a suitable caseload for professionals difficult. Routine patient surveys should be undertaken to ensure the patient experience is satisfactory and the desired outcomes of interventions are being achieved. This data should be used to inform service design and delivery.

ID	Stakeholder	Statement number	Comments[1]
	Merck Serono Ltd	Questions for consultation – Question 2	To ensure patients with symptoms and diagnoses are appropriately followed-up and have a good experience of integrated care across a complex treatment pathway, the data systems and coding for multiple sclerosis need to be consistent. Merck Serono therefore recommend that these measures therefore need to be implemented in parallel with a review of activity coding and mandatory input into relevant datasets.
	UKMSSNA	Questions for consultation – Question 2	**Data Collection Issues:** The national prevalence data for MS is not agreed and there is variance across the United Kingdom therefore local prevalence data needs to be collected using a single disease registry method that works across the health economy to avoid double counting Systems of data collection regarding treatment/management/support need to be in place in order to enable progress to be mapped against the quality statements. These should be embedded in service provision to avoid the collection of data being an extra burden on already stretched services. Current methods of data collection are related to patient notes, episodes of care, and clinical activity. Extracting statistics from these resources is time consuming and often imprecise. The GEMSS project has enabled MS Specialist Nurses to overcome these difficulties by helping them to set up a case load data base that enables overview of individual cases and trends in the service. After initial set up nurses have been able to maintain this database and use the data to inform service delivery and drive improvements. However anecdotally many services are facing a reduction or removal of clerical support and this would have a negative impact on efficient data collection. Smart IT systems that embed data collection in integrated records would reduce some of the barriers to data collection. For example an IT record that supports a relapse pathways could be both a driver of improvement and an instrument of data collection if it was accessible across the local health economy allowing inputs from GPs Neurologists and Specialist Nurses. In addition to service data, patient outcome measures and surveys of satisfaction will need to be undertaken to ensure changes are having a positive impact on the patient experience
	Teva UK Limited	Questions for consultation – Question 2	Yes, it should be possible to collect the data as outlined.
	Multiple Sclerosis Society	Questions for consultation – Question 3	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 (Multiple Sclerosis International Federation – Atlas of MS 2013) Professionals and people with MS frequently complain that their appointments are too short to adequately address the complex options for treatment and care. One in three people with relapsing MS said that they had not even discussed treatment options with their clinician (MS Society, Right Treatment, Right Time 2014). Defining appropriate caseloads and appointments times is crucial to deliver the standards of care outlined in the quality standards. It is likely that in some areas this will require increased NHS investment in specialists.
	Teva UK Limited	Questions for	Barriers include variations across the country in diagnosis and treatment, and the lack of a 'whole system' approach

ID	Stakeholder	Statement number	Comments[1]
		consultation – Question 3	(a synergistic multi-disciplinary approach).
	Biogen	Statement 1	Biogen feels further clarification is needed around this important Quality Statement. It is not clear how NICE would ensure synergy between Quality Standard Statement 1 and the NHS Outcomes Framework and The Adult Social Care Outcomes Framework. MS touches on both these frameworks, not least given that a significant part of the burden of MS impacts upon and falls on social care. Further clarification of the definition of "support" is needed, along with the method that would be used to measure this Quality Standard and therefore ensure appropriate outcomes are being achieved. Biogen would like to understand further how this Quality Standard aligns with the integrated of Health and Social Care in line with the 5 year plan.
	NHS England (& Association of British Neurologists)	Statement 1	Considering the complexity around the use of disease modifying therapies we would prefer this statement to refer to a neurologist with a specialist interest in multiple sclerosis and a multidisciplinary team. We would recommend that this statement is linked to a specific, and well-defined metric, which can be audited to assess the quality of individual MS services.
	The MS Trust	Statement 1	The MS Trust would like to see this statement revised to: Adults with MS are supported from the time of diagnosis by a consultant neurologist with a specialist interest in MS working within a multi-disciplinary team to understand MS and the ways it can be managed and treated. <u>Rationale</u> MS is a lifelong condition and PwMS will experience many biographical events that mean they have urgent and/or significant information and support needs throughout the disease trajectory. This statement should recognise the long-term nature of MS and the need for ongoing information and support. We therefore recommend changing the wording from 'at the time of diagnosis' to 'from the point of diagnosis'. We also recommend changing the wording 'to understand the condition, its progression and the ways it can be managed' to 'to understand MS and the ways it can be managed and treated'. While we recognise that DMTs are out of scope for the quality standard, the inequity in access to treatments, variation in prescribing rates, and the low proportion of eligible adults with MS in the UK who are taking DMTs compared with other European countries highlight that access to treatment is a key area for service improvement. Including a reference to treatment in this statement is one way to address part of this issue without adding a separate quality statement on DMTs. <u>Quality measures:</u> In order to audit this statement local areas would need to develop an audit tool to identify what should be included in the information provided at diagnosis. This should consist of both verbal and written information. This could be in the

ID	Stakeholder	Statement number	Comments[1]
			form of a checklist in patient notes for the kinds of information provided, which can be audited retrospectively. The MS Trust study 'The information needs of the newly diagnosed' identified the need for information to come from a trusted source. We would therefore like to see the process measure amended to the proportion of adults with a new diagnosis of MS who are given a range of quality assured information and support to understand their condition by the consultant neurologist at the time of diagnosis. The MS Trust study 'The information needs of the newly diagnosed' also identified the need for information provision to be supported with expert input from specialists to help people understand and apply the information provided. Although the quality statement itself says refers to 'being supported at diagnosis' the process measure for this statement focuses on whether information has been provided, and the definition of the term 'support' is oral and written information on a range of topics. We would like to see the definition of support broadened to acknowledge the importance of support to understand and interpret information, as well as support for the emotional burden on people with MS at diagnosis. We therefore recommend the following quality measures: • Proportion of adults with MS who are given a range of quality assured information about MS by the consultant neurologist at the time of diagnosis. We agree that metrics for the support provided should be collected through patient satisfaction data. We recommend including the following patient satisfaction measures within a regular patient survey programme. • % PwMS who are satisfied with the quality and appropriateness of the information provided at diagnosis; • % of PwMS who are satisfied with the support they received to understand and apply the information they received; • % of PwMS who are satisfied with the emotional support they received at diagnosis; • % of PwMS who feel confident to make choices about their care and treatment. It is also worth noting the requirements of the revised Accessible Information Standard to clearly record any information or communication needs in a person's file or notes, to share those with other providers of NHS care, and to take steps to ensure that people receive information which they can access and understand along with communication support if they need it.
	Multiple Sclerosis Society	Statement 1	**Comment:** We welcome this quality statement. People with MS have complex information needs. They have to be able to make informed decisions for both the short and long term. Comprehensive written and oral information for people with MS, their family & carers needs to be provided at diagnosis. The information should explain the condition,

ID	Stakeholder	Statement number	Comments[1]
			MS treatment (DMTs and symptom management), and include local support groups and services and DVLA, employment and appropriate social care information. The appointment with the neurologist must be of an appropriate length to deliver the full range of information expected. We are pleased that quality statement number 1 is complemented by quality statement 2 regarding a 6 week follow up appointment. Being diagnosed with a long term, progressive condition like MS can be extremely 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 and how to treat it. A consultation with a specialist can be stressful and is constrained by time so it is important that materials are provided to summarise the dialogue, resulting actions and provide further information that can be considered afterwards. However, we feel that quality statement 1 would benefit from a greater emphasis on how a management plan will be developed with the person with MS and their family/carers. A management plan is crucial to supporting effective self-management; facilitating self-referral, minimising hospital admissions and maintaining quality of life. Conversations regarding this should begin at diagnosis and continue at the 6 week appointment and onwards. It should contain the name of a person's single point of contact in the multi-disciplinary team and clear steps for what a person should do if they experience a relapse (quality statement number 4). The management plan should evolve with a person's condition and look to be integrated with social care services as these needs arise. The comprehensive annual review (quality statement 5) is a good opportunity to update the management plan. **Recommendation:** The wording of the standard should be amended to include the development of a management plan. It should read: people with MS are supported by the consultant neurologist at the time of diagnosis to understand the condition, its progression and how a comprehensive management plan will be developed with them. **Data collection:** This statement is measurable in a variety of ways. This should include locally administered surveys of patient experience of diagnosis and local data collection regarding referrals made for a 6 week follow up appointment and number of management plans created for people with an MS diagnosis. Neurologist caseloads and appointment length should be defined and monitored as appropriate. **Improvements/overcoming barriers:** patient organisations such as the MS Society provide high quality, patient friendly information materials. More collaborative work across sectors would ensure that clinicians have suitable information materials for patients and can enable them to signpost appropriately to where they can find further information.

ID	Stakeholder	Statement number	Comments[1]
			Improvements/overcoming barriers: With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services. This helps ensure they deliver best practice and meet local need effectively. For example, this will help ensure that appointments are of a suitable length and that there are enough MS specialists for people with MS to be seen in a timely and appropriate way.
	Novartis Pharmaceuticals UK	Statement 1	***Adults with MS are supported by the consultant neurologist at the time of diagnosis to understand the condition, its progression and the ways it can be managed*.** We support this quality statement and believe it reflects the key area for quality improvement – a patient should be seen by a consultant neurologist with a specialist interest in MS. However, we would also like to see greater recognition of the role that MS specialist nurses can also play in managing MS. Currently, there is varying access to specialist medical expertise – in some areas MS patients are managed by general neurologists who cannot initiate some of the NICE approved medicines for patients with MS. Early access to effective therapies is critical for people with MS to minimise relapses and irreversible disability and therefore retain quality of life. For example, the MS Society found that people who see a MS nurse or neurologist are more than twice as likely to take DMTs as those who do not. We do believe it would be possible to collect data for this proposed quality measure as you suggest via local data collection which would look at the proportion of adults with MS who are given information about their condition by the consultant neurologist at the time of diagnosis. The key barrier to this quality statement is the lack of neurologists in the UK. There are under 200 neurologists treating MS and less than 250 MS nurses for a 64 million population. Both these numbers would need to increase significantly to meet this target. There would also need to be clarity on commissioning changes - in particular reassurances that collaborative commissioning will not result in even greater regional variation, including variable access to specialists, driven by financial incentives.
	UKMSSNA	Statement 1	This quality standard appears to conflate two issues –that of a diagnosis being provided by a Consultant Neurologist and that of appropriate information and support being offered at the time of diagnosis by the Consultant. As a result the quality standard does not seem to accurately reflect the key area for quality improvement or align with NICE CG186 Recommendation 1.1.6 (key priority for implementation)- people suspected of having MS should be referred to a Consultant Neurologist for early diagnosis. The quality statement fails to address the concern of those responding to the engagement exercise that the time from

ID	Stakeholder	Statement number	Comments[1]
			suspecting MS to diagnosis is too long. This concern was demonstrated to be one of relevance and importance through evidence provided by the stakeholders. New evidence in the National Audit Office Report “Services for people with neurological conditions: progress review” published in July supports our view that this is an area of concern. The median waiting time for all NHS patients from GP referral to Consultant led care is 5 weeks whereas in neurology the median waiting time is 7.9 weeks. This demonstrates an unacceptable inequity in service provision. Shortening this wait would reduce the anxiety and frustration arising from a lack of diagnosis and a clear treatment plan. We suggest that the statement should read “Adults with a presentation consistent with MS should be referred to a Consultant Neurologist to ensure a prompt diagnosis. Appropriate information and support to understand the treatment options available should be provided by the Consultant Neurologist at the time of diagnosis.” This offers a greater potential to improve the quality of service at diagnosis and meets 2 of the key priorities for implementation in the Clinical guidelines. (1.1.6 :Diagnosis by a Consultant neurologist, and 1.2.2 : Information at time of diagnosis) The current statement does not explicitly state that the Consultant Neurologist should be the person making the diagnosis and suggests that it will be possible at the time of diagnosis to understand the “progression” of the disease. It may not be possible to predict the disease progression during this consultation as this is a picture that will evolve over time. The Association of British Neurologists (ABN) in their “Guidelines for prescribing disease modifying treatments in MS” (2015) underline this point. “In the individual patient, MS remains a fundamentally unpredictable condition. There are many factors that influence prognosis and disease course.” Rationale MS is a long term condition and early diagnosis with access to disease-modifying therapies clearly impacts upon the life chances and the choices that an individual makes. The rationale for early diagnosis by prompt referral to Consultant Neurologist is not only that the person should be “less anxious” and have more of “a sense of control.” when faced with the diagnosis. Early treatment is also associated with better outcomes so that the ABN recommend starting treatment as early as possible in eligible patients. To achieve this there must be timely access to a Consultant Neurologist. Quality measures Structure

ID	Stakeholder	Statement number	Comments[1]
			The collection of data to demonstrate adults with MS were given information about their condition at time of diagnosis would not necessarily indicate a significant improvement in the way the service was delivered as this could be achieved by the use of leaflets and written information that would not measurably increase the quality of the support experienced by the individual. Therefore patient experience will need to be evaluated to determine if the information and support has been helpful. Waiting time from Primary Care referral to Consultant led care is data that is already collected. Additional local data collection from time of first appointment to diagnosis would add significant information that could drive up service quality. For example it would highlight if there were long delays for follow up appointments or for accessing scans/ diagnostics. <u>Process</u> A more meaningful process measure would be: "Proportion of adults with MS that wait for longer than 8 weeks from referral to Consultant Neurologist to receiving a diagnosis and management plan." This is in line with the NHS Cancer target and would reduce the period of limbo between referral and diagnosis. The numerator would be the number in the denominators who were seen with a diagnosis and given a plan within the target time and the denominator would be individuals with a new diagnosis of MS. <u>Data source</u> It would be possible to collect data for the proposed quality measure. The data collection would need to reflect the quality of the information provided as well as the nature of the information provided and would therefore need to include patient outcomes as well as numerical measures. The UKMSSNA supports the collection of data as part of the process of identifying need and evaluating services. However the systems to do this need to be adequately resourced by service providers through commissioning arrangements. If they are not there may be additional pressures on stretched services that will impact upon the quality of the patient experience. <u>What the quality statement means for Commissioners</u> In order to support these improvements Commissioners need to resource the development of shared systems of data collection to avoid double counting and embed the process in clinical practice. Further development of Local Neurological Networks would help to support the Quality standards and help to overcome organisational barriers. <u>Definition of terms used in this quality statement support</u> Consultant Neurologists that work from tertiary centres see individuals from many different areas. They may not be familiar with local services but they could provide the contact details for the local single point of contact so that this

ID	Stakeholder	Statement number	Comments[1]
			information could be ascertained locally.
	Roche Products Limited	Statement 1	The proposed Quality Statement is less specific than recommendation (1.2.2) on which it is based [1] – specificity is needed to facilitate local data collection and to add a clear qualitative dimension to the measure. We would suggest rewording as follows: *Adults with MS are supported by a consultant neurologist at the time of diagnosis so that they and, with agreement, family members or carers, receive written and verbal information about their condition, its progression, the ways it can be managed and support options in the local area.* [1] NICE, *Multiple sclerosis: management of multiple sclerosis in primary and secondary care*, CG186, October 2014.. Definition of terms To be consistent with the Clinical Guideline [1], it should be made clear that support should be personalised and not limited to the stated list. In our opinion, a structured education programme would be preferable. In addition, the Association of British Neurologists (ABN) state the importance of shared conversations about disease activity, risk and benefit, to make the choice that is right for the individual and their circumstances. [2] [1] NICE, *Multiple sclerosis: management of multiple sclerosis in primary and secondary care*, CG186, October 2014. [2] Association of British Neurologists, *Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis,* Pract Neurol, June 2015. Suggestions to support improvement and help overcome barriers A written personalised care plan will help those with MS, their family and carers reflect, retain and act on the information provided by the consultant neurologist at the time of diagnosis. Roche agrees with the ABN that people with MS are best supported by neurologists with specialist experience of managing patients with MS. [1] [1] Association of British Neurologists, *Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis,* Pract Neurol, June 2015.
	Teva UK Limited	Statement 1	There needs to be consistency in the quality and scope of the materials provided from centre to centre. How will patient satisfaction be meaningfully evaluated? In addition to the comments for Q1 above, would advocate development of a national register for MS patients. A discussion of treatment options should be included within the scope of the support provided here.
	Salford Royal NHS Foundation Trust	Statement 1	• We feel that this QS encompasses 2 important components: the diagnosis and information & support at time of diagnosis, so there needs to be very clear elements to this QS to encompass both. • We feel that the statement needs to be more robust to state that it is the Neurologist who imparts the

ID	Stakeholder	Statement number	Comments[1]
			diagnosis as the current statement of "Adults with MS are supported by the consultant neurologist at the time of diagnosis" we feel under values this important aspect of care. • **We feel that it is important that continuity of care is essential at this crucial time, in that it should be the same neurologist at the initial consultation that is giving the test results with the diagnosis** • However, with respect to information as most patients will be diagnosed by general neurologists whose experience, expertise and views in MS in respect to current trends, care & treatments etc may vary, so they are not always the best person to be imparting information at this crucial time. This aspect of the QS and QS 2 are very closely interlinked and we feel this is the crucial time frame that needs to be very clearly defined and stated. • A step before this though, is to state that all patients suspected of having MS have a timely referral to a Consultant Neurologist, and a time frame for this to occur attached, this would ensure that it would be a Consultant Neurologist imparting the diagnosis. Given that the emphasis of treating early in MS is now accepted and as such the referral process into services need to be improved. The time frame from seeing the neurologist to diagnosis may be difficult to have a specific time frame attached due to the variability of presentation, the wait for clinical investigations (particularly the carrying out and reporting of MRI scans) within the time frame, due to other demands on the service. The gold standard would be as in cancer, however, there would need to be significant investment from commissioners for all aspects of services involved. • With respect to the aspect of information giving at this point, again clarity is needed as this will be very variable and in turn difficult to measure. A caveat to this is that patients vary as to the degree of information they want (if any) at this point so there needs to be a "basic" information requirement that is then tailored to the patients individual wishes. Very closely linked to this is QS2 where in reality most of the information giving will take place, as stated above.
	University Hospital Birmingham	Statement 1	General There are a number of issues around this standard. 1. Capacity issues with Consultant Neurologist clinics, both access to the services ie waiting times and allocated time in clinic ie 20 – 30 mins. This clearly is not sufficient time to cover all of the aspects indicated. It does not include possible delays for 2nd opinions, MRI scans not being sent in advance or other essential information. Statement Clarification is required as to who should make the diagnosis ie Consultant Neurologist. Ratonale

ID	Stakeholder	Statement number	Comments[1]
			There is a need to emphasise early access to treatments. A timely referral for diagnosis is required whether treatments are required or not. <u>Quality measures</u> <u>Structure</u> Data collection is an essential aspect, however, the current tools used are very variable with no gold standard ie Somerset used in cancer services. <u>Data source</u> The need to collect data is essential and evident through the MS Trust GEMS project, however, due to capacity issues this is not always met. <u>What the quality statement means for Commissioners</u> A wide range of tools are used across the country with no gold standard being available. Admin support needs to be incorporated into any structure, which is often lacking. <u>Definition of terms used in this quality statement: Support</u> Some Consultant Neurologists provide a regional service. it would be impossible for them to have and maintain up to date knowledge of those services. Quality Statement 2 is an essential follow on to this one.
	British Medical Association	Statement 2	We agree that it should be acknowledged that people with MS could forget their appointments, due to the wide range of difficulties they experience, and should thus be reminded before hospital appointments and followed up if they do not attend. We believe that the secondary care should be responsible for this, and in such cases the patient should not be discharged and sent back to the GP for a further referral.
	Biogen	Statement 2	Ensuring follow-up for patients after diagnoses is an important part of the patient journey in MS. In order for patients to fully benefit from this Quality Standard, the patient pathway needs to be mapped out following an integrated approach across health and social care. For example, how will care for patients in social care be linked to health? Further clarity is needed around the measurement of this Quality Statement; who is responsible for collecting these data and the associated metrics; and whether these data will be published and thus be made publicly available. It will also be important to ensure a national review on performance and within local areas is undertaken to evaluate the effectiveness of the Quality Standard. Biogen feels that it is important for the Quality Statement to align with NHS Outcomes Framework and The Adult Social Care Outcomes Framework.
	NHS England (& Association of British Neurologists)	Statement 2	This statement needs to be more specific and define the healthcare professional. We would support it being a neurologist with a specialist interest in multiple sclerosis or a MS clinical nurse specialist. The latter needs to be supported by recommendations regarding appropriate staffing levels, e.g. the maximum number of people with MS

ID	Stakeholder	Statement number	Comments[1]
			per clinical nurse specialist and full time equivalent neurology posts. We would recommend that this statement is linked to a metric with an acceptable variance that can be audited to assess the quality of individual MS services.
	The MS Trust	Statement 2	The MS Trust would like to see this statement revised to: Following diagnosis, all adults with MS are contacted by an MS specialist nurse and receive a face-to-face appointment within one month. Rationale The MS Trust would encourage NICE to take this opportunity to further clarify the Clinical Guideline by stating that all PwMS should see a MSSN for a follow-up appointment after diagnosis. We also consider that six weeks is too long for an aspirational quality statement, and that the timeframe should be shortened to one month. We would suggest that the quality statement leaves local teams the flexibility to decide how initial contact following diagnosis is made, but sets a deadline of one month from diagnosis to follow-up. In the responses to our survey, when asked who the most helpful health professionals are in helping you to learn about MS, over 95% picked the two core roles of MS neurologist and MS specialist nurse, with more than half of these ranking their MS nurse as their first preference. Helping PwMS understand about their MS, how it may affect them, and how it can be managed is a core part of the work of MS nurses. Data to be published in the final report of the MS Trust GEMSS project shows that MSSNs are the most consulted professional about MS. 78% of GEMSS patient survey respondents (n= 1,254) had consulted their MS nurse at least once in the past year. When asked what, if any, difference the MSSN service made to them over the past year the most frequently reported benefits were information and education on MS, advice on physical symptoms on MS, emotional support, and advising on medications. PwMS overwhelmingly have trust and confidence in their MSSN, with over 95% of GEMSS survey respondents agreeing. Within the GEMSS project, local teams set themselves a target of between 10 to 20 working days for the specialist nurse to make contact with newly diagnosed patients. Most teams met their targets. This is in line with the quality standards in Scotland where Standard 15.2 states that ‘Contact with a clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of the diagnosis.’ A more challenging target of one month for contact and follow-up might help stimulate quicker and greater improvement in this area. http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf If likely to be eligible for DMDs, the person with MS will also need to see a neurologist who can prescribe. Ideally, this

ID	Stakeholder	Statement number	Comments[1]
			should happen at the follow-up appointment, either through holding a joint appointment or for the neurologist to be available at the end of the appointment with the specialist nurse. As a minimum there should be a defined timescale to see the neurologist. Service barriers The experience of services taking part in GEMSS is that delays between diagnosis and being seen by a specialist nurse are only partly because of MS nurse capacity. Administrative support to both neurologist and MS nurses is key to address common delays in referral letters being typed and sent. Delays in the local specialist nurse receiving referrals have been cited as a barrier in Scotland where a quality standard on follow-up already exists. This issue has also been raised by participants in the GEMSS programme and by respondents to our survey. Capacity is a significant service barrier. Between one-third to a half of respondents to our survey said their service would not currently be able to meet the 6-week target for follow up appointments. Quality measures: The MS Trust recommends including the following quality measures: • Length of time between being seen by the neurologist and referral being received by the MSSN service; • % of newly referred patients who receive a comprehensive assessment by the MSSN within one month of diagnosis. • We also recommend adding a patient satisfaction measure within a regular patient survey programme.
	Multiple Sclerosis Society	Statement 2	**Comment:** We welcome this quality statement. As explained in our response to quality standard 1, the 6 week follow up appointment is crucial to ensure information is provided effectively and that the management plan continues to develop. An MS nurse's knowledge of the condition, accessibility and place within the MDT makes them well placed to conduct the 6 week follow up appointment. Local services must be designed to ensure all patients have access to an MS nurse and that the appointment is of an appropriate length to ensure that the range of information can be given fully and any questions or concerns addressed effectively. **Data collection:** This statement is measurable in a variety of ways. Locally administered surveys of patient experience should collect data on the 6 week follow up appointment. Local data should also be collected regarding referrals made for a 6 week follow up appointment, MS nurse caseloads and number of management plans created

ID	Stakeholder	Statement number	Comments[1]
			for people with an MS diagnosis. **Improvements/overcoming barriers**: patient organisations such as the MS Society provide high quality, patient friendly information materials. More collaborative work across sectors would ensure that clinicians have suitable information materials for patients and can enable them to signpost appropriately to where they can find further information. **Improvements/overcoming barriers:** With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services. This helps ensure they deliver best practice and meet local need effectively. For example, this will help ensure that appointments are of a suitable length and that there are enough MS specialists for people with MS to be seen in a timely and appropriate way.
	Novartis Pharmaceuticals UK	Statement 2	***Adults with MS are offered a follow up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis.*** We do not support this quality statement because it lacks clarity and detail. Whilst we agree adults with MS need to be offered a follow up appointment, the quality statement needs to define with whom, specifically, this is with and justify the timeline that the follow up is given in. We recommend that the quality statement is amended to clearly state that the follow up appointment with either a specialist neurologist or a MS specialist nurse and feel that a shorter timeline would be appropriate, particularly where there is growing emphasis on the early treatment of MS to optimise long term outcomes. The terminology as it stands is too loose and could be open to interpretation. Further, patients also need greater clarity on what the follow up appointment will achieve. For example, is it to ensure successful targeting of social care resources? Is it to ensure appropriate physiotherapy appointments are made? Is it to consider the initiation of DMTs? We believe without this level of granularity, the quality standard will not best serve the patient's interests of ensuring rapid diagnosis and follow up support. This level of detail is particularly important because 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 DMTs is likely best undertaken by a MS specialist neurologist or MS specialist nurse. There are 10 licenced DMTs with different forms of delivery and monitoring that need to be matched to the individuals' eligibility, motivation and lifestyle. We do believe it would be possible to collect data for this quality statement as you suggest by providing evidence of

ID	Stakeholder	Statement number	Comments[1]
			local arrangements to ensure that adults with MS have a follow up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis. As with quality statement one, the key barrier to achieving this quality statement is access to specialists to conduct the follow up appointments.
	UKMSSNA	Statement 2	This quality statement specifies that the 6 week follow up appointment should be with a healthcare professional with expertise in MS. We support the need for timely follow up of newly diagnosed patients and agree that it is an area that would be improved by the development of this standard. We support the 6 week time scale but have concerns that there are barriers that will need to be overcome to reach this target. For example: Diagnosis may be made by a general neurologist with the follow up appointment to discuss treatment options being provided by an MS Specialist Neurologist. In some areas the referral on has to be made by the GP adding one more hand off to the pathway and exacerbating delay. Similarly problems may arise if the person is diagnosed in a tertiary centre and the follow up is expected to take place in primary care. In this case there are two potential problems. The first is a delay in communication from one area to the other, often caused by slow processing of letters. This delay may impact upon the ability of the specialist nurse to make an appointment within the time frame because MS Specialist Nurses working in primary care are often working alone and rarely have “cover” for their service during periods of leave. The second issue is that of capacity. The increasing demand for outpatient appointments generated by the need to monitor individuals who are receiving disease modifying medications has left little capacity to accommodate extra appointments on an ad hoc basis. Commissioners will need to ensure that they fund MS Services that are sustainable with a manageable case load. Currently there is an estimated shortfall of 62.3 whole time equivalent MS Specialist Nurses nationally (Mynors G and Bowen A, 2014, MS Specialist Nursing in the UK 2014: *The case for equitable provision*. MS Trust Publication) These are barriers that could be overcome with the organisational will to do so. We also have concerns that the statement may have unintended consequences. By specifying the need for access to expertise within the first 6 weeks without signifying the need for ongoing specialist support, there may be a shift in resources from longer term provision to early management. If organisations concentrate resources at the point of diagnosis without adding any capacity this will have the unintended consequence of disadvantaging services offering on-going specialist support throughout the disease trajectory. The need of the person living with MS for expert guidance and information continues to evolve and change over time and encompasses disease management and life choices. It would be helpful therefore if either Quality Standard 2 or Quality Standard 3 reflected the need for ongoing access to this specialist resource.

ID	Stakeholder	Statement number	Comments[1]
			We suggest adding a statement such as " Thereafter further opportunities for discussion and information giving should be made available through follow up appointments and telephone contact." <u>Rationale</u> "This means they have time to adjust to their diagnosis…" it might be more accurate to refer to adjustment as a process not a single event. Individuals living with MS experience many episodes of change and adjustment caused by the succession of losses they experience throughout the course of the illness. There will be other periods of adjustment, triggered by loss of independence in walking or loss of ability to care for a child that require further advice and support. We suggest the following wording be used instead "This gives them time to recover from the shock of diagnosis and consider the information they have already been given. Access to a specialist enables them to clarify matters that they didn't understand and ask any questions they may have about the future." <u>What the quality statement means for patients, service users and carers</u> The sentence that ends with "…the opportunity to have any questions answered by a healthcare professional with experience in MS." Should be changed to "a Neurologist MS Specialist, MS Specialist Nurse or equivalent AHP MS Specialist." to be consistent with the terms used in the rest of the statement. <u>Definitions</u> We welcome the inclusion of MS Nurse in the definition of "healthcare professional with expertise in MS" We believe that this quality statement needs to be delivered by either a Neurologist with special interest in MS or a Specialist Nurse (or Therapist with appropriate knowledge of DMTs) in MS but feel this should be explicitly stated in this quality statement.
	Salford Royal NHS Foundation Trust	Statement 2	We fully support the need for timely follow up of newly diagnosed patients and agree that it is an area that would be improved by the development of this standard. This quality statement specifies that the 6 week follow up appointment should be with a healthcare professional with expertise in MS. Logistically there are things that needed to be taking into consideration about the achievement of this QS: • Referral pathways differ that will influence this being achieved. i.e. if someone who is seen and diagnosed within a tertiary centre is then referred to the "healthcare professional with expertise in MS" who is based within a community setting, this can often take longer to achieve. Plus if this person is a "lone worker" and when off, the service is not covered then this also needs to be factored in. **We feel that an aspect of the QS that needs to be stated is that all patients diagnosed with MS are referred to the "healthcare professional with expertise in MS" we welcome this being defined as "A neurologist or**

ID	Stakeholder	Statement number	Comments[1]
			another healthcare professional such as an MS nurse" but this needs to be very clearly stipulated within the QS - Even within neurology centres not all patients diagnosed with MS by general neurologists are referred to a "healthcare professional with expertise in MS"; this is often determined by the neurologist as the patient is "well" and they do not need any other input at that time. In this scenario the patients at this point are often not aware that there may be a "healthcare professional with expertise in MS" that they could be referred to. An "opt out" system rather than an "opt in" system for patients and neurologists alike should form part of the QS. - Referral pathways and requirements may be a hindrance to this being achieved, if once a diagnosis is made it is up to the GP to referrer to the "healthcare professional with expertise in MS" this adds often weeks at a time of high anxiety to the patient - Clinical letters are often not dicated/typed/sent within this time frame so again delaying the time frame. - Logistically there may not be a "healthcare professional with expertise in MS" within the immediate healthcare area for the patient**..** - There may very well be an issue of clinic capacity given the ever increasing demands on current MS nursing services for "monitoring" of newer treatments. - Diagnosis is one of many critical times within the pwms journey, and whilst we welcome the focus on this point it should not be at the detriment of any ongoing support throughout the disease trajectory.
	Royal College of Nursing	Statement 2	This would be hard to measure where neurologists refer to community based MS specialist nurses to follow up. When does the 6 weeks begin, bearing in mind that clinic letters can often take longer than this to reach community teams?
	University Hospital Birmingham	Statement 2	General There are a number of issues affecting this Quality Statement being met. 1. Delays in referrals made to the appropriate HCP. 2. Delays in the referrals being generated ie lack of admin support 3. Some external Consultant Neurologists cannot refer direct and have to request the GP makes the referral. 4. Delays in being able to review – ie lone workers, annual leave, sick leave, capacity issues, Statement Would suggest changing this to 'to take place within 6 weeks of the referral being received' Rationale The 'adjustment' to a diagnosis is not straight forward neither is the process of taking on board the information provided at that time. For some this process may be achieved for others this is delayed, particularly if the recovery of

ID	Stakeholder	Statement number	Comments[1]
			a recent relapse is ongoing. <u>What the quality statement means for patients, service users and carers</u> This process is an ongoing one, not just at diagnosis.
	Teva UK Limited	Statement 3	Needs to be clear who this single point of contact is – for consistency, should be same function (e.g. MS Nurse) for every MS patient
	MacGregor Healthcare Limited	Statement 3	Strongly agree that the provision of continence assessment and advice is critical. In particular bowel assessment - Utilising the Royal college of surgeons commissioning guide for faecal incontinence (2014) pathway. Where appropriate rectal irrigation should be offered to prevent faecal incontinence and constipation.
	The British Association of Prosthetists and Orthotists (BAPO)	Statement 3	The draft guidance provides a list of professionals 'who can best meet the needs of the person with MS'. BAPO note that this list omits the orthotist and his/her unique skill set. BAPO provide the following definition of an orthotist: 'Orthotists are autonomous registered practitioners who provide gait analysis and engineering solutions to patients with problems of the neuro, muscular and skeletal systems. They are extensively trained at undergraduate level in mechanics, bio-mechanics, and material science along with anatomy, physiology and pathophysiology. Their qualifications make them competent to design and provide orthoses that modify the structural or functional characteristics of the patients' neuro-muscular and skeletal systems enabling patients to mobilise, eliminate gait deviations, reduce falls, reduce pain, prevent and facilitate healing of ulcers. They are also qualified to modify CE marked Orthoses or componentry taking responsibility for the impact of any changes. They treat patients with a wide range of conditions including Diabetes, Arthritis, Cerebral Palsy, Stroke, Spina Bifida, Scoliosis, MSK, sports injuries and trauma. Whilst they often work as autonomous practitioners they increasingly often form part of multidisciplinary teams such as within the diabetic foot team or neuro-rehabilitation team.' The use of orthoses in cases of MS is well documented(1-5). BAPO believe that through provision of orthoses (splints, braces, calipers, insoles, collars and footwear) to people with MS to be a regular practice and advocate the role of such devices in maximizing function, mobility and balance whilst preventing deformity, managing spasticity, controlling pain and limiting the energy costs of walking. Furthermore, there is evidence to support adopting an individualised approach to prescription of orthoses to people with MS as their may be several options available and the most appropriate may be more easily identified through discussion of patient preference and experience(6). Given the Orthotist's unique skill set BAPO champions the role orthotist as the best placed healthcare professional to provide orthotic care for people with MS and as such consider orthotists to be an important member of the multidisciplinary team. Citations:

ID	Stakeholder	Statement number	Comments[1]
			1. Bregman DJJ, Harlaar J, Meskers CGM, de Groot V. Spring-like Ankle Foot Orthoses reduce the energy cost of walking by taking over ankle work. Gait & Posture. 2012;35(1):148-53. 2. Bregman DJJ, van der Krogt MM, de Groot V, Harlaar J, Wisse M, Collins SH. The effect of ankle foot orthosis stiffness on the energy cost of walking: A simulation study. Clinical Biomechanics. 2011;26(9):955-61. 3. Donzé C. Update on rehabilitation in multiple sclerosis. La Presse Médicale. 2015;44(4, Part 2):e169-e76. 4. McLoughlin JV, Lord SR, Barr CJ, Crotty M, Sturnieks DL. Dorsiflexion Assist Orthosis Reduces the Physiological Cost and Mitigates Deterioration in Strength and Balance Associated With Walking in People With Multiple Sclerosis. Archives of Physical Medicine and Rehabilitation.96(2):226-32.e1. 5. Wening J, Ford J, Jouett LD. Orthotics and FES for maintenance of walking in patients with MS. Disease-a-Month. 2013;59(8):284-9. 6. Bulley C, Mercer TH, Hooper JE, Cowan P, Scott S, van der Linden ML. Experiences of functional electrical stimulation (FES) and ankle foot orthoses (AFOs) for foot-drop in people with multiple sclerosis. Disabil Rehabil Assist Technol. 2014.
	British Medical Association	Statement 3	The quality statement states that "Service providers (GPs and secondary care neurology services) ensure that processes are in place for adults with MS to have a single point of contact to co-ordinate access to care from multi-disciplinary services." We believe that in this statement GPs should be replaced by 'Commissioners of Primary Care' as it is not within the daily responsibilities of GPs to ensure that such processes are in place.
	Biogen	Statement 3	Biogen feels that co-ordinated care is an important Quality Standard for MS patients and would like to understand how does NICE envisage this Quality Standard evolving as plans for integrating health and social care advance across England?
	NHS England (& Association of British Neurologists)	Statement 3	We agree with this metric but would encourage the statement to be more specific in relation to point of contact. At present it could refer to a telephone messaging service, email account or online e-medicine portal. We would encourage this to be a named healthcare professional, preferably a MS clinical nurse specialist. We would also encourage the quality guidance to define what is meant by a multi-disciplinary service; the statement needs to be specific about the minimum requirements. We would recommend that this statement is linked to a metric with an acceptable variance that can be audited to assess the quality of individual MS services.
	The MS Trust	Statement 3	The MS Trust would like to see this statement revised to: Adults with MS have a single named health professional to co-ordinate access to the care and support they need from multi-disciplinary services.

ID	Stakeholder	Statement number	Comments[1]
			Rationale The MS Trust agrees that a single point of contact is important to include. However, we would like to see the statement specify that the point of contact must be a qualified health professional from within the multi-disciplinary team. This should be a health professional with expertise in managing MS, as the single point of contact will need a deep understanding of MS in order to exercise clinical judgment about the relevance and importance of different symptoms and to make appropriate referrals or case management decisions. Health professionals and people with MS responding to our survey were agreed that the best-placed person to act as the single point of contact is the MS specialist nurse. However, a range of other options, including MS neurologists and neuro-specialist AHPs, were considered suitable depending on the person's specific needs and point in their disease trajectory. The MS Trust acknowledges that flexibility may be beneficial, but in practice it is likely to be the MS specialist nurse who takes on this role in the majority of cases. While we were pleased to see a reference to the need for a multi-disciplinary team, the MS Trust would like to see a separate quality statement on the need for every person with MS to receive care from a co-ordinated multi-disciplinary team which can be audited separately. The issue of having a named person to help co-ordinate care and the issue of whether the multi-disciplinary service that a person with MS may need actually exist within an area are very different, and we believe conflating them in one quality statement emphasises the more easily measurable single point of contact standard at the expense of a focus on ensuring everyone with MS has access to the multi-disciplinary services they need. There should be a measure of whether the service has been accessible and responsive when contact is made by the person with MS. Within the GEMSS programme teams work to a KPI of 2-3 working days for the MS nurse to respond. Ability to meet this target was mixed (between 40%-90%). Services staffed by a lone, part-time nurse found it most difficult to meet the target. Quality measures The MS Trust recommends including the following quality measures: • % of people diagnosed with MS know who their point of contact is; • The measure could be % of incoming phone calls from patients responded to within 2 working days; • We recommend adding a patient satisfaction measure within a regular patient survey programme.
	Multiple Sclerosis Society	Statement 3	**Comment:** We welcome the inclusion of the single point of contact to co-ordinate access to care from multi-disciplinary services as people with MS can find it difficult access a specialists. As we detailed in our response to

ID	Stakeholder	Statement number	Comments[1]
			topic engagement, an MS Society survey of ~8,500 people with MS in England found that: 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). 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) MS Society (2013). A lottery of treatment and care – technical report http://www.mssociety.org.uk/sites/default/files/Documents/Research/A lottery of treatment and care - technical report.pdf The single point of contact should help provide a responsive and holistic package of care for people with MS. However, its utility is contingent on local services being designed appropriately. People with MS must be able to access a full multi-disciplinary team (MDT) of MS specialists (e.g. MS Specialist neurologist, neuro-physiotherapist specialising in MS, MS nurse) to ensure people with MS receive the best care and treatment across the duration of their life. **Comment:** 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 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. Other specialists such a continence advisor or neuro-physio may also be appropriate depending on a person’s needs. A GP should not undertake this role. **Data collection**: This statement is measurable in a variety of ways. Data should be collected from locally administered surveys of patient experience of the single point of contact and accessibility of services. Data must also be collected regarding number of management plans with a named single point of contact and regarding local service design including the members of the multidisciplinary team; caseloads of the point of contact; referral records from single point of contact to members of the MDT and waiting times for referrals.

ID	Stakeholder	Statement number	Comments[1]
			Improvements/overcoming barriers: With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services. This helps ensure they deliver best practice and meet local need effectively. For example, this will help ensure that people with MS receive support from the most appropriate person and that there are enough MS specialists for people with MS to be seen in a timely and appropriate way.
	Novartis Pharmaceuticals UK	Statement 3	***Adults with MS have a single point of contact to co-ordinate access to care from multi-disciplinary services.*** We support this quality statement and believe it reflects the key area for quality improvement. A multidisciplinary approach to treating MS leads to improved health and work outcomes. An approach that includes physical, psychological and vocational support has been proven to be more effective than focusing on one treatment in isolation. However, evidence suggests that across the NHS the treatment of MS is not well integrated and there are gaps in the provision of specialist care. We believe the single point of contact should also be clarified in this quality statement and the most appropriate person to be this single point of contact would be a specialist MS nurse. We believe that it would be possible to collect data for this quality statement as you suggest by providing evidence of local arrangements to ensure that adults with MS have a single point of contact (an MS specialist nurse) to co-ordinate access to care from multi-disciplinary services via local data collection. The barriers to achieving this quality statement would be the lack of integration between health and social care and the fact that many people with MS suffer from co-morbidities, which makes a single point of access for managing their condition a challenge. In addition, there is a lack of integration between primary and secondary care. This leads to potential symptoms indicating disease progression and/or relapses not being communicated to the specialist team.
	UKMSSNA	Statement 3	We agree that a single point of contact to coordinate access to care has the potential to significantly improve the experience of people living with MS. However the statement needs to clearly articulate the quality of the service providing the contact and coordination in order to meet the aim of driving up standards in service provision. While it is possible for the individual manning the telephone to be clerical in the first instance we do not believe the role of responding to requests and coordinating services could be undertaken safely by anyone other than a clinician with expertise in MS. This is because in order to establish the correct appropriate advice or select a service to meet the individual's needs clinical assessment reasoning and judgement need to be exercised. Currently MS Specialist Nurses fulfil this role, sometimes without the benefit of clerical support. They provide valuable continuity of care for the person living with MS. As the quality statement is currently written it would be possible for providers to subsume the existing services into a hub or single point of access that deal predominantly with less complex conditions. This could diminish rather than

ID	Stakeholder	Statement number	Comments[1]
			improve the quality of the service provided. It would also put the onus on the caller to give a full and accurate medical history and presenting problem, rather than relying on the operator to illicit the information needed to exercise their clinical judgement. The term single point of contact does not describe the service only the access to it. Making appropriate onward referrals and coordinating care is a function of case management. We suggest it may be clearer to write: “Adults with MS will be provided with a single point of contact to access specialist advice and case management.” Rationale A single point of contact will not necessarily ensure access to “health and social care practitioners to meet their specific needs”. This will be dependent upon the expertise of the person managing the single point of contact and their knowledge of the resources and help that is available. Quality measures Structure The evidence of local arrangements needs to include evidence of the quality of the support offered by the single point of contact. For example someone “who can provide advice and support while exercising clinical judgement to assess need and coordinate appropriate interventions from multi-disciplinary services.” Process In order to measure the improvement in the quality of the process it would be more meaningful to collect data on the responsiveness of the service ie speed of access to a clinician with expertise in MS who can coordinate the appropriate response. For example the number of phone calls responded to within 2 working days. The denominator in this process is the number of adults with MS but evidence suggests that local data to determine the true prevalence of MS in different areas is very scarce this may impede accurate data collection. Outcomes Satisfaction with the coordination of care will not necessarily arise from the access to a single point of contact although there may be a correlation with these arrangements. Possible confounding factors would include a lack of appropriately skilled clinicians and a lack of capacity to meet local need. What the quality statement means for commissioners The wording of this section is not specific enough to bring about the desired improvement. There needs to be specific reference to the expertise that will be available through the single point of contact. It may be helpful to add in this

ID	Stakeholder	Statement number	Comments[1]
			section that the capacity to meet the needs of the local MS population will need to be monitored in order to take into account the local geography and configuration of health and care services. The additional information may be included as: "…ensure that they commission services that have a single point of contact with clinical expertise in MS and the capacity to coordinate access to care from multi disciplinary services. Definition of terms used in this quality statement The inclusion of specialist clinicians in the definition of the term multi-disciplinary services is welcome but should be expanded to include Specialist Therapists (AHPs) as well as specialist nurses in MS. Similarly Consultants in Rehabilitation Medicine should be included as they offer valuable oversight in the management of primary progressive MS.
	British Association of Urological Surgeons	Statement 3	BAUS agrees that coordinated care is essential for patients with MS. Approximately 80% of patients with MS will develop urinary symptoms including incontinence, poor bladder emptying and infections. This is often complicated by immobility. It is suggested that each MS MDT have regular input from a named Urological Consultant with a special interest in neurourology who can provide advice and clinical input for affected MS patients when needed. It is suggested that an addition be made to Quality Statement 3 to ensure that MDTs have a pathway in place for the referral of MS patients with urinary problems, where necessary, to a named Urological Consultant with a special interest in neurourology.
	Roche Products Limited	Statement 3	Suggestions to support improvement and help overcome barriers Any member of a team undertaking the coordinator role should have appropriate knowledge of MS, its treatment and local pathways. Commissioners of services should recognise this need and the benefits associated with keeping those with MS in touch with the specialist multidisciplinary team and under the supervision of specialist MS neurologists and nurses. Medicines use can be optimised by encouraging adherence to an individualised monitoring protocol that enables the specialist MS team to assess treatment effectiveness and to document relapses. [1] Different models of care should be subject to audit against agreed guidelines and/or research that assesses appropriate patient outcomes. [1] Association of British Neurologists, *Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis,* Pract Neurol, June 2015.
	Royal College of General Practitioners	Statement 3	To include self referral after discharge
	Salford Royal NHS Foundation Trust	Statement 3	• We fully endorse the concept of a single point of contact but we feel that this needs to be further defined. There needs to be very clear processes in place for this single point of contact in terms of personnel,

ID	Stakeholder	Statement number	Comments[1]
			pathways, IT, competency. - Within an infrastructure there should be availability of pwms to contact the person at the single point of contact by varying communication (phone/ e mail/text). **However, we firmly believe that all communication should be directed to the MS personnel and not dealt with in a call centre situation, as in third parties not associated with the service.** - Key performance indicators should be set by services to monitor responsiveness of a service (GEMSS, MS Trust). - If the person is acting as a “triage” resource they should follow very clear protocols and competencies. - Often it is the MS nurse who deals with all communication from pwms, and have no administration and clerical support. If the person is a lone worker then there is often no cover at times of leave/ absence. - These initial point of contact often generates onward referral/ reviews and as such the QS needs to be quite clear that contact is not seen as a single entity, commissioners will need to invest in the whole pathway from a point of contact, personnel both initially and ongoing. Changes to many services configuration to achieve this would require investment.
	British Society of Rehabilitation Medicine	Statement 3	While it is laudable that the complexity of need for patients with progressive MS is recognised, there should, perhaps, be more directed guidance as to who could take on the responsibility for co-ordination of care. For patients with problems within the domains of spasticity, continence, pain and cognitive impairment, a physician in rehabilitation medicine is often best placed to address these needs directly and organise subsequent referrals efficiently and appropriately ensuring a smooth transition between services. Given that Patient feedback from the neurological alliance and the MS trust highlights the frustration of having atomised incoherent service delivery, the use of a rehabilitation medicine physician would significantly address this issue. The ability to work across inpatient and community settings is also an advantage of this particular professional group having a co-ordinating role for more complex levels of need. At very least, “Rehabilitation Medicine Specialist” should feature of the list of MDT professionals on page 15 of the document. In terms of measurement would suggest; “All adults with MS should have a named individual or team who takes responsibility for ensuring delivery of a multidisciplinary management plan”. It would also be worth thinking about outcomes rather than just processes. A very important indicator may be number of unplanned admissions for patients with progressive MS per population.
	Royal College of Nursing	Statement 3	This statement seems very hospital focused and bears no resemblance to community services across the country. Secondary care is often minimal for a number of people with MS. The statement requires further development and clarity to match the different services provided.
	University Hospital Birmingham	Statement 3	General The single point of contact is an essential quality statement.

ID	Stakeholder	Statement number	Comments[1]
			Statement There needs to be clearer definition on what the service should encompass. It is also essential that the single point of contact is a person with expertise in MS. Rationale There are limitations to this role and will require referrals to many healthcare professionals, depending on the level of disability or persons needs at any one time. Access to multi disciplinary services will vary from area to area. Quality measures Process There is a need to capture this essential data, however as detailed in statement 1, the current tools used are very variable with no gold standard. Outcome Satisfaction may not be met due to factors such as access to other HCP when managing symptoms, waiting times etc. What the quality statement means for commissioners Clarification is required first for this statement. Definitions of terms used in this quality statement The ‘single point of contact’ needs to be more clearly defined and should include expertise in MS.
	British Medical Association	Statement 4	The quality statement states that “Service providers (GPs, community health teams and secondary care neurology services) ensure that local pathways for managing relapse are in place so that adults with MS who have a relapse are offered treatment as soon as possible but within 14 days of the onset of symptoms.” We believe that in this statement GPs should again be replace by ‘Commissioners of Primary Care’ as it is not within the daily responsibilities of GPs to ensure that local pathways for managing relapse are in place.
	British Society of Neuroradiologists (BSNR)	Statement 4	The BSNR strongly supports any initiative or measure which improves outcomes and quality of life in this debilitating disease. This includes prompt diagnosis and treatment of relapses. The proposed 14 day timescale from symptom onset to treatment may involve the need for MRI scanning of the neuraxis to be performed urgently or within a few days. MRI services are already under considerable pressure from nationally rising demand across a broad range of clinical specialities including primary care. The ability to increase scanning capacity and respond to urgent requests is limited

ID	Stakeholder	Statement number	Comments[1]
			by both equipment and radiographer availability. A national under provision of radiologists and neuroradiologists is well recognised. • Guidance on when MRI scanning is and isn't necessary in a relapse would help to maximise the clinical contribution and cost effectiveness of MRI and to reduce unnecessary scanning. It should be recognised that adoption of any standard that increases the demand for MRI, especially urgent scans, will for many centres be difficult to deliver without a concomitant increase in funded scanner time, radiographic staff and radiologists.
	The Royal College of Radiologists	Statement 4	The Royal College of Radiologists (RCR) has seen and endorses the comment made by the British Society of Neuroradiologists (BSNR) on this draft quality standard *"The BSNR strongly supports any initiative or measure which improves outcomes and quality of life in this debilitating disease. This includes prompt diagnosis and treatment of relapses.* *The proposed 14 day timescale from symptom onset to treatment may involve the need for MRI scanning of the neuraxis to be performed urgently or within a few days.* *MRI services are already under considerable pressure from nationally rising demand across a broad range of clinical specialities including primary care. The ability to increase scanning capacity and respond to urgent requests is limited by both equipment and radiographer availability. A national under provision of radiologists and neuroradiologists is well recognised.* • *Guidance on when MRI scanning is and isn't necessary in a relapse would help to maximise the clinical contribution and cost effectiveness of MRI and to reduce unnecessary scanning.* *It should be recognised that adoption of any standard that increases the demand for MRI, especially urgent scans, will for many centres be difficult to deliver without a concomitant increase in funded scanner time, radiographic staff and radiologists."*
	Biogen	Statement 4	At the time of a patient presenting to their healthcare professional with a relapse, Biogen feels this may be an opportunity to review their current treatment with disease modifying therapies and discuss alternative options. It would be potentially favourable to specifically include this stipulation as part of the metrics for assessing this Quality Statement.
	NHS England (& Association of British Neurologists)	Statement 4	This should read advice within 48 hours and treatment within 7 days.
	NHS England (& Association of British Neurologists)	Statement 4	We disagree with this metric and don't think it is appropriate that someone with MS who is having a relapse is necessarily seen and offered treatment within 14 days. The severity of relapses are highly variable and therefore a service needs to be flexible enough to triage people with MS having relapses for an acute assessment and possible treatment.

ID	Stakeholder	Statement number	Comments[1]
			We would recommend that this statement is linked to a metric with an acceptable variance that can be audited to assess the quality of individual MS services.
	The MS Trust	Statement 4	The MS Trust would like to see this statement revised to: Adults with acute deteriorating symptoms (including suspected relapses) are contacted by a specialist MS service for assessment and appropriate management within 2 working days of alerting the service. Rationale The MS Trust disagrees with the emphasis of this statement, which risks prioritising treatment over proper assessment. The most important issue is to ensure, when people with MS experience new or worsening symptoms, that they have rapid access to assessment by a health professional with specialism in MS to diagnose whether they are having a relapse and to access appropriate treatment and rehabilitation. It is also important that this statement refers not just to relapse but to acute deteriorating symptoms in order to capture the breadth of need of people with different forms of MS, not just RRMS. The most pressing need is to identify what is causing a change in symptoms, and whether someone is having a relapse that needs treating. In Scotland, quality standard 16.2a states that 'patients with MS with suspected relapse have access to a relapse assessment clinic supported by a multi-disciplinary team within five working days of contact.' http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf We would support a similar approach in this quality standard. The MS Trust wants all people with acute deteriorating symptoms, including suspected relapses, being treated by a specialist MS service. Quality measures The proposed denominator of the number of relapses for adults with MS is not currently collected, and would be very difficult to collect. It is often not clear until after the fact if worsening symptoms were actually a relapse. The proposed outcome measure of unplanned hospital admissions for MS is extremely blunt, and we do not think it will help to measure the quality of relapse services. The proportion of unplanned admissions that are due to relapse is currently not defined in Hospital Episode Statistics, which only code an admission as 'MS'. These admissions could be due to a range of issues that are not relapses, such as bladder or bowel problems, or falls. To be fairer to services the quality measures should take the point of contacting the service, rather than onset of symptoms, as the starting point. It is not within the control of services how long a PwMS waits after the onset of symptoms before contacting the service, and they may enter the system at many different points (e.g. through their GP, phoning the specialist nurse service, through A&E).

ID	Stakeholder	Statement number	Comments[1]
			We recommend changing the quality measures to: • % of people with MS with acute deteriorating symptoms (including suspected relapses) contacted for assessment and appropriate management within 2 working days of alerting the service; • % who receive a comprehensive assessment by an MS specialist nurse or MS neurologist within 5 working days of alerting the service; • Length of time from contacting the service to be fully assessed and receive appropriate treatment and management; • We also recommend adding a patient satisfaction measure about the relapse assessment service within a regular patient survey program
	Multiple Sclerosis Society	Statement 4	**Comment:** The nature and severity of relapses are highly variable and therefore a service needs to be flexible enough to triage people with MS having relapses for an assessment by an MS specialist and possible treatment as required. Whilst steroids can bring symptomatic relief and be prescribed in primary care, people need to have access to an assessment by an MS specialist so they can access the full range of therapeutic interventions. For example, if someone is having a relapse, it may be suggestive that a person with MS should be starting or switching treatment with a disease modifying therapy, a matter than can only be dealt with by a neurologist or a consultant MS nurse. What should be done in the event of a relapse should be contained within the patient's management plan. Further definition of this statement is required for it to improve clinical practice in this area. **Data collection:** This statement is measurable in a variety of ways. Data should be collected from locally administered surveys of patient experience of relapse management. Other metrics should be developed on definition of the local service. **Improvements/overcoming barriers**: With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services for relapses. What to do in the event of a relapse should be contained within a person with MS's management plan.
	Novartis Pharmaceuticals UK	Statement 4	***Adults with MS who have a relapse are offered treatment as soon as possible but within 14 days of the onset of symptoms*** We support this quality statement but would ask for clarification about how the 14 day timescale has been arrived at and query whether a shorter period would be beneficial to patients. We would also want it to be specified that a

ID	Stakeholder	Statement number	Comments[1]
			relapse should also trigger review of disease modifying therapy as it is indicative of poorly controlled disease. As you state in your draft consultation, rapid treatment of relapse can improve recovery and long-term outcomes of people with MS and prevent unnecessary unplanned hospital admissions so a shorter timescale for review post relapse would be preferable. In addition, the quality standard should note that a relapse should also trigger a review of social care provision and a review of DMT. This is because clinical relapse is a marker of disease activity in MS 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 to what constitutes best practice in relapse management. 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. Some doctors seem to be accepting relapses as inevitable without considering alternative treatments, which could have catastrophic effects on health, finances & family life. The quality statement to define the timescale and process for managing relapses could therefore have a significant impact on life with MS. We believe it would be possible to collect data for this quality statement from evidence of local pathways to ensure that adults with MS who have a relapse are offered treatment as soon as possible but the agreed timeframe from the onset of symptoms The key barrier to achieving this quality statement would be to ensure that patients and clinicians are properly aware of the symptoms of relapses so that action could be taken in a timely manner. It would also be necessary to ensure there are sufficient neurologists and MS specialist nurses available to carry out a review within an agreed timescale. The utilisation of apps and education of patients to recognise, record and report relapses will support the implementation of this standard.
	Merck Serono Ltd	Statement 4	Merck Serono propose that there is more clarity around the definition of relapse within Statement 4 and that there is alignment with other clinical guidance to enable patients to receive appropriate earlier treatment options with a CIS diagnosis versus RRMS. A number of DMTs are only licensed for RRMS, which is described as two clinically significant relapses. However, some DMTs i.e. Beta Interferon are licensed for treatment earlier where there is evidence of a clinically isolated syndrome. This is stated in the NHS England (2014) Clinical commissioning policy: disease modifying therapies for patients with multiple sclerosis (MS) based upon the criteria outlined in the Association of British Neurologists (ABN) Guidelines, which can be found in Appendix IV of the DH HSC 2002/04 and the Department of Health (2011) The risk sharing scheme for disease modifying therapies in MS

ID	Stakeholder	Statement number	Comments[1]
			Beta interferon for relapsing remitting disease **A.1 Starting Criteria** All of the following criteria must be met. The patient: • has had at least 2 clinically significant relapses in previous 2 years* • is able to walk 10m or more** • is not pregnant or attempting conception • is aged over 18 years • has no contra-indications * Neurologists may, in certain other circumstances where the evidence for efficacy is less secure, also consider advising treatment after discussion with the patient concerning the risks and benefits. For example; (i) Patients within 12 months of a clinically significant clinically isolated syndrome when MRI evidence predicts a high likelihood of recurrent episodes (i.e. development of MS). (ii) patients with only a single major relapse in the preceding two years, but combined with MRI evidence of continuing disease activity (i.e. meet the revised McDonald criteria for MS) (iii) individuals aged less than 18 with relapsing remitting MS ** For patients who can walk between 10 and 99 m (aided or unaided, EDSS 6.0 to 6.5), treatment with DMTs is permitted bur recommended less strongly than for patients able to walk more than 100m unaided (EDSS 5.5 or less).
	UKMSSNA	Statement 4	This quality statement focuses on the treatment of a relapse it does not prioritise assessment. An individual with Primary Progressive MS may also experience a sudden exacerbation of symptoms although this would not be defined as a relapse it would require urgent assessment. Although the definition of relapse does state that it should be diagnosed by a healthcare professional with expertise in MS the statement as a whole does not mention this initial stage of assessment. Currently many areas have local care pathways to ensure appropriate relapse treatment but these areas report that delays occur as a result of establishing that a sudden change in an individual's condition is as a consequence of a relapse. It is therefore important to include this within the process. The statement also fails to mention that rehabilitation may be needed as part of the management approach in order to maximise recovery. We suggest this should read: "Adults with MS who experience a sudden deterioration in their condition should have an urgent assessment by an MS specialist to establish if they are having a relapse. They should be aware of local pathways for relapse management and be offered treatment and a rehabilitation plan as soon as possible but within 14 days of the onset of symptoms." Rationale

ID	Stakeholder	Statement number	Comments[1]
			A further rationale for the accurate diagnosis and recording of an individual's relapses is that this gives the MS Specialist valuable information on the efficacy of any disease management and progression of the disease. This information can be used to inform future management plans. Quality measures Structure This would benefit from a more robust and detailed wording such as: "Evidence of access to a collaborative care pathway for the timely assessment and treatment of adults with MS who may be experiencing a relapse." In many areas MS Specialist Nurses working in primary care act as the instigator and coordinator of this pathway as they are able to understand the significance of changes in the individuals' health in a way that supports both the GPs and Neurologists to deliver the best management. Process The length of time measured would need to be from the initiation of the care pathway rather than from onset of symptoms as the specialist can only assess when made aware of the deterioration. Data collection Recording the number of relapses is normally carried out in the patient's notes. Gathering of data to denote the denominator and the numerator may prove problematic unless the pathway were to have a data collection process embedded in the record that could be completed and collated on line. HES data is unlikely to be helpful in identifying hospital admissions caused by a relapse as the coding is unreliable and clinically the cause of the admission may not be apparent when coding takes place. What the quality standard means for service providers The local pathways will need to be collaboratively developed, be accessible across the health economy and designed in a way that they can be shared to avoid duplication of effort and double counting. What the quality statement means for commissioners There may be an initial start-up resource required to set up a collaborative interactive care pathway record and data collection mechanism. A national audit of services for people with MS (RCP 2011) found that 20% of trusts do not provide any inpatient or outpatient rehabilitation services and only a third of community trusts provide specialist neurological rehabilitation. This will impact on the ability of local pathways to deliver the outcome of avoiding hospital admissions. There is a need for Commissioners of Primary care to purchase community neuro rehabilitation services to support care at home

ID	Stakeholder	Statement number	Comments[1]
			following a relapse to avoid secondary complications and reduce the accumulation of disability What the quality statement means for patients, service users and carers Adults with MS would also be able to access the pathway and participate in the process. This would give them a sense of control and enhance partnership with health professionals.
	Roche Products Limited	Statement 4	Recommendation 1.7.14 identifies that the MS multidisciplinary team needs to be told that the person is having a relapse, because relapse frequency may influence which disease‑modifying therapies are chosen and whether they need to be changed. This forms part of a structured assessment of therapeutic control essential to optimising the contribution of medicines to the treatment pathway. The proposed quality statement misses a qualitative element to address this need e.g. *Adults with MS who have a relapse are assessed by a healthcare professional, with expertise in MS and access to the personalised care plan, as soon as possible but within 14 days of the onset of symptoms***.** Suggestions to support improvement and help overcome barriers The need for treatment supervision when patients are being treated for MS is considered essential by the ABN both to assess treatment effectiveness and to document relapses. [1] Once started on therapy, the ABN recommends that patients remain under the supervision of specialist MS neurologists and nurses; an important aim of this is to encourage adherence to a monitoring protocol tailored to the safety profile and recommended risk monitoring programme of the individualised therapy. Treatment choices should be based on the best available evidence and not determined by referral patterns or hospital trust service capacity. Roche commissioned market research has identified capacity constraints, inconsistent referral practice and poor information transfer between larger and smaller MS centres in the UK. Roche believes that inadequate service capacity—in particular of day-case infusion facilities—has the potential to be a barrier to treatment within 14 days of symptoms. [1] Association of British Neurologists, *Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis,* Pract Neurol, June 2015.
	Teva UK Limited	Statement 4	14 days does not constitute ‘rapid treatment’. The ‘treatment’ should also include review by a specialist
	Genzyme Therapeutics (a Sanofi company)	Statement 4	We would suggest a quality standard that patients who experience a relapse should receive a face to face appointment with a health care professional specialised in MS care. At present much of the care of relapses is via the telephone / e mail which does not meet the patient’s needs fully to receive support and treatment. The wording of the statement we would suggest should be “Statement 7. Patients who experience a relapse should receive a face to face appointment within 14 days of the onset of symptoms.” The metric that should be used is the proportion of patients with a relapse who attend an appointment within 14 days of symptom onset. The numerator should be patients who attend an outpatient appointment within 14 days of the onset of a relapse and the

ID	Stakeholder	Statement number	Comments[1]
			denominator should be patients who have a relapse. At this appointment EDSS rating, MRI review, DMT and Symptom treatment review should be carried out and wording to make this explicit should be included within the definitions associated with this standard.
	Salford Royal NHS Foundation Trust	Statement 4	• We agree with the aspect of relapse being included in the QS. However, we feel that the whole pathway of relapse needs to be incorporated, not just around treatment. • Assessment and review is just as critical. Determining if someone is experiencing a relapse is not an exact science so people with a deteriorating condition, whatever their MS need the same level of service provision which encompasses assessment, management plan & review. • We agree with the time frame stated in the QS as we feel most services should be able to accommodate this. **We also feel that a timeframe for review of relapse should be included**. • Having a fully integrated system that all patient contact can be recorded on will aid collection of data. • Relapse management is a MDT approach and as such both medical, nursing and rehabilitation services (medical & therapy) need to be commissioned so that timely assessment occurs to help reduce long term disability accumulation. • Pathways should be developed accordingly. The gold standard would be for all patients thought to be having a relapse to be triaged and then seen if appropriate by an MS expert, medical, nursing or AHP. • Clear guidance needs to be in the QS for GPs re accessing specialist advice for patients thought to be having a relapse to prevent secondary complications. Having a robust relapse pathway will help to reduce unavoidable hospital admission. Collection of HES data is at best unreliable due to the inaccuracy of coding.
	University Hospital Birmingham	Statement 4	General Although local pathways exist for relapse management, these vary from area to area. There are no national relapse management guidelines at present detailing the gold standard for relapse management. Access to relapse management services also varies with some centres not having the infrastructure to provide this service ie capacity, availability of HCP with expertise. it does not encompass what is required in relapse management ie is it a relapse or something else such as infection, progression. Rationale Other factors required include patient information and education regarding relapse management, the importance of accessing appropriate services in a timely manner. Data collection Again there needs to be an appropriate data collection tool that can encompass MS as a whole.

ID	Stakeholder	Statement number	Comments[1]
			What the quality statement means for commissioners For those areas that do not have a relapse service, resources need to be looked at to meet these needs. There may also be a need to look at additional resources once a relapse has been identified ie rehab, physio, OT, rapid response/intermediate care.
	British Medical Association	Statement 5	We believe that it would be beneficial to have the annual review performed by consultants in the primary care setting.
	Biogen	Statement 5	Biogen feels the comprehensive review is essential part of the care plan for patients providing it allows for early access and referral to treatments, and access to services such as MRI and an MS nurse. The above comments on who is responsible for collecting the data and reviewing performance would also apply to this Quality Statement.
	NHS England (& Association of British Neurologists)	Statement 5	We disagree with this metric and don't think it is appropriate that someone with MS necessarily needs a 'comprehensive' review by a healthcare professional with expertise at least once a year. The course of MS is variable and therefore a service needs to be flexible enough to be able triage people with MS based on their needs. The use of the adjective 'comprehensive' is open to interpretation and needs to be defined. For example, does this include an annual MRI study to monitor the response to or lack of response to disease-modifying therapy?
	The MS Trust	Statement 5	The MS Trust supports this quality statement. We recognise the value in allowing local areas to design and deliver their services in the way that best meets the needs of individual people with MS. The best placed healthcare professional to conduct the annual review may vary depending on the person's point in the disease trajectory. However, in most cases it would make sense for the review to be carried out by the same person acting as the single point of contact, as they will have the best knowledge of and relationship with the person with MS. This would not only offer the person with MS the greatest consistency in their care, but would enable the review to be conducted in the most efficient manner. We acknowledge the basic definition of a comprehensive review set out in the quality standard and agree with the areas that are listed. However, the definition is not specific enough to be helpful or auditable in a clinical setting. A more detailed specification of what the annual review should cover is needed. For example, the quality standard states that a comprehensive review should assess the course of the disease and number of relapses in the past year. The growing consensus around the importance of early treatment and regular monitoring of the effectiveness of treatment in order to preserve brain health means that reviewing the course of the disease requires monitoring both clinical and sub-clinical activity (through the use of regular MRI scanning). The results may mean that the PwMS may wish to consider the possibility of switching to another drug should their MS continue to be active, and be supported by the MS team to understand their options and make the choice that is right for them.

ID	Stakeholder	Statement number	Comments[1]
			We suggest this is a project which would benefit from being taken forward jointly by the ABN and UK MS Specialist Nurse Association (UKMSSNA), supported by the MS Trust and other patient organisations. There is a range of data from within GEMSS and existing nursing literature that can provide a useful foundation. For example, one of the GEMSS teams developed a Specialist Neurological Intervention Audit Tool (SNIAT) which was used by several GEMSS team to track 19 different domains covered in each MSSN consultation. This has provided valuable information on variety and frequency of different issues that MS specialist nurses deal with and which are important to PwMS which could form the basis of a specification for the annual review. Service barriers Offering an annual assessment to every PwMS who wants one will be a challenging quality statement for MS teams to meet as it is not happening consistently within MS services. Within our GEMSS project the proportion of patients on the caseload who were seen in the last year varied from 75-90%. Where patient databases exist it will be easy to audit the contact offering an annual review. However, not all services have a disease register or caseload database. In order to facilitate meeting this statement, every area needs a caseload database and every person newly diagnosed with MS must be recorded on the database. Lack of wider prevalence data also represents a barrier to achieving this statement. We simply often do not know how many people with MS live in a specific area, especially if they have not been in contact with services for a long time. Joining up of data held by GP practices is essential to understanding the prevalence of MS within a local population, and enabling MS services to ensure everyone with MS is offered an annual review. This will require initiatives like care.data to make progress quickly. Some local areas have made efforts to create a local prevalence database by working with GP surgeries within their referral area (see Lost to follow up?, wayahead, MS Trust, July 2015) However, this approach is highly resource intensive. Service capacity also presents a barrier. The capacity to hold an annual review, which would need a double clinic appointment to be comprehensive, will be limited. Pressures within the service to see more newly diagnosed patients more quickly, to act as a single point of contact co-ordinating care, and the increased demands of monitoring associated with DMDs, mean that the capacity of MS services is stretched incredibly thin in many parts of the country. To enable the quality standard to be implemented, every area needs to properly understand the prevalence of MS within their area and have the required number of WTE MS specialist nurses working to a sustainable caseload. This relies on MS services being supported to work as effectively and efficiently as possible. In some areas where there is already significant shortfall, this may require additional investment in MS specialist nursing posts.

ID	Stakeholder	Statement number	Comments[1]
			Quality measures The quality statement itself is worded ‘adults with MS are offered a comprehensive review’, but the process measure is worded ‘proportion of adults who receive a comprehensive review’. We think that both things should be measured, with the ability to record where the patient declined a review. The MS Trust recommend including the following quality measures: • % of adults with MS* who are offered a comprehensive review within 12 months of their last review • % of adults with MS* who are offered a comprehensive review who decline • % of adults with MS* who have a comprehensive review within 12 months of their last review *Until prevalence data is available, the denominator will need to be ‘adults with MS on the service caseload’. To address the data barriers we recommend including the following measures: • % of MS teams with a caseload database in place. • % of MS teams who have access to robust prevalence data / evidence of local arrangements to collect prevalence data There are no outcome or patient satisfaction measures specified. We would recommend adding a patient satisfaction measure about whether the annual review met their needs within a regular patient survey programme.
	Multiple Sclerosis Society	Statement 5	**Comment:** We welcome the inclusion of the comprehensive annual review as a quality standard. 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 disease modifying therapy or being referred to another member of the MDT. The management plan should be updated accordingly during this meeting. **Comment:** However, we know there is significant regional variation in access to specialists and reviews. An MS Society survey of ~8,500 people with MS in England found that 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). MS Society (2013). A lottery of treatment and care – technical report

ID	Stakeholder	Statement number	Comments[1]
			http://www.mssociety.org.uk/sites/default/files/Documents/Research/A lottery of treatment and care - technical report.pdf Also, we know there are Professionals and people with MS frequently complain that their appointments are too short to adequately address the complex options for treatment and care. In one study, one in three people with relapsing MS said that they had not even discussed treatment options with their clinician Holloway E, Redford-Totts D (MS Society). Right Treatment, right time? How people with MS make decisions about disease modifying drugs http://www.treatmerightms.org.uk/wp-content/uploads/2014/04/Right-treatment-right-time.pdf To ensure all aspects of the annual review can be covered in a consultation between patient and neurologist, local services must have sufficient capacity in numbers of specialists available and that appointments are of a sufficient length. Comment: MRI scanning has become increasingly important in the diagnosis and inform decisions regarding the treatment of people with MS e.g. starting or switching a DMT. This has been recognised in key policy documents including the NICE clinical guideline for MS and the Association for British Neurologists prescribing guidelines (2015 http://pn.bmj.com/content/early/2015/06/20/practneurol-2015-001139.extract) which recommend its use in the comprehensive annual review. However, anecdotal reports show that are still not routinely used in clinical practice. An explicit recommendation/metric regarding the importance of MRI scanning in the comprehensive annual review would help prevent variation in relation to this. **Data collection**: Data should be collected from locally administered surveys of patient experience of the comprehensive annual review. Data should be collected regarding the numbers or people with MS receiving a comprehensive annual review, length of appointment, caseloads for specialists, waiting times for review and use of MRI scanning within the appointment. **Improvements/overcoming barriers**: With the data received from patient experience surveys and using local patient engagement organisations and mechanisms such as local branches of the MS Society, Healthwatch, GP practice patient groups, CCG patient engagement forums/events, commissioners should work with people affected by MS and health care professionals to co-design local services. This helps ensure they deliver best practice and meet local need effectively. For example, this will help ensure that appointments are of a suitable length, MRI scanners are available and that there are enough MS specialists for people with MS to be seen in a timely and appropriate way.
	Novartis Pharmaceuticals	Statement 5	***Adults with MS are offered a comprehensive review by a healthcare professional with expertise in MS at least***

ID	Stakeholder	Statement number	Comments[1]
	UK		***once a year.*** We support this quality statement and believe it reflects the key area for quality improvement, although could be strengthened with the addition for this comprehensive review to include an MRI scan for patients with relapsing disease. This is because although it is essential for patients with MS to receive at least an annual review with a neurologist with a specialist interest in MS or MS specialist nurse, for this to have full value for relapsing patients on therapy, patients also need to be given access to an MRI scan at this annual review. This would enable response to treatment to be monitored. Data collection is achievable via evidence of local arrangements to ensure that adults with MS are offered a comprehensive review by a healthcare professional with expertise in MS at least once a year. The key barrier to the achievement of this quality statement is again, access to specialists to conduct this review and the availability of MRI scans in all centres
	UKMSSNA	Statement 5	We welcome the inclusion of the comprehensive annual review as a quality standard and acknowledge its value in providing clinical oversight and support to those who are most vulnerable in the MS population. A combination of loss of community presence and reduced participation often results in some of the most disabled individuals living with MS falling through appointment systems and missing out on helpful reviews and advice. For these people appointments to undertake a comprehensive assessment often need to take place in their home and may take a considerable length of time. In order to support the implementation of this quality improvement some areas will require additional resources to ensure this case load commitment is sustainable. Similarly a comprehensive assessment may raise many issue that cannot be addressed by the individual carrying out the assessment. This could generate referrals to services that are not commissioned in all areas, for example a referral to psychology services for assessment of cognition. Quality measures Process The denominator in this process is the number of adults with MS. The estimated prevalence rate for MS is not universally agreed with several different estimates in use. There is also variance within the United Kingdom with the highest rates being in the North of Scotland. Local data collection will be needed to determine the true prevalence of MS in different areas. This may delay or skew accurate data collection and will need to be addressed. In the meantime the denominator could be the number of adults with MS on the local MS Specialist Nurse's caseload. A case load data base would be needed to ensure monitoring and timely offering of appointments. This would also facilitate data collection.

ID	Stakeholder	Statement number	Comments[1]
			Problems may occur if an individual is on two lists for example seeing an MS Specialist Nurse in a tertiary centre and locally. There would need to be clarity over who was responsible for carrying out the assessment in these circumstances to avoid duplication of effort. Definitions of terms :comprehensive review The definition suggests an activity arising from a comprehensive review might be referral to other members of the “MS multidisciplinary team”. Many areas do not have access to such a team and this could be a barrier to a successful outcome for the individual living with MS.
	Royal College of Psychiatrists	Statement 5	Definitions of terms used in this quality statement. The term “comprehensive review” should include mental health and cognitive functioning
	Roche Products Limited	Statement 5	A personalised care plan that documents goals and actions agreed between an adult with MS and their multidisciplinary health and social care team as well as health care underpins high quality care. [1] Suggested wording: Adults with MS are offered a comprehensive review by a healthcare professional with expertise in MS at least once a year, supported by a documented personalised care plan [1] Comptroller and Auditor General, *Services for people with neurological conditions: progress review,* Session 2015-16, HC 301, National Audit Office, July 2015. Suggestions to support improvement and help overcome barriers To ensure comprehensive annual review disease activity should be adequately monitored. To support improvement and optimise the use of disease-modifying medicines, Roche agrees with the ABN that more research is required on the frequency of MRI imaging. However, the role of MRI in helping decisions concerning either the escalation or the stopping of treatments is recognised in Europe, the USA and increasingly in the UK. Neuroscience centres with expertise in MS will increasingly need ready access to MRI and other investigatory services, such as cardiac monitoring or optical coherence tomography, in order to monitor disease-modifying treatments safely and facilitate comprehensive annual review. [1] Association of British Neurologists, *Revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis,* Pract Neurol, June 2015.
	Royal College of General Practitioners	Statement 5	is amended to include a multidisciplinary team review
	Teva UK Limited	Statement 5	The comprehensive review should utilise a standardised approach and template. Need a fast track process for patients who have experienced an acute event or deterioration between comprehensive reviews.

ID	Stakeholder	Statement number	Comments[1]
	Genzyme Therapeutics (a Sanofi company)	Statement 5	Under the definition of comprehensive review to support the implementation of Standard 5: Adults with MS are offered a comprehensive review by a healthcare professional with expertise in MS at least once a year. We would suggest the following wording: The review should be carried out by a healthcare professional with expertise in MS and its complications, be tailored to the needs of the person with MS, and assess the following: • MS symptoms • The course of the disease and number of relapses in the past year • General health • Social activity and participation • MRI • EDSS • Treatment review • Patient goals / quality of life experience
	Salford Royal NHS Foundation Trust	Statement 5	We fully support the inclusion of a comprehensive review on an annual basis. Logistically this will need extra resourcing in terms of people, at point of assessment and ongoing management as determined at the review (medical & AHP). As there is currently no national MS database the actual numbers of people with MS within a given geographical area is difficult to determine. Many hospital based services do not know all people with MS. The QS almost has 2 elements to it: those on treatment and those not. Each as important and both need to be carried out by MS expert either medical, nursing or AHP. Historically annual reviews have been carried out on those on treatment. For **ALL** pwms there would need to be funding secured for assessment to take place within community settings/ patient home to ensure equity of access.
	British Society of Rehabilitation Medicine	Statement 5	A yearly review is sensible and meets the needs of a group of patients as long as the professional conducting that review has the clinical skills and access to/knowledge of appropriate pathways for overall disease management. Where there are complex needs that may require input from an MDT, a rehabilitation medicine physician is best placed to carry this out. Management of the various areas of symptom management referred to in the consultation document are all part of the skill set of physicians specialising in rehabilitation medicine as these activities form a core part of their post-graduate training. The ability to manage these problems directly and to understand how and when specific therapy services may be required is both more cost-effective and efficient than a review which flags up problems without having the ability or resources to address them. Having more complex patients reviewed by a physician specialising in rehabilitation medicine allows discussions around prognosis and medical management to form part of this review with the potential to reduce unplanned admissions and to offer care pathways that are more patient-focussed. Page 22 should, therefore, explicitly refer to “Rehabilitation Medicine Specialist” as another

ID	Stakeholder	Statement number	Comments[1]
			healthcare professional in this context. In terms of measurement would suggest; "All adults with MS have an annual review which results in an explicit multidisciplinary management plan which aims to improve participation and social integration. Again, thinking about outcomes rather than processes, the number of unplanned admissions for patients with progressive MS per population would be a good way of assessing the net benefit of these reviews in audit-friendly terms.
	Royal College of Nursing	Statement 5	Clarity is required with regard to who can carry out the annual reviews. This should detail that MS specialist nurses and therapists are able to do so and should not be targeting GPs who in the whole may not have the experience to carry out holistic MS assessments.
	University Hospital Birmingham	Statement 5	General There is a real need for this QS to ensure that all people with MS are reviewed and their needs met. There has been a risk of people who are secondary progressive or primary progressive MS not having their needs met due to the input those on therapy require. Quality measures Structure Although this is an essential QS, issues around capacity, timing of appointments etc to cover such a comprehensive assessment will be required, particularly those with more complex needs. There is a need for other infrastructures to be in place as there may be an increase in referrals to other HCP ie physio, rehab, OT Process Please refer to previous QS comments around data collection and limitations.

Registered stakeholders who submitted comments at consultation

- Biogen
- British Association of Urological Surgeons
- British Medical Association
- British Society of Neuroradiologists (BSNR)
- British Society of Rehabilitation Medicine

- Genzyme Therapeutics (a Sanofi company)
- MacGregor Healthcare Limited
- Merck Serono Ltd
- Multiple Sclerosis Society
- Novartis Pharmaceuticals UK
- NHS England (& Association of British Neurologists)
- Roche Products Limited
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Psychiatrists
- Salford Royal NHS Foundation Trust
- Teva UK Limited
- The British Association of Prosthetists and Orthotists (BAPO)
- The MS Trust
- The Royal College of Radiologists
- UKMSSNA
- University Hospital Birmingham

Appendix 2: Quality standard internal checks table

Comment number	**Page number** Or **'general'** for comments on the whole document	**Statement number** Or **'general'** for comments on the whole document	**Comments**
QS team			
1		2,3 and 5	'with expertise in MS' - Should we include this throughout the statements?
2		5	Is it the offer of treatment or the treatment that needs to occur in the timeframe?
3	General		Are there any other priority areas in relation to access to therapies (possibly supported by Technology Appraisals)?