Multiple Sclerosis in Adults: Management

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Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association for Palliative Medicine	General	General	There is no reference to managing end of life in patients with MS which we feel should be included	Thank you for your comment. This guideline will cross-refer to the NICE guidelines on end of life care for adults: service delivery (NG142). The guideline will address palliative care needs specific to multiple sclerosis for relevant topics (information and support, pain and spasticity).
Association for Palliative Medicine	005	010	1.6 Comprehensive review. It is felt this area needs review as MDT has been found to be useful in other dx groups such as MND	Thank you for your comment. The surveillance review did not identify any new evidence that would change the recommendations in this section https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal. An MDT approach is recommended in 1.3.1 in the current guideline.
Association for Palliative Medicine	005	010	1.7 Relapse and exacerbation. We feel this should include 'deterioration and death'	Thank you for your comment. This section of the guideline is not being updated and we are therefore unable to change the wording
Association for Palliative Medicine	005	010	1.8 We feel palliative care should be considered as an 'other treatment'	Thank you for your comment. This section Is not being updated as the surveillance review did not identify and new evidence that would change the recommendations **https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal.** Palliative care is included in the review questions on information and support and the draft review question on symptom management and rehabilitation.
Association of British Neurologists	001	017	The MS specialist nurse role is sometimes carried out by allied health professionals other than nurses. This should be recognised in the review.	Thank you for your comment. The draft review question 4.1 has been expanded to include other health professionals.
Association of British Neurologists	004	011	It is clearly stated that the guideline covers adults, although may be applicable to young people aged 16 and 17. However, why has the paediatric population been excluded from the guideline? There is no NICE guideline for the management of multiple sclerosis in the paediatric population. Therefore, either a specific guideline needs to be developed for the paediatric population, or the scope of this guideline should be expanded to give specific consideration to the paediatric subgroup.	Thank you for your comment. We recognise the problems that children may have in terms of diagnosis and management and have carefully considered the guideline population. We considered we could not adequately address the needs of younger people with MS within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s. Also, people under 18 years are not included in other NICE guidance that we expect to refer to and these gaps would require additional consideration of evidence.

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Association of British Neurologists	005	005	Although people receiving palliative care are included in the questions about MS symptom management and rehabilitation in Section 3.5, why is palliative care not included as an area for specific review in the guideline?	Thank you for your comment. This guideline will focus on aspects of palliative care specific to MS. We have added people with palliative care to draft review questions 3.1-3.5. More general aspects of palliative care are covered by existing NICE guidance for example end of life care for adults: service delivery NG142.
Association of British Neurologists	005	009	1.4 – Why is there no evidence review for modifiable risk factors for relapse or progression? On Page 2, line 21, it is stated that the main modifiable risk factors are vitamin D deficiency, tobacco smoking and obesity. However, the current NICE guidance CG186, recommends that vitamin D should not be given, and there is no recommendation about obesity.	Thank you for your comment. The surveillance review did not identify any new evidence that would change the current recommendations in this section https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal. CG186 refers to vitamin D not being given to treat MS but does not preclude it being used for deficiency (recommendation 1.8.1). This guideline may cross-refer to existing NICE guidelines on obesity CG189 as the management is not specific to MS.
Association of British Neurologists	005	009	1.6 - Comprehensive review should be reviewed as the current guideline does not include any comment on reviewing disease modifying therapy (initiation/continuation/switching or stopping) which is an essential part of routine management	Thank you for your comment. Disease modifying therapies are outside of the scope of this guideline.
Association of British Neurologists	005	009	1.7 – Relapse management should be reviewed to look at role of plasma exchange, and to consider the possibility of PML in patients at risk due to their disease modifying treatment	Thank you for your comment. Disease modifying therapies are outside of the scope of this guideline.
Association of British Neurologists	005	009	1.8 – Why is there no review of the evidence for vitamin D?	Thank you for your comment. The surveillance review did not identify any new evidence that would change the recommendations on vitamin D https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal
Association of British Neurologists	008	022	Why have interventions for the following symptoms not been included for review – bladder, bowel, sexual, psychiatric, visual, bulbar and respiratory dysfunction, vertigo, paroxysmal symptoms, restless legs and sleep disorders?	Thank you for your comment. These symptoms were not prioritised for inclusion in the guideline as they are not specific to people with MS. We may cross refer to existing NICE guideline on bladder and

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				bowel problems for example incontinence in neurological conditions CG148 and faecal incontinence CG49
Association of British Neurologists	008	022	Why has the intervention of vocational rehabilitation not been included for review?	Thank you for your comment. Vocational rehabilitation is outside of the remit of NICE guidelines.
Association of Chartered Physiotherapists in Neurology	General	General	Does access to comprehensive early rehabilitative/preventative therapy & education input (as opposed to drug therapies) from the point of diagnosis improve long term outcomes of people with MS	Thank you for your comment. When interventions should be offered will be considered by the guideline committee when discussing relevant review protocols for the scope topic symptom management and rehabilitation.
Association of Chartered Physiotherapists in Neurology	General	General	Do supported exercise programmes from point of diagnosis reduce the development of disability	Thank you for your comment. When rehabilitation should be offered will be considered by the guideline committee when discussing the review protocols for the scope topic symptom management and rehabilitation. We will make the committee aware of your comment when they discuss these.
Association of Chartered Physiotherapists in Neurology	Comment form question 1	N/A	***Q. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?*** A. Collaboration between rehabilitation and leisure services do deliver both rehabilitative input and disability preventative programmes for people with MS An ACPIN member has completed a "Redesigning Services for the Future" and the assignment was based on admissions avoidance and community support for those with MS. Happy to share to see if it is feasible.	Thank you for your comment. Service delivery is outside of the remit of this guideline.
Association of Chartered Physiotherapists in Neurology	001	017	The role of the MS nurse is to be explored. ACPIN asserts that the multidisciplinary team, is as integral to the care of patients with MS. Therefore, there is a need to establish and explore the role of the MS Multi-disciplinary team. e.g. Physiotherapist, Occupational Therapist,	Thank you for your comment. The scope of this guideline includes the role of the MS nurse. An MDT approach is recommended in the current guideline CG186 (1.3.1). This recommendation will be carried over to the update and a new evidence review will not be conducted. The surveillance review did not identify any new evidence that would

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			Speech and Language Therapist, Dietician etc. who may work alongside the MS nurse in clinic. The inclusion of the MDT in terms of role is further highlighted by this statement on page 2, lines1-3: "*Particularly in the light of this statement" physical disability and cognitive impairment, which negatively affect the person's quality of life and ability to work and study. It is associated with high costs for people with MS, their families, and society as a whole."*	change this recommendation https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal.
Association of Chartered Physiotherapists in Neurology	002	023	Whilst ACPIN acknowledges the fact that the exclusion of other neurological conditions are standard, it also emphasises that this should include those conditions which are not as common, eg.: HTLV Associated myelopathy. There have been many instances where patients were diagnosed with MS only to be found many years later to have HTLV associated myelopathy - and this is still happening - with devastating effects on the patient.	Thank you for your comment. This guideline is expected to cross refer to the NICE guideline on suspected neurological problems: recognition and referral NG127. The focus of this guideline is the diagnosis of MS and the related conditions specified in the McDonald criteria.
Association of Chartered Physiotherapists in Neurology	003	004 - 011	Rehabilitation is discussed in terms of reducing the impact of disability. The current approach assumes disability will develop and then should be addressed after the fact. ACPIN strongly feels that it is imperative that the role of pre-habilitation: preventative targeted therapy input should be included. It is easier to prevent disability with appropriate therapy input than it is to reverse the impact of symptoms	Thank you for your comment. The role of the MS nurse including in education is in the scope of this guideline. The guideline committee will therefore consider making recommendations on interventions to prevent disability. See draft question 4.1. The recommendations in the existing guideline CG186 on comprehensive review (1.6) are also aimed at preventing disability.
Association of Chartered Physiotherapists in Neurology	003	014 - 015	Will the revised McDonald Criteria be detailed in the guideline?	This guideline will refer to the revised McDonald criteria.
Association of Chartered Physiotherapists in Neurology	003	008	Evidence that one disease modifying drug can slow the progression of disability – ACPIN argues that in future, exercise should be evaluated alongside drug intervention to assess its impact on slowing disease progression.	Thank you for your comment. The guideline committee will consider this comment when they discuss the review protocols on symptom management and rehabilitation. The protocols may include trials comparing exercise with drug depending on what the guideline committee decide to include. In the existing guideline CG186

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				recommendation 1.4.1 on exercise as a modifiable risk factor will not be updated but will be retained in this update
Association of Chartered Physiotherapists in Neurology	003	015	ACPIN wishes to highlight that the role of the advanced practitioner has also been developed in recent years and whilst the role of the MS Specialist nurse is important, attention needs to be directed to the role of the Advanced Practitioner – which can be an AHP - and the contribution of this role to patient care in the context of MS needs to be explored	Thank you for your comment. The draft review question 4.1 has been expanded to include other health professionals.
Association of Chartered Physiotherapists in Neurology	003	017	ACPIN welcomes the acknowledgement of variability in access to services, rehabilitation and integrated services. However, ACPIN also wishes to highlight that while there is a real shortage of specialist services, it wants to emphasise that there is even more variability and less opportunities for supported exercise in community settings such as gyms, therapy centres and community groups. It is very important that this is addressed in the upcoming guideline review. Services that do exist are often not well promoted.	Thank you for your comment. The scope includes MS symptom management and rehabilitation including for example mobility. It is outside of the remit of the guidance to make recommendations on how services are provided as these decisions will be made locally.
Association of Chartered Physiotherapists in Neurology	004	013	ACPIN understands that it has been identified that there is no specific subgroup needing special consideration. However, we wonder what the review groups arrangements will be to cover people with MS managed jointly with other services e.g. those with a Learning Disability?	Thank you for your comment. We are not seeking to make different recommendations for people managed jointly with other services. For example, the management of MS would be the same if a person had a learning disability.
Association of Chartered Physiotherapists in Neurology	004	025	ACPIN wishes to highlight that the current guideline states: "*The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written information at the time of diagnosis*". We suggest that this statement could be further expanded to include not only the consultant neurologist but also the other members of the multidisciplinary team.	Thank you for your comment. The recommendations on information and support will be revised as part of this update.
Association of Chartered Physiotherapists in Neurology	004	026	ACPIN wishes to highlight that: *MS symptom management & rehabilitation* – this is a very reactive rather than pro-active title. Surely the scope of the guideline should be starting with interventions that can prevent/reduce symptom	Thank you for your comment. The role of the MS nurse in education is included in the scope of this guideline. The guideline committee will therefore consider making recommendations on interventions to prevent symptoms. The recommendations in the existing guideline

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			development rather than looking at what can be done after the symptoms have already developed.	CG186 on comprehensive review (1.6) are also aimed at the prevention disability. These recommendations will be carried over to the update and a new evidence review will not be conducted.
Association of Chartered Physiotherapists in Neurology	004	026	ACPIN also suggests that there is an opportunity to ensure that physical activity and sedentary behaviours is listed under management and rehabilitation of MS. There is evidence to show the benefits to the overall health and wellbeing of people with MS.	Thank you for your comment. This guideline may cross-refer to existing NICE guidelines on lifestyle modifications. The existing recommendation on comprehensive review 1.6 in guideline CG186 covers general health. These recommendations will be carried over to the update and a new evidence review will not be conducted.
Association of Chartered Physiotherapists in Neurology	005	001	As discussed above on page 1: line 17; page3, line 15.	Thank you for your comment.
Association of Chartered Physiotherapists in Neurology	005	009	ACPIN wishes to highlight that it would be very productive to see recommendations on the amount of exercise people with MS should be aiming for from a review of the available evidence in the rehabilitation update.	Thank you for your comment. The scope includes symptom management and rehabilitation. We will make the guideline committee aware of your comment when they discuss the review protocols on this scope topic. In the existing guideline CG186 recommendation 1.4.1 on exercise as a modifiable risk factor will be retained in this update and a new evidence review will not be conducted.
Association of Chartered Physiotherapists in Neurology	005	009 (Table: 1.4 & 1.5)	ACPIN wishes to highlight that there is growing evidence that exercise and physical activity is a modifiable risk factor, and therefore suggests that this is included in the current scope. The current guideline only refers to exercise which is only one aspect of physical activity. Physical activity on the other hand takes into consideration a broader range of activities which include exercise. People with MS should be encouraged to participate in exercise and physical activities and reduce sedentary behaviours. The current guideline does not address sedentary behaviours but there is evidence to suggest that this is just as harmful as being physically inactive. Physiotherapists should address this within clinical practice and are best placed	Thank you for your comment. The existing recommendations on comprehensive review 1.6 in guideline CG186 cover general health including exercise. This recommendation will be carried over and a new evidence review will not be conducted. We may cross-refer to the existing NICE guidelines on lifestyle.

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			to support people with MS to become physically active and reduce sedentary behaviours.	
Association of Chartered Physiotherapists in Neurology	005	009	ACPIN wishes to assert that rather than just reviewing the current evidence of how we manage existing symptoms and provide rehabilitation for existing disability, the scope should also include therapeutic input which prevents/reduces symptom and disability development.	Thank you for your comment. The role of the MS nurse in education is included in the scope of this guideline. The guideline committee will therefore consider making recommendations on interventions to reduce symptoms and disability development. The recommendations in the existing guideline CG186 on modifiable risk factors (1.4) and comprehensive review (1.6) are also aimed at preventing disability. These recommendations will be carried over to the update and a new evidence review will not be conducted.
Association of Chartered Physiotherapists in Neurology	005	009 (In table: 1.6)	Comprehensive review: The previous guidance outlines clearly the importance of a comprehensive review, unfortunately this is not often done in its entirety. There is still an emphasis on medication review rather than providing a holistic screening and assessment during the annual review process. ACPIN wishes to highlight that whilst there may be many reasons for this, it does highlight that there is a dire need for a comprehensive MDT review. Unfortunately, people with MS are still falling through the gaps within the current system. MS services are currently not prioritised within the NHS pathways, unlike stroke for example, and in some cases the MDT is underutilised. ACPIN suggests that more guidance and pathway development might be needed to provide some structure to the comprehensive review process.	Thank you for your comment. It is outside of the remit of the scope for this guideline to provide guidance on how recommendations are implemented locally. How guidance is implemented locally is outside of the remit of NICE guidance.
Association of Chartered Physiotherapists in Neurology	006	002	ACPIN queries the current draft scope exclusion of treatment of contractures at joints. We feel this should be covered in the guidelines because the current guideline covers spasticity management but does not cover contracture management. We feel that contracture management should be included in the guideline as if the individual's spasticity is not managed, guidance on contracture management will further inform the treatment plan. Once contractures develop in this patient cohort, it has a significantly debilitating effect on the individual. This leads to increasing costs of care, equipment and	Thank you for your comment. The focus of this guideline is on the prevention of contractures through the scope topic on symptoms management and rehabilitation. The regular assessment and review of people at risk of contractures is recommended in the current guideline (1.6.7 in CG186).

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			decreasing quality of life, which could be minimised if an appropriate pathway was detailed in the guideline. Spasticity management in MS has also been detailed in the research recommendations in CG186 (2014)	
Association of Chartered Physiotherapists in Neurology	008	022	ACPIN wishes to highlight whilst lines 23-31 all mention clinical and cost effectiveness, none mention impact on quality of life. We assert that impact on quality of life needs to be included into these key issues and draft questions as a priority	Thank you for your comment. Quality of life is listed as a key outcome in the scope. This will be considered for all relevant review protocols.
Association of Chartered Physiotherapists in Neurology	008	027	ACPIN wishes to query whether this statement can be adjusted to reflect not just mobility but include physical activity of which exercise is one component. We also wish to query whether adapted exercise be considered for people with high levels of disability in MS?	Thank you for your comment. We have edited draft review question 3.3 to specify that we are only covering pharmacological interventions.
Association of Chartered Physiotherapists in Neurology	009	001	ACPIN suggests that this needs to change to incorporate AHPs and suggests that this changes to the role of the Advanced practitioner role which will include AHPs.	Thank you for your comment. We have added other health professionals to draft review question 4.1.
Biogen	001	021	The prevalence of MS in the UK should be updated with the latest figures released from PHE – new estimate is around 130,000	Thank you for your comment. This has been edited as suggested.
Biogen	002	025	Reference should be made to the diagnostic criteria used in the 2017 McDonald criteria	Thank you for your comment. This guideline will refer to the revised McDonald criteria.
Biogen	008	017	This should include what information people with MS find useful about their disease modifying treatment options, as the number of available treatments has grown, with an increasing range of benefit: risk profiles	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol for the question on information and support
Biogen	008	020	In the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3), Wellings et al (Lancet 2013) found that in the British general population, "9·7% of women aged 16–44 years had pregnancies with known outcome in the year before interview, of which 16·2% (95% CI 13·1–19·9) scored as unplanned, 29·0% (25·2–33·2) as ambivalent, and 54·8% (50·3–59·2) as planned, giving an annual prevalence estimate for unplanned pregnancy of 1·5% (1·2–1·9).	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol for this question.

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			Pregnancies in women aged 16–19 years were most commonly unplanned (45·2% [30·8–60·5]). However, most unplanned pregnancies were in women aged 20–34 years (62·4% [50·2–73·2])". Although these results might not be directly applicable to people with MS, 45.2% of pregnancies were either unplanned or ambivalent in this survey. As MS is diagnosed earlier and and in light of the number of DMTs requiring contraception/contraindicated in pregnancy due to potential teratogenic effects, Biogen believe people with MS (male and female) should be given the opportunity to talk with a HCP about the risks of an unplanned pregnancy (both for the mother and the baby) before starting on a DMT.	
Biogen	008	028	NICE are currently considering whether to include Fampyra (fampridine) within their work programme. Fampyra is recommended for use within the NHS in Wales by the AWMSG	Thank you for your comment. This guideline will update the recommendations on fampridine.
Biogen	009	003	What is the role of the MS nurse, could be expanded to include role of MS pharmacist, MDT coordinator as they play an increasing role in ensuring high quality care for people with MS	Thank you for your comment. We have added other health professionals to draft review question 4.1.
Bristol Myers Squibb	002	025	The draft scope currently mentions MRI evidence of dissemination on lesions; for clarity and consistency with the McDonald criteria, we feel it would be worth expanding the concept of 'dissemination' of lesions to cover both 'Dissemination in Space (DIS)' and 'Dissemination in Time (DIT)'	This guideline will refer to the revised McDonald criteria.
Bristol Myers Squibb	002	026	Suggest rewording the sentence to read: The McDonald diagnostic criteria for MS were developed to diagnose MS in patients with at least a Clinically Isolated Syndrome (CIS), and not to differentiate MS from other neurological disorders.	Thank you for your comment. McDonald criteria were developed to make the diagnosis in people with a clinically isolated syndrome at onset and then modified for use in patients with progression from onset. We have edited the sentence to read 'at least clinically isolated syndrome'
Bristol Myers Squibb	005	General	In terms of recommendation, a key aspect to cover would regard lifestyle changes which may prevent or delay cognitive decline	Thank you for your comment. This guideline may cross refer to existing NICE guidelines on lifestyle. The existing recommendations on comprehensive review (1.6) cover general health in guideline

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				CG186. These recommendations will be carried over and a new evidence review will not be conducted.
Bristol Myers Squibb	008	008	In terms of economic evaluation, we would suggest taking in consideration the occurrence of UTI (urinary tract infection) and the occurrence of falls in patients with MS, which might be frequent cause of hospitalization, particularly in patients with cognitive decline e/o autonomic dysfunction	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocols.
Bristol Myers Squibb	009	017	In order to evaluate comprehensively and consistently the disability that the patient is facing, it would be crucial to identify a sustainable set of crucial assessments that every service should be able to perform	Thank you for your comment. The current recommendation s 1.6 CG186 on comprehensive review would include carrying out or arranging assessments as required. The surveillance review did not identify any new evidence that would change the recommendations **https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal**. This recommendation will be carried over and a new evidence review will not be conducted.
Bristol Myers Squibb	009	023	When discussing cognitive function, we suggest adding specific mention to Brief International Cognitive Assessment for MS (BICAMS) (or Symbol Digit Modalities Test (SDMT)) as a tool to measure cognitive function particularly in the context of evaluating its impact on quality of life and working status/activities of daily living	Thank you for your comment. The list of outcomes is not exhaustive, and these will be tailored to each review question. We will make the guideline committee aware of these outcomes when we discuss the review protocol on the clinical and cost effectiveness of interventions for cognition.
Bristol Myers Squibb	009	023	a harmonization in terms of cognitive function assessments among the different services would be a key factor in improving the care of MS patients and magnifying the possibility for centres on the territory to collaborate	Thank you for your comment. How to assess cognitive function is not specific to people with multiple sclerosis and will therefore not be covered by this guideline.
British Association of Urological Surgeons	General	General	With up to 87% of patient with multiples sclerosis reporting lower urinary tract symptoms [1] this is a significant impact on quality of life. The symptoms are most commonly related to the demyelination in both the spinal cord and the brain which can result in patients having neurogenic detrusor overactivity and poor bladder emptying. Patients with MS can also develop urological problems related to their mobility issues as well as urological problems unrelated to their MS but which other factors related to their MS make it more difficult to manage. Patients often have significant issues with incontinence	Thank you for your comment. People with MS are included in the NICE guideline on urinary incontinence in neurological conditions CG148. Recommendation 1.6.3 in the current guideline on MS CG186 includes an assessment of bladder and bowel symptoms and sexual function. This recommendation will be carried over.

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			There is evidence that patients with MS have a low risk of developing upper tract problems [2] compared to other forms of neurological disease such as spinal cord injury therefore urological management lends itself well to nurse led pathways. MS patients also can have issues with recurrent urinary tract infections. Unlike many other neurological conditions MS patients can be treated with immunosuppressive modalities which can patients more at risk of infection. Urinary tract infections not only affects patients with specific urological symptoms but can have significant impact on their MS symptoms causing deterioration in mobility which can then impact on patient ability to manage their bladder particularly in those managing with intermittent catheters exacerbating the urological problems [3]. References 1. Nazari F, Shaygannejad V, Mohammadi Sichani M, Mansourian M, Hajhashemi V; The prevalence of lower urinary tract symptoms based on individual and clinical parameters in patients with multiple sclerosis: BMC Neurol. 2020 Jan 17;20(1):24. doi: 10.1186/s12883-019-1582- 2. Litwiller SE, Frohman EM, Zimmern PE; Multiple sclerosis and the urologist; J Urol. 1999 Mar;161(3):743-57. 3 Phé V, Pakzad M, Curtis C, Porter B, Haslam C, Chataway J, Panicker JN. Urinary tract infections in multiple sclerosis; Mult Scler. 2016 Jun;22(7):855-61. doi: 10.1177/1352458516633903. Epub 2016 Feb 18.	
British Association of Urological Surgeons	General	General	BAUS is extremely disappointed by the lack of consideration of urological and other pelvic floor dysfunction (bowel and sexual function) in this document and feel it is a significant omission.	Thank you for your comment. People with MS are included in the NICE guideline on urinary incontinence in neurological conditions CG148. The NICE guideline on faecal incontinence CG49 is also

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				listed in the section on related NICE guidance. Recommendation 1.6.3 in the current guideline on MS CG186 includes an assessment of bladder and bowel symptoms and sexual function. This recommendation will be carried over.
British Association of Urological Surgeons	General	General	BAUS would also like someone with urological expertise in the management of patients with MS to be included in the requests for committee members. The present list does do not ask for anyone with any expertise in managing bladder , bowel and sexual dysfunction issues in these patients. Some of the MS nurse specialist have considerable expertise in this area and we would recommend this expertise be sought for developing these guidelines.	Thank you for your comment. This guideline is not covering the assessment and management of urological symptoms. A specialist with expertise in this area is therefore not being sought but the proposed guideline committee constitution includes people with experience of urinary symptoms, for example the two MS nurses.
British Association of Urological Surgeons	General	General	Urological issues BAUS would like to see addressed in this document include 1. In patients with MS who have incomplete bladder emptying, what is the optimum management strategy? Intermittent self catheterisation versus indwelling catheters and a wider exploration of this. 2. In patients with MS and overactive bladder symptoms (sometimes described by the patient as bladder spasms) how is this best managed? 3. In patients with MS, how to best manage incontinence 4. The issues of polypharmacy in patients with MS including anticholinergic side-effects	Thank you for your comment. People with MS are included in the NICE guideline on urinary incontinence in neurological conditions CG148. Recommendation 1.6.3 in the current guideline on MS CG186 includes an assessment of bladder symptoms. This recommendation will be carried over and a new evidence review will not be conducted. We will also consider a cross referral to the NICE guideline on medicines optimisation NG5 which includes recommendations on medication review.

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			5. Recurrent urinary tract infections in patients with MS	
British Association of Urological Surgeons	003	001 – 006	There is no mention of urological management we feel this should be part of the multidisciplinary rehabilitation programme. Urological problems should be identified, and sensible management plans put in place. All MS teams should have a named urologist who can lead on the management of these problems and create a pathway which allows this.	Thank you for your comment. People with MS were included in the NICE guideline on urinary incontinence in neurological conditions CG148. Recommendation 1.6.2 in the existing guideline CG186 refers to involving health professionals with expertise in specific areas and this will be retained in this update.
British Association of Urological Surgeons	005	009	Urological management should also be included in the proposed outline for the guideline in section 1.5 (MS symptom management and Rehabilitation). It should also be noted that when managing urological conditions in patient with neurological disease bowel management and sexual function should be considered in tandem.	Thank you for your comment. People with MS are included in the NICE guideline on urinary incontinence in neurological conditions CG148. The NICE guideline on faecal incontinence CG49 is also listed in the section on related NICE guidance. Recommendation 1.6.3 in the current guideline on MS CG186 includes an assessment of bladder and bowel symptoms and sexual function and this will be retained in this update.
British Association of Urological Surgeons	007	001	It is noted that in the section titled 'Related NICE the guidance'; 'urinary incontinence in neurological disease assessment and management' (2012) NICE guideline CG148 is referenced which is good but we feel it should be referred to in the main body of the guidelines also.	Thank you for your comment. Recommendation 1.6.3 in the current guideline on MS CG186 includes an assessment of bladder symptoms. This recommendation will be carried over and a new evidence review will not be conducted.
British Society of Neuroradiologists	Comment form question 1	N/A	***Q. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?*** • Consider recommendation of short protocol MR (3D FLAIR and DWI) for follow up, particularly in intensive follow-up regimes on disease-modifying treatments when the risk of progressive multifocal leukoencephalopathy is higher.	Thank you for your comment. The role of imaging in diagnosis is included in the scope of this guideline. Imaging will be considered when the guideline committee discussion the evidence reviews on diagnosis. The main role of imagining in follow up is in people on disease modifying therapies which is outside of the remit of this guideline. Decision support systems for MR interpretation would require a different guideline committee constitution to that proposed for example to including experts in imaging analysis

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 recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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			• Establish recommendations for minimum / core MR dataset for diagnosis and follow-up to allow for more accurate longitudinal comparisons and establish appropriate level of MR provision required. • MR utilisation in MS surveillance has increased considerably since this guideline was first introduced with attendant increased costs. Rational use of MR can contain these costs. Underutilisation may delay patients receiving appropriate treatment. Overuse of MR for follow up in patients increases costs and may affect health-related quality of life scores by increasing anxiety for patients. These costs are often not included explicitly in cost effectiveness assessments. • The role of decision support software and machine learning systems for MS MRI interpretation – many systems are currently available, but the evidence base is limited. If effective they may offer a partial solution to the current workforce pressures. This may be more appropriate for a technology appraisal.	
British Society of Neuroradiologists	Comment form question 1	N/A	***Q. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?*** • We think the appropriate use of MRI in diagnosis of multiple sclerosis in adults should be considered as this has changed since the previous guidelines were published.	Thank you for your comment. The role of imaging in diagnosis is included in the scope of this guideline. The main role of imagining in follow up is in people on disease modifying therapies which is outside of the remit of this guideline.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			• The appropriate use of MRI in the follow up of multiple sclerosis in adults should be considered as this is new literature on this since the previous guidelines were published. • The role of MRI in pharmacovigilance in disease modifying treatment in MS should be considered. • Imaging in MS accounts contributes significantly to the cost and workload of managing adult MS and also contributes to patient well being/ anxiety; therefore its appropriate use should be considered within the scope of the guidelines	
British Society of Neuroradiologists	003	009	There are now treatments licensed in the UK for primary and secondary progressive MS. The role MRI plays in determining eligibility for disease modifying treatment should be considered.	Thank you for your comment. Eligibility for disease modifying treatments is outside of the remit of this guideline. This guidance is expected to cross-refer to the NICE technology appraisals.
British Society of Neuroradiologists	003	013	MRI is now an important part of the McDonald criteria and should be considered as part of this guideline	This guideline will refer to the revised McDonald criteria.
British Society of Neuroradiologists	004	020	Advice with regard to appropriate imaging follow up would help manage system costs	Thank you for your comment. The main role of follow up imagining is in people on disease modifying therapies which is outside of the scope of this guideline. The need for imaging would also be identified through the existing recommendations on comprehensive review (1.6) in guideline CG186.
British Society of Neuroradiologists	004	020	Standardisation of imaging protocols will allow more accurate diagnosis and management	Thank you for your comment. The role of imaging as part of the McDonald criteria will be discussed in the evidence review on diagnosis.

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British Society of Neuroradiologists	004	024	Imaging is a key part of diagnosing MS and excluding differential diagnoses and should be considered as part of the scope of this guideline	Thank you for your comment. The scope of the guideline includes diagnosis and the McDonald criteria. These criteria included differential diagnosis.
British Society of Neuroradiologists	005	009	1.3 – coordination of follow up requires significant administrative support to allow for appropriate timing of review and investigations	Thank you for your comment.
British Society of Neuroradiologists	008	001	Economic aspects of imaging in MS should perhaps be considered as it is a large contributor to the NHS spend on MS	Thank you for your comment. The role of imaging is primarily in people on disease modifying therapies which is outside of the scope of this guideline.
British Society of Neuroradiologists	008	013	Role of imaging is not specified in this and we feel it should be as it is a key component	Thank you for your comment. The role of imaging will be considered under the draft review question 'What are the key diagnostic criteria for the following: multiple sclerosis; probable multiple sclerosis; neuromyelitis optica and clinically isolated syndrome?'
D.M. Orthotics Ltd.	Comment form question 1	N/A	**Q. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?** 1.1. Dynamic orthoses might reduce the risk of falls, through improved proprioception, pelvic and core stability. 1.1.1. Serrao, M. et al (2017) Use of dynamic movement orthoses to improve gait stability and trunk control in ataxic patients. European Journal of Physical and Rehabilitation Medicine 2017 Jun 19 1.1.2. Snowdon, NJ. (2019) Acceptability and feasibility of fabric orthoses for movement control in multiple sclerosis. Sheffield Hallam University. 1.2. Dynamic orthoses might reduce the dose, frequency or need for Botulinum Toxin Injection Therapy, through improved muscle tone and biomechanical alignment.	Thank you for your comment. We will make the guideline committee aware of your comments when they consider what interventions to include in the review protocols on symptom management and rehabilitation. Prioritisation is based on where there is controversy or variation in practice.

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			1.2.1 Stone, K. (2014) Dynamic Elastomeric Fabric Orthoses (DEFO) and physiotherapy after Botulinum toxin (BT) in adults with focal spasticity: A feasibility study using mixed methods. Exeter University.	
Medtronic Ltd.	005	009 (table row 1.3)	"The surveillance report describes an "access lottery" for patients with MS e.g. only 56% of those who could potentially benefit from taking a disease modifying therapy (DMT) are doing so. 81% of people who have access to MS specialists and the right information are taking a DMT but just 10% of people who could benefit from these treatments and did not have access to MS specialists are taking one. This demonstrates a lack of co-ordination of care and inequitable access to specialist treatments for many MS patients". "It is clear from the surveillance report that there is a poor co-ordination and inequitable access to specialist MS services. We suggest that this should be addressed in the updated guideline and that section 1.3: Co-ordination of Care, should make recommendations regarding the proactive identification of patients to facilitate equitable access to specialist MS care".	Thank you for your comment. The existing recommendations on comprehensive review (1.6) and co-ordination of care (1.3) support the timely access to treatment. These recommendations ensure that any symptoms are identified, and the person referred for intervention as appropriate. These recommendations will be carried over to the update and a new evidence review will not be conducted. The draft question 4.1 could also include the role of MS nurses and other health professionals in the identification of people who need to be assessed for intervention and support.
Medtronic Ltd.	005	009 (table row 1.5)	There is a significant body of evidence to support the use of intrathecal baclofen in patients with MS. We suggest that an additional section is created in the spasticity symptom management area of the guideline, to provide an overview of intrathecal baclofen in order to distinguish intrathecal baclofen from oral baclofen, and to highlight its place in the treatment pathway for management of spasticity for patients who are unable to tolerate the adverse effects of high dose oral antispasmodics. Oral baclofen is poorly transferred through the blood-brain barrier requiring high doses of the drug to be effective. The use of an implantable pump to deliver the drug intrathecally overcomes this obstacle and facilitates the use of much lower	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol on spasticity.

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			doses, avoiding the unacceptable side effects while still delivering a therapeutic benefit. Intrathecal baclofen is routinely used in NHS England for the treatment of spasticity and is commissioned via NHS England specialised commissioning.	
Multiple Sclerosis Academy	General	General	Should national or international examples of the best MS practice be part of this guideline even if they cover only part of the MS care such as neurorehabilitation or cognitive rehabilitation?	Thank you for your comment. This guideline can include research supporting interventions considered to be best practice. Neurorehabilitation and cognitive rehabilitation will be considered by the guideline committee when discussing relevant review protocols for the scope topic symptom management and rehabilitation.
Multiple Sclerosis Academy	General	General	Whereas in most centres (but not in all) infusions are given by non - MS nurses, shouldn't their role and responsibilities in managing these patients be unified?	Thank you for your comment. Who gives infusions is outside of the remit of this guideline.
Multiple Sclerosis Academy	General	General	There is heterogeneity in the roles of MS nurses of different banding across the country. It will be sensible that when the role of MS nurses is defined this is taken into account.	Thank you for your comment.
Multiple Sclerosis Academy	General	General	Very little is said about the role of the neuropharmacist and the role of neuroradiologist in this guideline. Both are integral part of running MS-MDTs and this should be emphasised especially as the Hub and Spoke model is the more common MS model service that is being adopted across the country.	Thank you for your comment. The current recommendation 1.3.1 refers to an MDT approach and the examples it gives is not meant to be exhaustive. This recommendation is not being updated.
Multiple Sclerosis Academy	001	017	There are MS nurses that are based purely in the community and some in hospitals only. It is important to ensure that their roles are clearly identified and if an MS patient sees more than one nurse or two MS-team nurses, clear roles and responsibilities are identified and it becomes very clear who remains the key worker for each MS patient.	Thank you for your comment. We will consider these different roles when the guideline committee devise the review protocols for this question. We have appointed an MS nurse based in the hospital and are seeking to recruit a nurse based in the community to the committee.

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			Monitoring of DMTs in some regions is divided between hospital-based and community-based MS nurses; this could lead to confusion and maybe examples of best practice should be part of this guideline to guide new developing centres or those who would like to restructure their services.	NICE guidelines are unable to signpost to examples of best practice but the NICE implementation team may use these to support the guideline https://www.nice.org.uk/about/what-we-do/into-practice .
Multiple Sclerosis Academy	001	020	1. Isn't the time to include the words degenerative in addition to the work inflammatory when we describe what MS is? 2. MS is also a progressive disease and this needs to be identified from the very beginning as progression is not simply a late stage process of the disease. 3. MS starts well before the first clinical presentation with a clinically isolated syndrome – this will need to be emphasised.	Thank you for your comment. We have added that neurodegeneration is the major cause of disability. We recognise that MS is a progressive disease and this needs to be identified early. Clinically isolated syndrome is included in the scope topic on diagnosis. See draft review question 1.1 in section 3.5.
Multiple Sclerosis Academy	002	013 - 016	It should be emphasised that people with progressive course of the disease do have periods of relapses and partial recovery. This is important as this will make them eligible to potential treatment with disease modifying treatment.	Thank you for your comment. The context provides a high level background to the scope and does not relate to any potential recommendations
Multiple Sclerosis Academy	002	005	Episodes of neurological deficit in MS occur over a period of days and sometimes weeks and months so strictly speaking not truly acute (although some episodes such as diplopia do manifest themselves acutely). Should we remove the word acute and replace it by subacute or give a more detailed definition of how the neurological deficit occurs in MS?	Thank you for your comment. We have added the term subacute.
Multiple Sclerosis Academy	003	004 - 006	I think part of the multidisciplinary rehabilitation programme should include neuropsychology. It takes for some of our patient a very long time – sometimes years for them to except their diagnosis and have a pro-active role in managing their disease. They end up isolating themselves and delay potential interventions or treatment.	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the evidence reviews on symptom management and rehabilitation and on information and support
Multiple Sclerosis Academy	003	017	I would include the variability on treatment initiation or treatment escalation across the regions.	Thank you for your comment. We have edited this as suggested.

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Multiple Sclerosis Academy	004	025 - 026	1. The role of MS society, MS trust and MS academy should be emphasised 2. The role and setting up the Wellbeing clinics should be part of both the support that MS patient should receive and part of their long-term rehabilitations.	Thank you for your comment. On the NICE website for each guideline there is a section 'information for the public'. This section signposts to sources of information and support. We will make the committee aware of wellbeing clinics when they discuss the review protocols.
Multiple Sclerosis Academy	004	013	People with Radiologically Isolated Syndrome or Clinically Isolated Syndrome are usually not followed-up by the MS nurses. Given that they are the group with the high risk of converting to MS, shouldn't they deserve a mention and therefore to part of the subgroup who MS nurses should be their point of contact?	Thank you for your comment. The scope of this guideline is people with suspected or diagnosed MS and we have therefore included clinically isolated syndrome. We refer to this in the draft review question 2.1.
Multiple Sclerosis Academy	004	024	1. Emphases should be given that the Imaging is reviewed by Neuroradiologists with an expertise in MS especially when the clinical or radiological presentation is not typical 2. To reduce the number of MS over-diagnosis, it is important to emphasise that McDonald criteria are applied only in the cases when a patients presents with a diagnosis of Clinically Isolated Syndrome 3. Recommendation of the typical (and minimum) MRI sequences required to make the diagnosis of MS should be included. 4. Importance of exclusions of MS mimics needs to be emphasised especially as some of the DMTs would not treat the underlying cause of inflammation / demyelination such as in cases of neuromyelitis optica spectrum disorder one of the most common differential diagnosis of MS 5. The existence of dual pathologies in MS and an increase risk or association of other autoimmune conditions should be emphasised as well.	Thank you for your comment. 1) Who reviews imaging it outside of the remit of this guideline. Recommendations are expected to be carried out by a person with appropriate competencies 2) This guideline will include a review of the McDonald criteria 3) This guideline will review the McDonald criteria including those on imaging 4) The diagnosis of neuromyelitis optica is included in the scope of this guideline 5) This guideline may cross refer to the NICE guideline on multimorbidity NG56. The association with other autoimmune conditions affects only a small proportion of patients and was therefore not identified as a priority area.
Multiple Sclerosis Academy	005	001	There is heterogeneity on the roles and responsibilities of the MS nurses across the country especially when it comes to the regions when two MS nurses team exist. Shouldn't this role be made more uniform?	Thank you for your comment. The scope includes a question on the role of MS nurses and will explore the different functions they perform.

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				How guidance is implemented locally is outside of the remit of NICE guidance.
Multiple Sclerosis Academy	008	013 - 015	I believe RIS (radiologically isolated syndrome should be included as well)	Thank you for your comment. This guideline will focus on people with suspected or diagnosed MS and radiologically isolated syndrome is therefore outside of remit of this guideline
Multiple Sclerosis Academy	008	018	1. Every MS patient should be provided with a list of all key people involved in their care including their main MS consultant, MS nurse, physiotherapist, OT ect. 2. When recommendations are made for patients to refer to a particular educational information, the direct link to that information is provided rather than simply the whole website (taking into account that the information is vast and this can be very overwhelming)	Thank you for your comment. This guideline will cross-refer to the NICE guideline on patient experience CG138 which makes a recommendation on this (recommendations 1.4.4 and 1.4.5) NICE guidelines do not directly link to educational information, but we will pass your comment onto the team responsible for the section on 'information for the public' on the NICE website.
Multiple Sclerosis Academy	008	020	1. Joint multidisciplinary team meetings involving the MS consultant, MS nurses and obstetric team should be set up to better monitor MS pregnant patients 2. Detailed information should be included in the conversations regarding the conception, effect of pregnancy and breastfeeding in MS and the effect of the disease modifying treatment in the fertility and outcomes of the newborn.	Thank you for your comment. How people who are pregnant are managed is outside of the scope of this guideline. The draft review question 'What information and support do adults with MS who may become pregnant find most useful?' will include what topics people want information on.
Multiple Sclerosis Academy	008	029	1. Distinguish between MS fatigue and other confounding factors 2. Role of occupational therapist in management of fatigue	Thank you for your comment. The draft review question for this topic focuses on interventions for the management of fatigue. Confounding factors may be considered by the guideline committee as part of this question.
Multiple Sclerosis Academy	008	032	Make cognitive assessment a routine part of MS patients assessment.	Thank you for your comment. Cognition is included in the current recommendation 1.6.3 CG186 comprehensive review. This recommendation will be carried over to the update and a new evidence review will not be conducted.

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Multiple Sclerosis Trust	001 009	017 004 - 006	**The MS Trust welcomes the proposal to review the role of the MS specialist nurse.** The MS Trust has championed the contribution of MS specialist nurses and campaigned for greater access to specialist services. Findings from GEMSS (Generating Evidence in MS Services) demonstrated the critical role of the MS specialist nurse: **For people with MS** MS specialist nurses are the health professionals most consulted about MS and play a vital role in the overall coordination of care. Their specialist expertise and continuity of availability enables them to improve outcomes for people with MS (pwMS) across all five domains of the NHS outcomes framework. **For other health professionals in the NHS** MS specialist nurses make a major contribution to increasing the capacity of other staff (particularly neurologists) and to building the skills and knowledge of other, less specialist professionals working with pwMS, including GPs, social care staff, other nurses and therapists, indirectly improving outcomes for PwMS. **For NHS commissioners** MS specialist nurses save costs elsewhere in the health system, both in ambulatory care costs (GP, A&E and neurology attendances) and prevention of unplanned hospital admissions resulting from complications of MS including MS relapses, bladder and bowel problems and respiratory infections. **For wider society** MS specialist nurses improve quality of life for pwMS and thereby help them to live full and active lives, including staying in work where this is possible. This benefits the economy and is of wider value to the families and carers of pwMS.	Thank you for your comment. We have noted your references, and these will be considered for inclusion in the evidence review to see if they meet the protocol criteria.

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			The GEMSS project and subsequent research carried out by the MS Trust has provided the foundation for Special Nurse Programme (SNP) which funds MS specialist nurses in areas of greatest need and Advanced MS Champions (AMSC) programme which funds specialist health professionals who coordinate care and provide specialist support to people with advanced MS. Preliminary results from the first three MS nurses we have funded indicate that each nurse saves the NHS an average of £72,000/annum. Our first Advanced MS Champion, based in Manchester, has saved the NHS £250,000 through avoidance of hospital admissions in the first 12 months in post. The evidence underpinning these projects is presented in the following reports published on the MS Trust website: Multiple Sclerosis Trust. **Defining the value of MS specialist nurses.** Letchworth: MS Trust; 2012 https://support.mstrust.org.uk/file/defining-the-value-of-ms-specialist-nurses.pdf Multiple Sclerosis Trust. **Evidence for MS Specialist Services: Findings from the GEMSS MS specialist nurse evaluation project.** Letchworth; MS Trust: 2015 https://support.mstrust.org.uk/file/Evidence-for-MS-Specialist-Services.pdf Multiple Sclerosis Trust. **Improving the efficiency of disease modifying drug provision** Letchworth; MS Trust: 2016 https://support.mstrust.org.uk/file/MSFV-DMD-report-10-5-17-2.pdf	

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			Multiple Sclerosis Trust. **Eight steps to improving your relapse service** Letchworth; MS Trust: 2016 https://support.mstrust.org.uk/file/8-Steps-Relapse-Guide-interactive-PDF.pdf Multiple Sclerosis Trust. **Improving services for people with advanced MS** Letchworth; MS Trust: 2016 https://support.mstrust.org.uk/file/MSFV-AMS-report.pdf Multiple Sclerosis Trust **MS Forward View: a consensus for the future of MS services** Letchworth; MS Trust: 2016 https://support.mstrust.org.uk/file/Future-of-MS-Services-WEB-FINAL.pdf Multiple Sclerosis Trust **MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Nurse Mapping Survey** Letchworth; MS Trust: 2018 Modelling Sustainable Caseloads: MS Specialist Nurses In addition, we are aware of these papers published in peer-reviewed nursing journals: Leary A, Quinn D, Bowen A.	

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			Impact of proactive case management by multiple sclerosis specialist nurses on use of unscheduled care and emergency presentation in multiple sclerosis: a case study. Int J MS Care. 2015 Jul-Aug;17(4):159-63. Abstract https://www.ncbi.nlm.nih.gov/pubmed/26300701 Full article https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4542710/ Quinn D, Bowen A, Leary A. **The value of the multiple sclerosis specialist nurse with respect to prevention of unnecessary emergency admission.** Mult Scler. 2014 Oct;20(12):1669-70. Letter to editor http://journals.sagepub.com/doi/full/10.1177/1352458514527865 Quinn D. **A collaborative care pathway to reduce admission to secondary care for multiple sclerosis.** Br J Neurosci Nurs. 2011;7(2):497-499. Abstract https://www.magonlinelibrary.com/doi/abs/10.12968/bjnn.2011.7.2.497 Mynors G. **Evaluating the role of the MS specialist nurse.** Br J Nurs. 2016 Feb 11-24;25(3):136. Abstract https://www.ncbi.nlm.nih.gov/pubmed/26878404 Bowen A, Mynors G, Suppiah J, Suppiah M. **Enabling specialist nurses to prove their value.** Nurs Times. 2016 Apr 6-12;112(14):16-9. Abstract https://www.ncbi.nlm.nih.gov/pubmed/27214969	

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			Leary A, Mynors G, Bowen A **Modelling the complex activity of multiple sclerosis specialist nurses in England.** Br J Neurosci Nurs 2015;11:170-176. Abstract https://www.magonlinelibrary.com/doi/abs/10.12968/bjnn.2015.11.4.170 Meehan M, Doody O. **The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review.** Mult Scler Relat Disord. 2020 Jan 3; 39:101918. Abstract https://www.ncbi.nlm.nih.gov/pubmed/31927154 Punshon G, Sopala J, Hannan G, Roberts M, Vernon K, Pearce A, Leary A. **Modelling the multiple sclerosis specialist nurse workforce by determination of optimum caseloads in the United Kingdom.** Int J MS Care. 2020 Jan 13; [In press] Full article https://ijmsc.org/doi/pdf/10.7224/1537-2073.2019-058 Roberts M, Hannan G, Govey H, Naik P. **Addressing unmet need in multiple sclerosis: the advanced MS champion role.** Br J Neurosci Nurs 2020 [In press]	
Multiple Sclerosis Trust	003 006	008 -009 003	We strongly disagree with the decision that disease-modifying therapies (DMTs) will not be covered by the guideline. At the MS Guideline workshop (12 December 2019) there was a strong view from all discussion groups that the guideline should include recommendations	Thank you for your comment. This guideline is expected to cross refer to the existing NICE technology appraisals on DMTs and therefore DMTs are outside of the scope of this guideline. The NICE pathway will link to the guidance on DMTs. We are also aware of the NHSE treatment algorithm on DMTs https://www.england.nhs.uk/commissioning/wp-

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			for a general pathway for DMT treatment, however, this feedback has been completely disregarded in drawing up the draft scope. Technology appraisals cover each of the DMTs approved for relapsing remitting MS and primary progressive MS (with one for secondary progressive at appraisal stage). The treatments are listed in the NICE pathway for MS. However, none of these documents give any guidance on when or how services should initiate and manage treatment with DMTs. The 2014 guideline makes very limited reference to DMTs. This makes the current guideline of limited value to commissioners and providers of services as there is no recognition of this vital aspect of MS services. Furthermore, the public version of the guideline makes no reference to DMTs at all. As a result, people affected by MS are given no indication of what they can expect from MS services, in terms of when they might have initial discussions about starting treatment or a review of their current treatment. This is in contrast to other NICE guidelines, such as those for rheumatoid arthritis and Parkinson's disease, which give significantly more detail of treatment options, recommend timescales for initial discussions and for treatment reviews. The introduction to the draft scope acknowledges the importance of initiating treatment early in the course of MS. Starting people on treatments and monitoring of DMTs represent a very significant proportion of MS teams' workload. A lack of guidance on the treatment pathway for DMTs is likely to have contributed to the considerable variance in DMT prescribing in England.	content/uploads/sites/12/2019/03/Treatment-Algorithm-for-Multiple-Sclerosis-Disease-Modifying-Therapies-08-03-2019-1.pdf

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			We consider it vital that the guideline provides at least basic recommendations for the treatment pathway. There is considerable published evidence to inform these recommendations.	
Multiple Sclerosis Trust	006	004	We note that autologous haematopoietic stem cell transplantation (AHSCT) was considered by NICE for a technology appraisal, but was not considered appropriate https://www.nice.org.uk/Media/Default/About/what-we-do/NICE-guidance/NICE-technology-appraisals/Block-scoping-reports/batch-block-scoping-report-B62.pdf. AHSCT is already commissioned by NHS England (NHSE) in specific circumstances as a treatment for some immune mediated diseases including severe, resistant multiple sclerosis. AHSCT is included in the NHSE DMT algorithm and is recommended for people with relapsing disease (not progressive) who have failed high-activity DMTs and are prepared to accept the significant risks of the procedure.	Thank you for your comment. We are unable to consider AHSCT for the same reasons it was considered not appropriate for a technology appraisal.
Multiple Sclerosis Trust	008	016 - 021	There are many stages at which people with MS, their families and carers may require access to information. These include but are not limited to pre-diagnosis, diagnosis, DMT treatment decisions, work-related issues, relapses, increasing disability and loss of mobility leading to wheelchair dependency, transition to secondary progressive MS, relationship breakdown, changes in care and support needed and received. Any review of information needs should take into consideration the on-going and critical need for information at all stages of MS.	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol for the question on information and support
Multiple Sclerosis Trust	008 009	027 - 032 001 - 002	We would include "people receiving palliative care" in draft questions 3.2 to 3.5, as for 3.1 and 3.2.	Thank you for your comment. This has been edited as suggested.
Multiple Sclerosis Trust	008	023 - 024	In the absence of NICE guidelines covering spasticity in adults, a review of pharmacological and non-pharmacological treatments for spasticity is	Thank you for your comment. This guideline is expected to cross-refer to the NICE guideline on cannabis-based medicinal products NG144.

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			welcomed. Good management of spasticity is vital; 1 in 5 people report that spasticity and spasms frequently affect their activities and 1 in 8 describe their symptoms as severe. After an exhaustive evaluation, nabiximols (Sativex) has been recommended as a treatment for people with moderate to severe spasticity which has not been improved by other treatments (Cannabis-based medicinal products NG144). We trust that the committee will acknowledge the meticulous assessment and detailed economic model developed for the review of cannabis-based medicinal products and retain the recommendation in 1.5.23, amended in 2019.	
Multiple Sclerosis Trust	008	027 - 028	We welcome the inclusion of interventions for mobility and anticipate that this will allow a reconsideration of the clinical and cost-effectiveness of fampridine (particularly in the light of the positive appraisal from AWMSG and imminent appraisal by SMC), and consideration of standing frames for people with advanced MS.	Thank you for your comment. This guideline will update the recommendations on fampridine. We will make the guideline committee aware of your comment on standing frames when they discuss the review protocols for the scope topic symptom management and rehabilitation.
Multiple Sclerosis Trust	008	027	3.2 is duplicated – should be 3.3 (and subsequent questions renumbered)	Thank you for your comment. This has been edited.
Multiple Sclerosis Trust	008	020 – 021	We entirely agree that information and support regarding family planning, pregnancy and childbirth is particularly important. MS is most often diagnosed among 20-40 year olds, two thirds of whom are women. Around this age, both men and women may be planning to have children. We anticipate that the committee will include in their review guidelines for pregnancy care in multiple sclerosis, drawn up in 2019 by a panel of UK experts: Dobson R, Passan P, Roberts M, Giovannoni G, Nelson-Piercy C, Brex PA	Thank you for your comment. We will consider your references when we conduct the evidence review for the draft review question 'What information and support do adults with MS who may become pregnant find most useful?'

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			UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines Practical Neurology 2019;19:106-114. https://pn.bmj.com/content/19/2/106	
Multiple Sclerosis Trust	009	030	In addition to the visual analogue scale used for pain, we would also wish to include other patient reported outcome measures, for example a numerical rating scale for spasticity which has been shown to be more sensitive to change that would be considered meaningful to individual patients than the clinician-measured Ashworth scale.	We will make the guideline committee aware of these outcomes when we discuss the review protocols on the clinical and cost effectiveness of interventions.
Multiple Sclerosis UK	**001**	021	Regarding prevalence figures. The latest published figures are 130,000	Thank you for your comment. This has been edited as suggested.
Multiple Sclerosis UK	**004**	003	Regarding Symptom management and rehabilitation: will there be any more detailed recommendations regarding exercise and complementary therapies, and whether a reference/link to the National MS Therapy Centres would be helpful	Thank you for your comment. The scope includes symptom management and rehabilitation. The guideline committee will prioritise what interventions to include when discuss the review protocol. Prioritisation will be based on areas of controversy or where there is variation in practice. On the guideline page on the NICE website there is a section on information for the public where we can signpost to organisations.
Multiple Sclerosis UK	**004**	025	Regarding providing information and support: Could there be consideration for guidance on when a patient should be seen by a clinician as there seems to be a postcode lottery at the moment across the UK. Such as once a year to be seen by a neurologist and every six months by the MS nurse	Thank you for your comment. We will make the committee aware of your comment when they decide on what to include in the review protocol on coordination of care.
Novartis Pharmaceuticals	General	General	The guidelines should emphasise the importance of facilitating early intervention in treating relapsing remitting multiple sclerosis (RRMS) and secondary progressive multiple sclerosis (SPMS)	Thank you for your comment. When to intervene will be considered when we discuss the review protocols for symptom management and rehabilitation.
Novartis Pharmaceuticals	General	General	**Coordination of care:** The current guideline includes extremely limited reference to SPMS – it acknowledges the large volume of MS patients that will	Thank you for your comment. People with SPMS will be included throughout the guideline.

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			go onto develop SPMS but doesn't include specific management or care recommendations, due to the traditional lack of treatments that have been available in the area. The current guidelines lack a clear definition of which patients should be under the care of a MS specialist service, and when a patient should be discharged to community or general practice. Currently, there is a lack of consistency in the management of progressive disease and some patients fall outside of the service and therefore have limited access to information, support and treatments.	
Novartis Pharmaceuticals	General	General	**MS symptom management and rehabilitation:** The guideline should set out clear standardised identification, referral and management pathways for those with MS who progress to a secondary progressive form of the disease. This should stress the importance of regular reviews by a specialist (including medication reviews) and encourage joined-up care between different parts of the local commissioning and service delivery pathway. These guidance needs to exist to allow consistency in patient management in order for all patients to receive the best care possible	Thank you for your comment. People with SPMS will be included throughout the guideline.
Novartis Pharmaceuticals	General	General	**Coordination of care:** Encourage care closer to the home of the patients. This would be beneficial to patients, reducing travel demands when they are already facing challenges with mobility and will free up resources in the specialist centres. There should be fast and efficient access to a multi-disciplinary team (MDT) to enable access to high efficacy treatments without delay due to restricted capacity of MDTs.	Thank you for your comment. This guideline will cross-refer to the NICE guideline on patient experience of adults NG138 which makes recommendations on 1.1 knowing the patient as individual including factors that impact on an individual ability to engage with care. The current guideline in the Multiple Sclerosis guideline recommends a MDT approach (recommendation 1.3.1). This recommendation will be carried over and a new evidence review will not be conducted.
Novartis Pharmaceuticals	General	General	**Coordination of care:** NICE guidance should support changes in HCP behaviours and practice. There has been a traditional sense of fatalism around SPMS, with clinicians sometimes being unenthusiastic about diagnosing someone with the form of the disease due to the implications around lack of management and treatment options. As this should no longer be the case, any	Thank you for your comment. People with SPMS will be considered throughout the guideline.

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			new recommendations around SPMS within the updated guidance should therefore be highlighted within the guideline. Information should include clear guidance on how to detect progression and what management pathways are available for patients with SPMS (nurse, rehab, physiotherapist, speech therapist etc.)	
Novartis Pharmaceuticals	003	006 - 008	Guidelines refer to licensed therapies in RRMS and 1 in PPMS. This should also refer to the licensed therapies in SPMS and should not be excluded	Thank you for your comment. This guideline is expected to cross refer to the guidance on Siponimod when it is published.
Novartis Pharmaceuticals	008	005	NICE may want to consider the EMA license for siponimod. Siponimod is currently undergoing a NICE appraisal (ID1304, GID-TA10436), which will be complete by the end of 2020. If positive, then it should be included in these guidelines under the related NICE guidance section	Thank you for your comment.
Novartis Pharmaceuticals	009	023	Cognitive decline in MS leads to a reduction in a patient's quality of life due to their inability to concentrate and carry out routine day-to-day activities. Outcome to asses cognitive decline such as Brief International Cognitive Assessment for MS (BICAMS) and Symbol Digit Modalities Test (SDMT) should therefore be encouraged as part of routine clinical practice in order to allow assessment and follow up treatment and support	Thank you for your comment. This list of outcomes is not exhaustive and will be revised for each review question. We will make the guideline committee aware of these outcomes when we discuss the review protocol on the clinical and cost effectiveness of interventions for cognition.
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop this guideline for Multiple Sclerosis in Adults: Management.	Thank you for your comment.
Royal College of Nursing	General	General	We welcome the review of the guidance and the opportunity to demonstrate the role of the MS practitioner.	Thank you for your comment.
Royal College of Nursing	Comment form question 1	N/A	***Q. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?*** A. It is suggested that NICE ask the ABN to consider the review of disease modifying treatments and develop a matrix to assist clinicians in prescribing of these. There is extreme variety across the Country within prescribing hence the need to review.	Thank you for your comment. Disease modifying therapies are outside of the scope of this guideline. We are seeking to appoint an MS nurse based in the community to the guideline committee.

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			Ensuring that Community care is recognised and the role of MS Nurse Specialists within the community setting (evidence includes relapse pathways, admission avoidance and proactive care)	
Royal College of Physicians	General	General	The RCP is grateful for the opportunity to respond to the above consultation. We would like to endorse the response submitted by the Association of British Neurologists (ABN).	Thank you for your comment.
SGBull & Co Ltd.	003	005	The draft scope currently excludes Orthotists as part of MDT rehabilitation programme. Orthotists knowledge of Orthoses and biomechanical understanding are key to many patient's rehabilitation in enhancing mobility levels. Early access can ensure that significant biomechanical deterioration does not occur.	Thank you for your comment. The guideline committee will prioritise what interventions to include in the review protocols on symptom management and rehabilitation. Prioritisation is based on where there is controversy or variation in practice.
Teva UK	004	011	The draft scope states that 'The guideline may also be applicable to young people aged 16 and 17 who are being treated in adult services'. We would emphasise that particular consideration does need to be given to this group of adolescents as at this age these individuals are transitioning between paediatric and adult care. Therefore, guidance should be put in place to allow the appropriate management of these young patients to ensure that their care is not interrupted during this transitional phase. Furthermore, it should be noted that the vast majority of disease modifying therapies available for the treatment of MS are not licenced for use in this subgroup, which presents an additional area of management that should be taken into consideration.	Thank you for your comment. We recognise the problems that children may have in terms of diagnosis and management and have carefully considered the guideline population. We considered we could not adequately address the needs of younger people with MS within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s. Also, people under 18 years are not included in other NICE guidance that we expect to refer to and these gaps would require additional consideration of evidence.
Teva UK	004	013	The draft scope currently states that *'No specific subgroups of people have been identified as needing specific consideration'* We disagree with this as there is a large proportion of women with MS that are of child bearing age whom are wanted to start, or continue to grow, their families. Recent evidence suggests that there are over 75,000 women in the UK living with MS. [1,2] We commissioned an online survey (10 August – 01 September 2017) among 1,000 women aged 25-35 who were diagnosed with Relapsing Multiple Sclerosis	Thank you for your comment. We focus on information and support for people with MS who may become pregnant. People with MS who may become pregnant will be included in all relevant questions and the evidence reviewed. We have noted your references for when we conduct the evidence review for this topic.

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			(RMS) within the last five years.[3] There were 200 women whom participated from the UK.[4] From the results of this survey it was identified that over 85% of the women had plans to have a child (n=170). However, many of these respondents had concerns at their time of RMS diagnosis. These concerns included their ability to care for their current or future children, the ability to have children or the ability to care for oneself. Ninety-five percent of women surveyed (n=189) identified important aspects that were not covered at the time of diagnosis. These included birth control, *post-partum* relapses, caring for children post pregnancy, what to expect during pregnancy and treatment options when trying to conceive. A large proportion of these women also stated that they had not spoken to a healthcare professional (HCP) about family planning, where HCPs included their neurologist, MS specialist Nurse or GP. The main reasons for why family planning was not discussed included not having enough time to ask, some thought having a family was not possible due to their MS, and certain individuals did not feel comfortable talking about family planning, whilst others stated that their HCP did not raise the subject. However, for those who did speak to a HCP about family planning, 99% of women with MS stated that they felt supported. Taken together, the results of this survey highlight that there is a need for additional considerations for women with RMS whom are of child bearing age/ planning to start or continue their families. These women require additional support with respect to family planning so that they are prepared and better informed of their options. It should also be noted that The Association of British Neurologists have recently published guidelines on MS and pregnancy.[5] These guidelines should be considered in the development of this guideline, as they bring together the consensus expert opinions of many physicians involved in the care of MS patients whom are planning to have a family. This guidance also advises that	

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			family planning discussions should be conducted soon after diagnosis, if not at the time of diagnosis for a women of child bearing age. In addition to the above, the Association of British Neurologists have included in their guidelines the use of disease modifying therapies in women with MS, where some specific therapies have been deemed to be appropriate for use, following the treating physician's clinical judgement on the benefit of continued therapy versus the potential risks, during pregnancy. This includes disease modifying therapies that have large data sets of evidence for no increased risk of malformations following use in early pregnancy.[6] Therefore, there are different considerations required in women with MS that are planning on having children that should be considered. Therefore, women with MS of child bearing age or those planning to become pregnant, should be considered as a specific subgroup that requires specific considerations. References: 1. MS Trust. About MS. Available at: https://www.mstrust.org.uk/ [Accessed February 2020] 2. Amato MP & Portaccio E. Fertility, pregnancy and childbirth in patients with multiple sclerosis: impact of disease-modifying drugs. CNS Drugs 2015; 29:207-220 3. Multiple Sclerosis and Family Planning – A Toolkit for Healthcare Professionals Managing Women with Multiple Sclerosis. *European Neurological Review*. 2018;13(Suppl. 1B):2–9. Available at: https://touchneurology.com/multiple-sclerosis-and-family-planning-a-	

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			toolkit-for-healthcare-professionals-managing-women-with-multiple-sclerosis/ [Accessed February 2020] 4. Data on File. Teva Pharmaceuticals Europe. 5. Dobson R, Passan P, Roberts M, Giovannoni G, Nelson-Piercy C, Brex PA. UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines. *Practical Neurology*. 2019;19:106-114 6. Sandberg-Wollheim *et al*. Pregnancy Outcomes from the Branded Glatiramer Acetate Pregnancy Database. *Int J MS Care*. 2018;20(1):9-14	
Teva UK	004	024	The scope outlines that a key area for focus covered in this update will be on the diagnosis and differential diagnosis of MS. We agree that this is a key area that should be updated in the new guidance, as there has been updated diagnostic criteria publications. However, we would also like to highlight the importance of a timely and early diagnosis for the increasing the quality of life of an MS patient and also potentially decreasing the economic impact of the condition. The Journal of Neurology, Neurosurgery & Psychiatry brought together a panel of experts on World MS Day 2017 to discuss the importance of time in MS.[1] The expert panel stated that there was increasing consensus about the importance of early intervention to maximise brain health. This would only be made possible if suspected MS patients are referred in a timely manner to a neurologist for confirmation of diagnosis and the subsequent initiation on appropriate therapy. The panel of experts also go on to state that *'MS is an expensive disease, and the costs rise sharply in line with increased disability and plummeting quality of life'*,[1] therefore early diagnosis and intervention may help to preserve brain health, particularly in individuals that are actively working and contributing to the economy. Thus, we would recommend that considerations are made to facilitate the early diagnosis of MS.	Thank you for your comment. We have added a draft review question 1.2 on early diagnosis.

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			References: Cerqueira JJ, Compston DAS, Geraldes R, *et al*. Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:844-850	
Teva UK	008	General	We welcome the opportunity to comment on this draft scope and believe that the key issues and draft questions overall are sufficient to capture updates in literature and current UK clinical practice for the management of Multiple Sclerosis. We have noted some additional considerations that are discussed below.	Thank you for your comment.
Teva UK	008	020	The scope has identified the query *'What information and support do people with MS who may become pregnant find most useful?'* We feel that this is query should be given a particular focus given the results of our survey in women with MS (details in row 2). The results of this survey have highlighted that often women with MS will not have information available to them, or discuss family planning with their HCP. Therefore, women with MS whom are planning to have a child should be referred to detailed accurate information on MS and pregnancy. In addition, HCPs and patients should be encouraged to speak about family planning at time of diagnosis, or early on in the family planning process. Information relating to this is already in existence, the Multiple Sclerosis Trust website has a number of articles that cover a range of aspects from contraception to pregnancy.	Thank you for your comment. We will make the guideline committee aware of the results of the survey when they discuss the review protocol for this question.
Teva UK	009	003	The scope has outlined a key issue as *'Coordination of care and the role of MS nurse specialists'*. We believe that the role of the MS nurse is critical for the effective management of MS patients. The MS specialist nurse role encompasses a number of different touch points with the patient, whether this is to explain the initial diagnosis and treatment options, supporting patients through life events, such as family planning, or helping patients with symptomatic control of their conditions, where the latter may involve other allied	Thank you for your comment. The role of the MS nurse in all aspects of care will be considered. This guideline will cross refer to the recommendations on continuity of care in the NICE guideline on patient experience of adult services CG138.

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			HCPs. Given that the MS nurse is often the patients' main contact point, we believe that the MS Nurse specialist should be considered in all aspects of this guideline, from diagnosis and beyond. Furthermore, coordination of care between the primary and secondary care settings is a crucial point that should be considered, particularly for those patients living in rural areas that find it difficult to access specialised services.	
The MS Society	006	003 - 004	We maintain the view that the management and monitoring of Disease Modifying Treatments (DMTs) should be included in the scope of this guideline, for the reason's set out in our response to the surveillance review of this guideline in September 2018. We appreciate specifics of each DMT are adequately covered by existing technology appraisals (TA). However, what TAs do not include is guidance on best practice in monitoring and managing DMTs as a whole. The prescribing, monitoring and management of this is becoming increasingly complex for prescribers to navigate. This complexity is reflected in the published NHS England DMT algorithm for MS published in September 2018. The algorithm includes numerous recommendations on best practice which ought to be reflected throughout this guideline. These include how to approach the topic of starting, switching and stopping treatment, with patients. We recommend a new section is added on pharmacological treatment (as seen in other neurological condition's NICE guidelines) to address these issues. A link to the NHSE DMT algorithm is needed as a minimum, in addition to links to the individual TAs.	Thank you for your comment. DMTs are outside of the scope of this guideline but it is expected that this guideline will cross-refer to the existing NICE technology appraisals.
The MS Society	008	016 - 021	These two review question should be expanded beyond palliative care and pregnancy. There are other transition points at which people with MS have	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol for the question on information and support

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			specific information, education and support needs that bear attention by the Committee, including: - Relapse - considering treatment options - considering leaving or returning to employment - reaching EDSS 7 i.e. starting to use a wheelchair - developing secondary progressive MS - relationship breakdown - withdrawal of driving licence - and change in care and support needed/received. Currently information needs at point of diagnosis are the only specific information needs addressed in the guideline. Evidence suggests information needs are not being met. In an MS Society survey (to be published in March 2020) of over 8,000 people with MS in the UK, over a quarter (28%) of respondents with MS in the UK said they have not been provided with enough information about available treatment options from health professionals.	
The MS Society	008	009	There are other key issues that would benefit from more detailed review: A) *what approaches to communicating diagnosis and stopping/switching treatment do patients find most useful?* People with MS tell us that the way in which professionals approach conversations with them about these sensitive topics has a big impact on their how they feel about their MS. When handled insensitively, with insufficient support or follow up offered, it can cause emotional distress. B) *what is the clinical and cost effectiveness of digital tools in supporting patients and professionals to manage that patient's MS well?* There is evidence that digital tools can effectively support people with MS and clinicians to manage the condition, as set out in the Nuffield Trust report, 2018:	Thank you for your comment a) We will make the guideline committee aware of your comment when they discuss the review protocols on information and support. b) We will make the committee aware of your comments when they discuss the review protocol on coordination of care. c) We will make the committee aware of your comments when they discuss the review protocol on coordination of care.

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			https://www.mssociety.org.uk/what-we-do/our-work/our-policies/ms-and-technology C) *what is the clinical and cost effectiveness of care planning for people with MS and how is this best defined and approached?* The current guideline includes references to both 'management plan' and 'care plan'. However, it does not define either of these terms, what should be included, how it should be developed with patients, expected outcomes or points of review. Evidence suggests few people with MS have care plan and there is a lack of understand as to what a care plans is. An MS Society survey (to be published in March 2020) of over 8,000 people with MS in the UK, only 16% of respondents said they have a care plan, 20% would like one but haven't got one and 13% don't know what a care plan is.	
The MS Society	008	009	We would appreciate clarity on the significance of, and development process of, the 'draft questions' detailed in the scope. Do the questions reflect where new evidence needs to be reviewed or do the questions imply area concern regarding the existing clinical evidence and/or cost effectiveness of the interventions referred to?	Thank you for your comment. The draft review questions are areas where new evidence has been identified by the surveillance review that may change the current recommendations https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal. The review questions also include some areas identified through the scoping process where there is controversy or variation in practice.
The MS Society	009	003 - 006	We very much welcome the inclusion of this question. There is a growing evidence base and consensus around innovative models of care that improve the efficiency and effectiveness of care, which should be reflected in this guideline. This review question should look at the role of data and technology, administrative and care coordination staff within MDTs, care planning (as above), and neurology nurses, as well MS specialist nurses who play a vitally important role in the treatment of care of people with MS. We would urge the Committee to consider in evidence the clinical and cost effective processes of care set out in the following:	Thank you for your comment. We will make the guideline committee aware of your comment when they discuss the review protocol for this question.

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			○ Optimum clinical pathway for MS developed by NHS England and various stakeholders ○ MS Society commissioned evaluations of two innovative models of care in 2019 (found here: https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/models-of-best-practise): ▪ *The Neurological Enablement Services (NES) and Neurological Case Management Service (CMS) are community services in Sheffield.* They support people aged 16 and over who are living with long-term neurological conditions, including MS. NES is a Multidisciplinary, integrated team (MDT) including Physiotherapists, speech and language therapists, psychologist, occupational therapists, assistive technology specialist and administrative assistants. NCMS is made up of three specialist case managers with senior clinical psychology input. The team focusses on patients with complex needs. Case management is a multiagency approach and works across Health and social care, third sector providers, housing and emergency services. ▪ *NeuroResponse (NR) service in Camden, London*, is a social enterprise organisation that aims to improve the lives of people with neurological conditions, including MS. It is delivered in partnership with LCW (an unscheduled care collaborative that incorporates aspects of the 111 service). NR provides urgent care for people with MS that can be accessed 24/7 through the 111 telephone number and delivered by	

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			IUC (integrated Urgent Care) GPs. The service represents a new way to support people with MS with common MS-related issues including UTIs and relapses. Innovative aspects include the use of technology to link in with existing services, the creation of digital care plans and bespoke QR labels, the use of couriers, the provision of out of hours specialist care and the co-design of the service with people with MS, staff and commissioners to ensure the service addresses local population needs. ○ NHS England RightCare toolkit for progressive neurological conditions, 2019: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf ○ The Neuro Network Vanguard (New Care Model Programme: Cheshire and Merseyside Acute Care Collaboration), Final Evaluation Report, November 2018: https://www.thewaltoncentre.nhs.uk/uploadedfiles/documents/Neuro%20Network%20Final%20Evaluation%20Report%20November%202018.pdf ○ Health Foundation, Neuro LTC: Online integrated care plan, University Hospital of Southampton NHS Foundation Trust in partnership with Solent NHS Trust, December 2018: https://www.health.org.uk/improvement-projects/neuro-ltc-online-integrated-care-plan ○ MS Society, My MS My Needs 2019 survey findings, to be published March 2020.	
Therapists in MS	001	017	It is felt that the area for review should be 'What is the tole of the MS Specialist Nurse/Practitioner' as there are a number of therapists who work in a	Thank you for your comment. The draft review question 4.1 has been expanded to include other health professionals.

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 recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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			practitioner role similar to that of the MS Specialist Nurse, especially in the area of advanced MS and with those not eligible for disease modifying drug treatment (DMD).	
Therapists in MS	003	016	The following should be included: self-management and staying well with MS through advice and education with associated recommendations on activity and exercise, diet, and hydration.	Thank you for your comment. This guideline may cross-refer to the existing NICE guidance on lifestyle modification. The recommendation on comprehensive review (1.6.3) in the existing guideline CG186 refers to general health. This recommendation will be carried over and a new evidence review will not be conducted.
Therapists in MS	005	001	Again, this should not leave out specialist MS therapists. Many therapists work as practitioners (in a similar role to MS Specialist Nurses) especially in the area of advanced MS and with those not eligible for disease modifying drug treatment (DMD). They also have a key role in coordination of care, assessment, advice and specialist rehabilitation throughout the disease trajectory.	Thank you for your comment. We have edited draft question 4.1 to include other health professionals.
Therapists in MS	005	009	1.6 There are additional areas which need to be added to the recommendations from existing guideline: a) In addition to muscle spasms and stiffness, postural management and management of complex spasticity need to be included, together with access to specialist equipment for postural management (e.g. sleep systems, T-rolls, specialist static seating…) b) In addition to access to adaptations and equipment at home, specific mention of access to environmental control systems and access to equipment for computer access. c) Advance care planning needs to be included in an area for consideration at comprehensive review. The current guidance states 'Refer people with MS to palliative care services for symptom control and for end of life care when appropriate' but MS nurses/practitioners and therapists will assess readiness for discussion of advance care planning, and will often be the key profession who supports a person with MS in writing advance care plans.	Thank you for your comment. a) We will make the guideline committee aware of your comment when they discuss the review protocol on spasticity b) We will make the committee aware of your comment when they discuss the review protocols on symptom management and rehabilitation. (c) The surveillance review did not identify any new evidence that would change the current recommendations in the section on comprehensive review https://www.nice.org.uk/guidance/cg186/documents/surveillance-review-proposal. We will cross refer to the NICE guideline on end of life care for adults: service delivery NG142 The existing recommendations on comprehensive review 1.6 in the existing guideline CG186 support the timely referral for therapy. These recommendations will be carried over and a new evidence

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Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			1.17 The following should be included in addition to the recommendations in the existing guideline: a) Availability of timely referral to specialist neurological therapists with expertise in MS at the time of relapse where there is physical and/or cognitive deterioration leading to the person being unable to function as prior to relapse. (This will include physiotherapy, occupational therapy, speech and language therapy). b) Availability of specialist community therapists (skilled in neuro-rehabilitation) as part of a multi-disciplinary team, to support safety and daily function at home, where there is impact on activities of daily living, at the time of MS relapse.	review will not be conducted. We now refer to the role of other health professionals in the draft review question 4.1.
Therapists in MS	008	016 - 019	a) This should also question the best methods of delivery of information/education. Areas such as: health coaching, cognitive behavioural therapy (CBT), readiness to change, acceptance and commitment therapy, should be considered. b) In addition, specific information regarding support to navigate benefits, should be included. c) Reference to accessing continuing health care (CHC) for those with advanced health needs should be included.	Thank you for your comment. We will make the guideline committee aware of your comments when they discuss the review protocol for the question on information and support. This guideline may cross refer to the NICE guideline on patient experience of adult NHS services CG134
Therapists in MS	008	022	As part of section 3, the following questions should be included: a) For adults with MS what is the clinical and cost effectiveness of exercise and physical activity? b) For people with advanced MS/higher levels of disability, what is the clinical and cost effectiveness of a standing programme/other therapeutic intervention?	Thank you for your comment. We will make the guideline committee aware of your comment when they devise the review protocols on symptoms management and rehabilitation.
UK Multiple Sclerosis Specialist Nurses Association	General	General	We welcome the review of the guidance and the opportunity to demonstrate the role of the MS practitioner	Thank you for your comment.

Multiple Sclerosis in Adults: Management

Consultation on draft scope
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Registered stakeholders