# Appendix B: Stakeholder consultation comments table

2018 surveillance of [Multiple sclerosis in adults: management](2014)

Consultation dates: 31 August 2018 to 13 September 2018

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Overall response</th>
<th>Comments</th>
<th>NICE response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coloplast Limited</td>
<td>Yes</td>
<td>The focus in this review on management of symptoms is very welcome. A very common symptom of all forms of multiple sclerosis is neurogenic bladder and bowel dysfunction. In particular, bowel dysfunction affects up to 68% of people living with MS (ref: Preziosi et al. Transanal irrigation for bowel symptoms in patients with multiple sclerosis. Dis of Col and Rectum. Vol 55, 2012). The current NICE CG186 does refer to the management of fatigue, spasticity, mobility, pain, visual problems, ataxia and tremor, emotionalism, memory and cognitive impairments, including the use of anti-depressants, neuropsychological rehabilitation are within the remit of this guideline. As there are existing NICE guidelines for these conditions, we aim not</td>
<td>Thank you for your comments. The scope for NICE guideline CG186 does not include interventions for the management of bladder or bowel dysfunction. The management of fatigue, spasticity, mobility, pain, visual problems, ataxia and tremor, emotionalism, memory and cognitive impairments, including the use of anti-depressants, neuropsychological rehabilitation are within the remit of this guideline. As there are existing NICE guidelines for these conditions, we aim not</td>
</tr>
</tbody>
</table>
management of bowel dysfunction in its section 1.6 (Comprehensive Review). We would suggest that management of bladder and bowel symptoms are included in section 1.5 (MS symptom management and rehabilitation) instead.

Neurogenic bladder and bowel problems are direct consequences of the neurological damage due to the disease progression. Hence, our view is that they should be addressed as a symptom of MS also in this Clinical Guideline.

When specifically referring to bowel management, the current guideline refers to the existing NICE CG49 (Management of faecal incontinence). Whereas faecal incontinence does occur as a consequence of neurogenic bowel dysfunction in MS patients, it is actually constipation that affects these patients to a higher degree.

As can be seen in the publication by Munteis E et al. (Anorectal dysfunction in multiple sclerosis. Multiple Sclerosis 2006; 12: 215/218), where a series of 193 MS patients were assessed for prevalence of anorectal symptoms, constipation alone was the largest single bowel symptom in these patients.

to repeat guidance, but to cross-reference them. We acknowledge the information you have provided concerning the prevalence of constipation in people with MS and the impact this can have on quality of life. Recommendation 1.6.3 does recommend assessing bowel function, which would include constipation, the reference to Faecal incontinence NICE clinical guideline 49 does not preclude assessment of constipation; and recommendation 1.6.4 recommends referring any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that these conditions can be managed.

When the guideline is updated, the scoping process will identify any further areas that may be considered for inclusion in the update.

<table>
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<tr>
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</tr>
<tr>
<td><strong>Affecting 41% of the sample.</strong> Incontinence alone was much less prevalent (1% of the sample). For this reason, we believe the current limitation to referring to CG49 is not enough to address the bowel problems of MS patients, which are very frequent and cause significant loss of quality of life.</td>
</tr>
<tr>
<td><strong>More focus on bowel problems management is suggested, including the management of constipation in these patients.</strong></td>
</tr>
<tr>
<td>Recently, a NICE MTG has been published, referring to a specific intervention to address constipation and faecal incontinence in patients with neurogenic bowel dysfunction (NICE MTG36 Peristeen Transanal Irrigation for the management of bowel dysfunction).</td>
</tr>
<tr>
<td>Transanal irrigation may be superior to standard treatments of bowel dysfunction, while it is likely not to cost any more than such standard treatments.</td>
</tr>
<tr>
<td>Evidence generated in a UK-based patient population exists on the long-term efficacy and safety of transanal irrigation in MS Patients (Ref: Passananti V et al. Long-term efficacy and safety of</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Organization</th>
<th>Response</th>
<th>Comments Provided</th>
<th>Acknowledgment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pernicious Anaemia Society</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Therapists in multiple sclerosis (TiMS)</td>
<td>Yes</td>
<td>Allied health professionals, especially physiotherapists and occupational therapists, are ideally placed to ensure that the new NICE recommendations for symptom management and rehabilitation are implemented.</td>
<td>Thank you for your comments. Physiotherapists and occupational therapists have been highlighted in NICE guideline CG186 as important in the co-ordination of care for people with MS (recommendation 1.3).</td>
</tr>
<tr>
<td>Department of Health and Social Care</td>
<td></td>
<td>I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Teva UK Limited</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Salford Royal NHS Foundation Trust</td>
<td>Yes</td>
<td>We welcome the update.</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>United Kingdom Multiple Sclerosis</td>
<td>Yes</td>
<td>We welcome the update.</td>
<td>Thank you for your response.</td>
</tr>
</tbody>
</table>

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Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple sclerosis in adults: management (2014)
### Specialist Nurse Association (UKMSSNA)

<table>
<thead>
<tr>
<th>Yes</th>
<th>We agree that the surveillance activity has identified new evidence that may be of sufficient significance to alter current recommendations.</th>
<th>Thank you for your comments.</th>
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<tr>
<td></td>
<td>We welcome the proposal to update.</td>
<td></td>
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<tr>
<td></td>
<td>We would welcome the possibility of not separating pharmacological from non-pharmacological interventions. If possible it would be useful to rank all interventions based on likelihood of benefit.</td>
<td></td>
</tr>
</tbody>
</table>

### Royal College of Nursing

<table>
<thead>
<tr>
<th>Yes</th>
<th>Although overall good there are some significant problems Diagnosis – List of tests is neither comprehensive nor justified in all people. Would be appropriate in chronic fatigue but does not include HbA1c, assessing if risks for HIV or testing for Lyme’s in prevalent areas, nor looking for vasculitis or antiphospholipid antibodies if appropriate. Some of this will be done in secondary care I very much</th>
<th>Thank you for your comments.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>We have recommended that a rehabilitation approach is taken when the recommendations for pharmacological and non-pharmacological interventions are updated. If information is available, the cost-effectiveness of interventions and resource impact information will be provided.</td>
<td></td>
</tr>
</tbody>
</table>

### Associations British Neurologists

| Yes |  | Thank you for your comments. |
| --- |  | --- |
|  | We will amend the update proposal to include updating the recommendation on diagnosis in light of the 2017 McDonald criteria and to consider any implications these criteria have on the recommendation concerning the information and support patients receive. Please note that only the diagnosis criteria for MS and possible MS including the revised McDonald criteria for MS, diagnostic criteria for neuromyelitis optica and the | |

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doubt more than an FBC and U&E will be done by GP pre referral.

Under the new MacDonald criteria, MRI may show both old and new lesions and oligoclonal bands to show dissemination in time. So there is an increased emphasis on LPs.

1.1.8 People with a single episode of demyelination should be told about the risk of developing MS and offered follow up. However, risk varies depending on MRI, OCB and if ADEM or NMO is a consideration. We could not follow up everyone with a few non specific dots (vascular, migraine, normal for age or similar).

Evoked potential studies can sometimes be helpful when MRI lesions are not diagnostic.

If urgent – not appropriate to be trying to speak to Neurology consultant, need to admit to appropriate local team eg for rule out of cord compression in severe cord syndromes. If unsure could discuss with local Neurology on call service.

Not just optic neuritis but in many cord syndromes and odd brain stem syndromes (like area postrema) does NMO spectrum disorder need appropriate investigation for people with clinically isolated syndrome is within scope of NICE guideline CG186. The evidence indicates that AQP4 detection in serum with immunoassay may be useful in differentiating NMO from MS; however, the current recommendation highlights the need to refer to specialists who will use established up-to-date criteria for diagnoses and it is felt that detailing specific tests goes beyond the intended level of detail for this recommendation.

In relation to your concern that bladder, bowel and sexual function are not discussed, these are highlighted in recommendation 1.6 Comprehensive review. The recommendation also states ‘Ensure that people with MS are offered a medication review in line with Medicines adherence (NICE clinical guideline 76)’, which would necessitate recording DMTs.

Thank you for your comments on exercise and fatigue, the management of fatigue will be considered in the update. In relation to exercise, NICE guidelines are clear that patient-centred care is key and the recommendations reflect different exercises that may be of benefit to people with MS.

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Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple Sclerosis in adults: management (2014)

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<tr>
<td>to be considered and the aquaporin 4 antibody performed. Information at time of diagnosis may need to be staged with more information following eg with meeting with MS nurse. Odd list of information on follow up includes cognition and contraception but not bladder, bowel and sexual function. Exercise is good but the huge list of different sorts is prescriptive. For fatigue a comprehensive stepped advice- look for exacerbating factors, pain, poor sleep, other disease, advice, exercise then medication. There is often no clear link to social services to whom the patient can be referred. 1.2.5 not mention fatigue as cause of cognitive issues – it is the most common problem leading to multitasking issues and not taking information in. 1.5.28 SSRIs can be used for emotional lability too. Relapse treatment does not mention that it improves speed but not extent of recovery.</td>
</tr>
<tr>
<td>In the absence of evidence concerning the use of SSRIs for emotional lability in people with MS, this can not be updated. In relation to relapse, plasma exchange is not within scope for NICE guideline CG186 but all steroids are within scope. Please note that vocational rehabilitation is not within scope for NICE guideline CG186.</td>
</tr>
</tbody>
</table>
Relapse treatment does not include the use of Plasma exchange for severe steroid non responsive episodes.

Relapse treatment does not include options for those allergic to methyprednisilone – other steroid groups like Dexamethasone or use of ACTH – eg by specialist neurologists only.

The list for annual review includes issues that may be best dealt with by other team members eg in general practice. Time in clinic needed would be long and if need to do EDSS even longer.

No comment on sleep disorders being a possible cause of fatigue in MS with up to 65% of patients having RLS

The comprehensive review section doesn’t include recording their medication or DMTs

The relapse section should include reference to a relapse triggering review of DMT and not just giving steroids for patients at risk of PML?

No mention of vocational rehabilitation – review of evidence here

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<th>Response</th>
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<tbody>
<tr>
<td>NHS England</td>
<td>No comments have been received from NHS England colleagues.</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Medtronic Ltd</td>
<td>Yes, no comments</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>MS Society</td>
<td>Yes and no We agree for a need for a review of the guidelines but would not like to see sections closed to consultation at this stage. We feel that it is important that NICE are able to consider evidence submitted on every guideline recommendation when this goes to public consultation. The surveillance has not considered many sources of evidence (non-peer reviewed grey literature) which provide new evidence on how MS care should</td>
<td>Thank you for your comments. Please note that this is the consultation for the decision to update NICE guideline CG186. When the guideline is updated, stakeholders will be consulted on the draft guideline. For information on NICE processes please see <a href="#">NICE guidelines: the manual</a>. The surveillance process is to consider published evidence and determine whether it is likely to have an impact on recommendations. In order to be confident that evidence</td>
</tr>
</tbody>
</table>

A systematic review of research undertaken in vocational rehabilitation for people with multiple sclerosis

Article · Literature Review (PDF Available) in Disability and Rehabilitation 34(24):2031-8 · April 2012 with 308 Reads

DOI: 10.3109/09638288.2012.669019 · Source: PubMed

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operate. There are also currently areas being researched by the MS Society and others which could influence the recommendations. Therefore we ask the NICE allow consultation on all the recommendations within the MS guidelines will have an impact on recommendations and that an update is therefore appropriate, we generally focus on evidence published in peer-reviewed journals, not grey literature at this stage. We would encourage researchers to publish their research in peer reviewed journals.

When the guideline is updated this involves evidence reviews and economic analyses which are considered by the committee developing the guideline, plus any additional evidence deemed necessary such as expert testimony, views of service users from a reference group, information from focus groups or other exceptional consultation activity. The committee discusses how these answer the review questions and summarises each area of evidence (see NICE guidelines: the manual).

<table>
<thead>
<tr>
<th>Roche Products Ltd</th>
<th>Yes</th>
<th>No comments provided</th>
<th>Thank you for your response.</th>
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</thead>
<tbody>
<tr>
<td>Biogen Idec</td>
<td>No</td>
<td>Biogen agree there is new evidence relevant to section 1.5: MS symptom management and rehabilitation. However, Biogen also believe that there is sufficient new evidence in other sections, e.g. diagnosis of MS (section 1.1), Monitoring of</td>
<td>Thank you for your comments supporting the update of recommendation 1.5. We will amend the update proposal to include updating the recommendation on diagnosis in light of the 2017 McDonald criteria and to consider any</td>
</tr>
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Disease (section 1.6), and treatment with DMTs (disease modifying therapies). Therefore, the full guideline should be updated (see comments below).

Please note that treatment with disease-modifying treatments (DMTs) is specifically outside of the scope of NICE guideline CG186. The guideline states in recommendation 1.6.5 ‘Ensure that people with MS are offered a medication review in line with Medicines adherence (NICE clinical guideline 76)’. The overview page of the guideline also provides a link to the technology appraisals on the multiple sclerosis page of the NICE website which provide details of DMTs.

| Novartis Pharmaceuticals UK Limited | Yes | Section 1.2.2 : It is not clear if NICE intends to just add in the four different 'types' of MS and/or delete the other information the patient should be given. We feel the original categories of help groups etc. should still be discussed with patients on diagnosis. Novartis' understanding is that the guidelines are being updated to segment MS into categories when the MS community is trying to describe the journey of MS as a continuum. We think it would be much more effective if the guidelines were to describe the implications these criteria have on the recommendation concerning the information and support patients receive.

To confirm, we are not suggesting that any information in recommendation 1.2.2 is removed, but that it is updated in relation to Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria. Thank you for the information concerning the MS community’s view of MS as a continuum. In light of this, we will remove the editorial change to recommendation 1.2.2 and instead ask developers of the guideline update to consider this as an area for update. |

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‘phases’ of MS, as this discourages continued segmentation.

Section 1.5.2: Consider rewording sentence

Section 1.6.3: MS disease course – Novartis feels that this should go beyond being an assessment of relapses in the past year but also potential progression noted by the patients and/or carers in the past year.

Section 1.7.4: “differentiate between relapse and fluctuations in disease or progression” – it may be required to define ‘fluctuations in disease’ further, as if they meet the criteria of a relapse then they should be classified as so. If this is progression, then you would only know after the patient does not return to baseline, therefore relating to our previous comment on assessing annually for potential progression as well as relapses.

The Royal College of Physicians
Not answered

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).

It is unclear what should be re-worded in recommendation 1.5.2, or the reason for this being requested.
Thank you for your comment on recommendation 1.6.3. All comments will be shared with the developers.
In relation to recommendation 1.7.4, the previous recommendation clarifies what a relapse is and therefore what a fluctuation would be.

Thank you for your response.
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<tbody>
<tr>
<td>NTW Foundation Trust</td>
<td>Yes</td>
<td>The amended guidelines reflects current rehabilitation practice in our area with the focus on rehabilitation working outside the acute/diagnostic setting.</td>
<td>Thank you for your comments.</td>
</tr>
<tr>
<td>Coloplast Limited</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Pernicious Anaemia Society</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Therapists in multiple sclerosis (TiMS)</td>
<td></td>
<td>The rehabilitation section does not include: 1. the effects of exercise on motor function e.g. transfers 2. the effects of exercise on people with severe MS (EDSS ≥ 6.5) A recent randomised controlled trial conducted in the UK has shown that a self-managed, physiotherapy intervention (standing frame) was feasible and significantly improved motor function</td>
<td>Thank you for your comments and for highlighting this research. We will share this information with the developers responsible for updating NICE guideline CG186 so that it can be considered, once published, during the update of the guideline.</td>
</tr>
</tbody>
</table>

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(strength) in people with severe MS (EDSS ≥ 6.5). The intervention was also cost effective in line with NICE’s QALY threshold. **This is the first RCT looking at the effects of exercise on people with severe MS and has important implications for maintaining function in people with severe MS and minimising the costly secondary complications of immobility.** The findings have been presented at the RIMS conference in May 2018 (and published) and will be published in peer review journals shortly (**ECTRIMS abstract added below**). The protocol has also been published.

<table>
<thead>
<tr>
<th>Department of Health and Social Care</th>
<th>Not answered</th>
<th>No comments provided</th>
<th>Thank you for your response.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teva UK Limited</td>
<td>No</td>
<td>It is assumed that the list of associated NICE TAs will be updated (e.g. TA32: Beta interferon and glatiramer acetate for the treatment of multiple sclerosis, updated and replaced with TA527)</td>
<td>Thank you for your query. NICE guideline CG186 does not list technology appraisals within the guideline, but provides a <a href="#">link</a> to the relevant TAs which are updated when they are published. This page has TA527. The pdf of the full guideline does not get updated with new TAs.</td>
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We feel that the specific role of the MS Specialist Nurse needs to be highlighted as yet again it is not. There is evidence from the MS Trust as to the impact nurses have at all crucial points of a patient's MS role of specialist nurses has been identified and highlighted as pivotal in other NICE guidance for long term conditions.

Thank you for your comment.

Published evidence in peer-reviewed journals concerning the role of the MS nurse was searched for. Evidence was identified concerning the patient experience and the barriers faced by people with MS in accessing services and in receiving healthcare that meets their needs. The evidence indicates that there is a problem with the implementation of person-centred care and in accessing services that meet the needs of people with MS. While there appear to be issues with the implementation of recommendations in recommendation 1.2 on providing information and support and recommendation 1.3 on the coordination of care, the evidence does not indicate that the recommendations themselves are incorrect or require updating. The current recommendations highlight the importance of providing information and support at the time of diagnosis, that the care for people with MS should involve a coordinated multidisciplinary approach with professionals who have expertise in MS (including MS nurses) and that people with MS should be offered a single point of contact to coordinate care and help them access services.

We will share your concerns about the role of the MS specialist nurse with the developers responsible for...
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</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom Multiple Sclerosis Specialist Nurse Association (UKMSSNA)</td>
<td>Yes</td>
<td>We are very disappointed that during this update that the role of the MS Specialist Nurse is not being enhanced throughout the guideline – this is an ideal opportunity to ensure the pivotal role that Specialist Nurses provide within MS diagnosis, treatment and care, as outlined in the Parkinsons NICE guidance.</td>
</tr>
</tbody>
</table>

Thank you for your comment. We will share your concerns about enhancing the role of the MS specialist nurse with the developers responsible for updating NICE guideline CG186 and recommend that the role of the MS nurse is considered during the scoping process. Please note that this consultation is not for an updated guideline – this is for views concerning the proposal to undertake an update of the guideline. When the updated guideline is in development draft copies of the scope and guideline will be published for consultation. For information on NICE processes please see NICE guidelines: the manual.

During this surveillance review published evidence in peer-reviewed journals concerning the role of the MS nurse was searched for. As stated in the surveillance report, evidence was identified concerning the patient experience and the barriers faced by people with MS in accessing services and in receiving healthcare that meets their needs. The evidence...
indicates that there is a problem with the implementation of person-centred care and in accessing services that meet the needs of people with MS. While there appear to be issues with the implementation of recommendations in recommendation 1.2 on providing information and support and recommendation 1.3 on the coordination of care, the evidence did not indicate that the recommendations themselves are incorrect or require updating. The current recommendations highlight the importance of providing information and support at the time of diagnosis, that the care for people with MS should involve a coordinated multidisciplinary approach with professionals who have expertise in MS (including MS nurses) and that people with MS should be offered a single point of contact to coordinate care and help them access services.

Royal College of Nursing

Yes

We are very disappointed that the proposal to update the guideline, the role of the MS Specialist Nurse has not been enhanced throughout the guideline – this is an ideal opportunity to ensure the pivotal role that Specialist Nurses provide within MS diagnosis, treatment and care.

Thank you for your comment. We will share your concerns about enhancing the role of the MS specialist nurse with the developers responsible for updating NICE guideline CG186 and recommend that the role of the MS nurse is considered during the scoping process. Please note that this consultation is not for an updated guideline – this is for views concerning the proposal to undertake an update of the guideline. When the updated guideline is in

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development a draft copy of the guideline will be published for consultation. For information on NICE processes please see NICE guidelines: the manual.

During this surveillance review published evidence in peer-reviewed journals concerning the role of the MS nurse was searched for. As stated in the surveillance report, evidence was identified concerning the patient experience and the barriers faced by people with MS in accessing services and in receiving healthcare that meets their needs. The evidence indicates that there is a problem with the implementation of person-centred care and in accessing services that meet the needs of people with MS. While there appear to be issues with the implementation of recommendations in recommendation 1.2 on providing information and support and recommendation 1.3 on the coordination of care, the evidence did not indicate that the recommendations themselves are incorrect or require updating. The current recommendations highlight the importance of providing information and support at the time of diagnosis, that the care for people with MS should involve a coordinated multidisciplinary approach with professionals who have expertise in MS (including MS nurses) and that people with
| Associations British Neurologists | There are links to other guidelines but has not said that disease modifying therapies should be offered where appropriate. A passing reference to urgent but not defined and not given clear pathways No mention of sexual dysfunction management No comment on need for disability services such as rehabilitation medicine to follow up. Need for palliative care and care at home in the most disabled. | MS should be offered a single point of contact to coordinate care and help them access services. Thank you for your comments. Please note that NICE guideline CG186 does not cover disease-modifying treatments. These are covered by the technology appraisals on the multiple sclerosis page of the NICE website, which is highlighted on the overview page of NICE guideline CG186. There are also several recommendations within the guideline that highlights treatments, including disease-modifying therapies (recommendation 1.2.2, 1.5.1, 1.7.14). We will pass on your comment concerning the need to define what is considered as ‘urgent’ in recommendation 1.1.6 on speaking to the ‘consultant neurologist if you think a person needs to be seen urgently’ to the developers responsible for updating NICE guideline CG186. The need to assess sexual function is highlighted in recommendation 1.6.3 but the management of sexual dysfunction is not within scope of the guideline. We have highlighted that the update of NICE guideline CG186 should take a rehabilitation approach. The coordination of care and for people with MS is within the |
Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple sclerosis in adults: management (2014)

NHS England | Not answered | No comments provided | Thank you for your response.

Medtronic Ltd | Yes | **Section 1.3: Coordination of care.** 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 treatments for many MS patients. | Thank you for your comments. We will share your suggestion concerning the need to improve the uptake of DMTs in people with MS with the developers responsible for updating NICE guideline CG186. No evidence was identified concerning the use of intrathecal baclofen, as such it will not be highlighted as an area for update in NICE guideline CG186.
We suggest that the co-ordination of care section needs to be updated with strengthened recommendations for proactively identifying patients and ensuring they have equitable access to co-ordinated MS care.

**Section 1.5: MS symptom management and rehabilitation.**

We suggest that an overview of intrathecal baclofen for the treatment of spasticity be added to this section.

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| MS Society | Yes | **Diagnosing MS**  
Diagnostic criteria including what has changed in diagnosing MS in recent years is detailed in the British Medical Journal (last updated May 2018) and can be found here  
https://bestpractice.bmj.com/topics/en-gb/140  
New guidelines on referring suspected neurological conditions are due to be published by NICE soon and should be reflected within the diagnosing MS recommendation. | Thank you for your comments.  
**Diagnosing MS**  
We will amend the update proposal to include updating the recommendation on diagnosis in light of the 2017 McDonald criteria and to consider any implications these criteria have on the recommendation concerning the information and support patients receive.  
**Providing Information and Support - Early Treatment Consensus** |

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Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple sclerosis in adults: management (2014)
<table>
<thead>
<tr>
<th><strong>Providing Information and Support</strong></th>
<th>Thank you for noting the importance of early treatment with a DMT, we will pass this information on to the developers responsible for updating NICE guideline CG186.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Treatment Consensus</strong></td>
<td><strong>Smoking and MS</strong></td>
</tr>
<tr>
<td>The importance of early treatment with a disease modifying therapy (DMT) for MS should be emphasised. It has now been established within clinical evidence and elsewhere about the importance of early treatment with a DMT in improving health outcomes. The MS Society facilitated the creation of consensus on this issue in 2015, which was endorsed by the MS Trust and Shift.MS, as well as recognised in subsequent policies (for example the Brain Health initiative. This should be reflected in the background information as it is important that people with MS should be able to choose their first line of treatment when consulting with a neurologist as soon as possible after diagnosis. Please see the following links for more information:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘Advise people with MS not to smoke and explain that it may increase the progression of disability’ and as such this will not be proposed as an area for update. Your views will be shared with the developers of the guideline update and editorial changes to the care plan section will be considered when the updated guideline recommendations are developed.</td>
</tr>
<tr>
<td>MS Society website</td>
<td><strong>Co-ordination and care</strong></td>
</tr>
<tr>
<td><a href="http://www.mssociety.org.uk/earlytreatment">http://www.mssociety.org.uk/earlytreatment</a></td>
<td>As noted in the surveillance report, published evidence in peer-reviewed journals concerning the role of the MS nurse was searched for. Evidence was identified concerning the patient experience and the barriers faced by people with MS in accessing services and in receiving healthcare that</td>
</tr>
</tbody>
</table>

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Smoking and MS

While the previous NICE guidelines highlight that the importance of stopping smoking should be raised (1.4.7), evidence soon to be published by the MS Society compiles a number of more recent clinical trials which show there is a clear link between MS and disability progression, increased brain lesions, and increasing the risk of someone with relapsing MS getting secondary progressive MS sooner. Qualitative research we have commissioned has also found that most people with MS are not aware of these risks as it has never been mentioned to them by their MS specialists, despite the previous NICE guideline recommendation. As the evidence is now clearer than ever before we advise that the recommendation be updated with stronger language. This evidence will be published by the end of September 2018.

Data, Technology and digital care plans
### Care Planning

Recommendation 1.2.6 states ‘Ensure people with MS and their family members or carers have a management plan that includes who to contact if their symptoms change significantly’. We believe this should be edited to include changing circumstances of a carer or the person with MS, not only their symptoms. It is important that a management plan for the person with MS contains contingency arrangements should the circumstances of the carer change. This is well established in the Care Act guidance which sets out that contingency must be made for circumstances in which an unpaid carer is unable to care for any period of time (due to ill health or employment, for instance) and this should prompt intervention from social care services. In addition, if the circumstances of a person with MS change this could have a huge impact on the management of their condition. For instance, pregnancy or retiring or starting work. It is vital that these are considered as part of management plan and that the person with MS knows who to contact in such circumstances.

Thank you for highlighting the report by the MS Society and Nuffield Trust on Improving care for people with MS via the use of data and technology and the on-going research on digital care plans. This is however beyond the remit of NICE guideline CG186.

#### Neuro rehabilitation in MDTs and Role of Neurology Nurse Specialists

In relation to professionals highlighted in recommendation 1.3.1 as part of the MS multi-disciplinary team, the list of is not meant to be exhaustive, but indicative that a variety of different professionals should be involved in co-ordinating the care of people with MS.

#### Modifiable risk factors for relapse or progression of MS

In relation to your comment on the lack of information on specific disease-modifying treatments (DMTs) in NICE guideline CG186, please note that treatment with DMTs is specifically outside of the scope of NICE guideline CG186; this would also include haematopoietic stem cell transplantation. The guideline does state in recommendation 1.6.5 ‘Ensure that people with MS are offered a medication review in line with Medicines adherence (NICE clinical guideline 76)’. The overview page of the guideline also provides a link to the technology section.

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In addition, new evidence regarding the needs of carers of people with MS should be considered, namely Bulley, C., Baer, G., Mahal, D., Buckton, C., Donald, S., Lugton, K., Gillespie, D., and McCormack, B., 2017. Scoping the needs of family and carers of people with Multiple Sclerosis: Final Report – Executive Summary. Edinburgh: Queen Margaret University for the MS Society (not yet published – available from the MS Society on request). The report recommends the following improvements to carers’ support and interventions that are evidence based:

- **Personalised coaching** is a strategy that has potential to support carers of people with MS
- **A stable point of contact for information and advice**, which signposts to a variety of different services, resources and entitlements is important and should make use of varied media.
- **Training** in capabilities to enhance caring, such as emotional resilience and moving and handling, could support the emotional and physical wellbeing of family and carers.

appraisals on the [multiple sclerosis page](https://nice.org.uk/) of the NICE website which provide details of DMTs.

**MS symptom management and rehabilitation**

Thank you for your comments concerning the use of cannabinoids in treating pain in people with MS. Only non-pharmacological management of pain is within the scope NICE guideline CG186; and the cannabinoid-based agent Sativex, is the only licensed treatment for spasticity in people with MS, therefore cannabinoids for managing pain cannot be included in the update of NICE guideline CG186. NICE has however received a referral on ‘cannabis based products for medicinal use’, so the non-licenced use of cannabinoids for pain may be picked up in the new guideline, but this is will be determined through scoping.

‘Aspects missing in the current guideline’

Children with MS are not within scope for NICE guideline CG186 and as NHS England has already produced guidance, we would aim not to replicate work.

**Care Planning; Emerging Evidence**

Thank you for all the unpublished and on-going research you have highlighted. We would encourage researchers to publish their research in peer reviewed journals. Once

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• **Improving quality, access and flexibility of home care and to respite** facilities with nursing care, as well as localised signposting to care services.
• **Improving people’s social support** e.g. through volunteer support, well facilitated peer support, and counselling.

**Coordination and Care**

The MS Trust report *MS Specialist Nursing in the UK 2016* details the importance of MS Nurses and the support that is needed to see that their role utilised as best as possible.

The MS Society’s report *MS treatment in England: is access still a lottery? July 2016* found that 81% of people who have access to MS specialists and the right information, as well as a relapsing form of MS were taking a DMT. Just 10% of people who could benefit from these treatments but did not have access to any of these services were taking one. This highlights the important of good care coordination, access to MS specialists and providing information on treatments.
## Data and Technology

New evidence on the role of technology and new uses of patient data could impact guidance on coordination of care, provision of information and advice. The following report should be considered:

**MS Society and Nuffield Trust, Improving care for people with MS: the potential of data and technology, July 2018.**

Key findings and recommendations include:

- Clinicians across the UK need to be aware of a patient’s level of activation, health literacy and understanding when they are producing a care management plan or giving them advice on how to manage their MS.
- Health care providers should build on existing work to provide online information that is tailored to different stages of the condition, being mindful that patients often find overly negative information frightening and disengaging.
- People with MS benefit from patient networks, which offer practical and emotional support to deal with their illness effectively. People who are part

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of online patient networks report becoming more knowledgeable and feeling more socially supported and empowered. They also have improved behavioural and clinical outcomes compared with non-users.

- Online access to medical records and care plans is one of the most effective ways to engage patients. Evidence shows that it can improve patient understanding, confidence, communication, adherence to lifestyle advice and a sense of involvement in their own care. Evidence from the general population shows that patient access to medical records is highly valued, leading to improved satisfaction and perceived savings in time and money (through savings on transport costs and telephone calls). A recent systematic review found that patients were more satisfied with the automatic communication of test results and with online information about their treatment or condition compared with those who accessed this information in person or by telephone.

**Neuro rehabilitation in MDTs**

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We believe the list of professionals in the MS MDT should include neuro-rehabilitation specialists in order align with the mobility section of the guideline which states: ‘ensure people with MS with mobility problems have access to an assessment to establish individual goals and discuss ways in which to achieve them. This would usually involve rehabilitation specialists and physiotherapists with expertise in MS’.

**Role of Neurology Nurse Specialists**

New evidence should be considered on the role of Neurology Nurse Specialists in an MDT, as well as the use of telephone advice lines. In 2017, the Walton Centre Vanguard Site introduced Interactive Neurology Nurse Specialists (INNS) to increase the number of community clinics available to patients with long-term neurological conditions, as well as a Consultant Neurologist Advice Line for GPs and Nurse Advice Line for patients. The evaluation demonstrates myriad positive impacts on patient care. See The Neuro Network Vanguard Evaluation Group, Tranche 4 Final Independent Evaluation Report of the Cheshire and Merseyside Neuro

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Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple sclerosis in adults: management (2014)

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Network Vanguard Programme, July 2018 (not currently online, available on request from the MS Society).

**Digital care plans**

The role of digital care plans in coordinating care more effectively should be considered. A project is underway in Southampton, led by University Hospital Southampton NHS Foundation Trust and in partnership with Solent NHS Trust, which will create personalised, online integrated care plans for 400 patients living with long-term neurological conditions (https://www.health.org.uk/programmes/innovating-improvement/projects/neuro-ltc-online-integrated-care-plan). It aims to improve communication and integration across various care settings, improve patient care and increase self-management capabilities. By empowering patients to have a central role in their care plan, and creating a single space for sharing information, the team hopes to increase self-management capability, and improve integration of health care across settings.

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This project commences in September 2017 and run for 15 months.

In addition, in March 2018, the Professional Record Standards Body published a digital care and support planning standard, having built consensus about what should be included in a generic integrated care plan between organisations including Royal College of Physicians, the Royal College of Nursing and the Association of Directors of Adult Social Services. The standard will be used to create a technical specification by NHS Digital, which will in turn be implemented in North West London as a national accelerator site. Although this work is not specific to MS, it may provide learnings about how care planning can be embedded in clinical practice in a way that improves outcomes for patients. See: [https://theprsb.org/standards/dcsp/](https://theprsb.org/standards/dcsp/)

Further evidence on digital care plans is due to emerge latter this year and next. A project is underway in Southampton, led by University Hospital Southampton NHS Foundation Trust and in partnership with Solent NHS Trust, which will create

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personalised, online integrated care plans for 400 patients living with long-term neurological conditions

[https://www.health.org.uk/programmes/innovating-improvement/projects/neuro-ltc-online-integrated-care-plan](https://www.health.org.uk/programmes/innovating-improvement/projects/neuro-ltc-online-integrated-care-plan) It aims to improve communication and integration across various care settings, improve patient care and increase self-management capabilities. By empowering patients to have a central role in their care plan, and creating a single space for sharing information, the team hopes to increase self-management capability, and improve integration of health care across settings. This project commences in September 2017 and run for 15 months.

The NHS England National Neurology Advisory Group is also undertaking a project (to report early next year) to identify how to embed care planning in specialist care for neurological patients include people with MS, looking specifically at digitised care plans. This will provide insight into the benefits of care planning for patients with MS and how
Clinicians can offer patients the holistic benefits of a care plan.

**Modifiable risk factors for relapse or progression of MS**

Notably absent from the current MS guideline is the array of disease modifying therapies (DMTs) available on the NHS for relapsing forms of MS. There are currently 14 DMTs on the NHS which are available to different subgroups of people with MS. How many relapses, which DMTs a person with MS has had in the past and whether they have experienced side effects all play a role in which DMTs they are eligible to take. The prescribing, monitoring and management of this is becoming increasingly complex for prescribers to navigate. This complexity is reflected in the now published [NHS England DMT algorithm for MS, September 2018](https://www.england.nhs.uk/wp-content/uploads/2018/09/MS-Algorithm.pdf).

The DMT algorithm is already operational across England through the blueteq prescribing system. It includes numerous recommendations on best practice that should be reflected throughout the

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recommendation sections of the MS guideline, including how to approach starting treatment, when to switch and when and how to approach stopping treatment. We recommend a new section is added on pharmacological treatment (as seen in other neurological condition’s NICE guidelines) to address these issues.

**MS symptom management and rehabilitation**

**Cannabis and the changing law**

While the clinical evidence for cannabinoids in treating MS symptoms has been acknowledged within the surveillance proposal consultation document for spasticity, it should also be considered as a treatment for chronic pain caused by MS. Trials include:

<table>
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</tbody>
</table>

<table>
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<tr>
<th>multicentre randomised placebo-controlled trial. Lancet 2003;362:1517–1526</th>
</tr>
</thead>
</table>
It is important to include these sources of information when considering medicinal cannabis as a symptom management option because changes in the law are currently being reviewed which would likely see some forms of cannabis (beyond Sativex) available to people with MS for pain and spasticity. The strong likelihood of this is seen within the evidence review carried out by the Chief Medical Officer Dame Sally Davies Cannabis scheduling review part 1: July 2018. This report recommends moving cannabis out of its current schedule so that it can be prescribed, highlighting that there is ‘conclusive or substantial evidence’ that cannabis is an effective treatment for chronic pain and improving patient-reported spasticity for MS.

Emerging Evidence
NHS England are funding an Integrated Personalised Commissioning pilot focused specifically on patients with potential neurorehabilitation needs in North East Essex, running February – October 2018. The findings of this work should be taken into account in considering revision to the guideline around symptom management and rehabilitation. The pilot will explore:

- The impact of more proactive system navigation and case management
- Rapid access to specialists in the event of fluctuation
- Effectiveness of personal health budgets for exercise and physiotherapy, which could offer particular flexibility to people who work 9-5pm.

**Comprehensive review**

**Relapse and exacerbation**

**Other treatments**

A new treatment that has not yet been reviewed in a NICE appraisal but is nevertheless being made available for people with MS on the NHS is haematopoietic stem cell transplantation (HSCT).
This is currently being made available as third line treatment within the NHS England treatment algorithm. However, it comes with significant risks and greater standardisation of level of care that should be involved would be welcome by people with MS.

**Other comments**

**Inclusion of Children with MS**

The current MS guidelines do not include children with MS. Since they were published NHS England has now developed a [MS Management Service for Children 2017](#) based on numerous sources of evidence.

**Emerging Evidence**

As mentioned previously there are numerous pieces of evidence which are due to be published early next year which should be included in a guideline update but can’t be examined at this juncture. We implore NICE to allow for new sources of evidence to be examined for all existing recommendations within the guidelines when they fully launch the

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consultation process. General evidence expected by January 2019 not already mentioned above includes:

- A RightCare optimisation pathway for MS (and other progressive neurological conditions) drawing together a range of evidence and best practice on local MS care
- A new estimate of the prevalence and incidence of MS from Public Health England
- NHS England neurology service specification setting out expectations for specialised neurology services
- A report from the MS Society on how employment can be supported by the health and care system

| Roche Products Ltd | Yes | 1.6 Comprehensive review. The comprehensive review should include assessment of MS disease course by both clinical (relapses) and sub-clinical (MRI) disease activity. This is supported by the findings of the MAGNIMS working group’s consensus Guideline on the use of brain MRI in prognosis and monitoring of patients (Wattjes et al. 2015). They state that “Follow-up MRI should be conducted at least once every year in patients with MS, but patients at risk of serious treatment-related adverse events may need to be monitored more | Thank you for your comments. The MAGNIMS MRI criteria for the diagnosis of MS is referenced in the 2017 McDonald criteria and the update proposal will be amended to include updating the recommendation on diagnosis in light of the 2017 McDonald criteria; however the latter recommends that ‘a provisional disease course should be specified as soon as the multiple sclerosis diagnosis is made, and periodically re-evaluated based on accumulated information.’ |

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frequently, for example, every 3–4 months”. The value of these scans lie in monitoring disease course and activity beyond the clinically apparent and detection of comorbidity or DMD related adverse events and they can reveal multiple measures of disease pathology. The Guideline suggests contrast-enhanced T1-weighted scans and T2-weighted scans can reveal inflammation and the development of new and/or enlarging lesions but suggests limitations in the value of whole brain volume and spinal MRI measures.

2. Research recommendations. The topics for research should include early initiation of disease modifying therapies. This is an area of interest for the clinical community as evidenced by the Brain Health initiative (Giovannoni et al. 2016), where a worldwide group of MS clinical experts and patient organisations presented a report that summarised an expert, evidence-based position for policy recommendations aimed at improving outcomes for people with MS. One of the major positions outlined in this report is that the goal of treating MS should be to preserve brain tissue and maximize lifelong brain health by reducing disease activity as early as possible. Additionally, evidence of the need for research in this area can be seen with the imminent opening of the Deliver MS trial.

Recommendation 1.6 comprehensive review is in line with this guidance as it highlights the need to review MS disease course and relapse and recommends referring any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed.

Research recommendations are not made as part of the surveillance review process, they are developed by the committee responsible for developing the guideline. For further information please see section 9.5 Formulating research recommendations in NICE guidelines: the manual. The related NICE guidelines information will be updated as part of the development of the updated guideline but please be aware that treatment with disease-modifying treatments (DMTs) is outside of the scope of NICE guideline CG186 and as such this information is provided via a link on the overview page of the guideline to the technology appraisals on the multiple sclerosis page of the NICE website which provide details of DMTs.

Thank you for sharing these references, however, they do not meet the inclusion criteria for the surveillance review.
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There is also growing evidence (see Giovannoni et al) suggesting that early diagnosis and early treatment is key in managing patient outcomes (See section below: Other aspects missing in current guideline)

**Section 1.2 – Providing information and support**

Agree with the editorial comments and should be updated.

**Section 1.3 – Coordination of care**

MS Specialist pharmacist should be added to the MDT approach.

**Section 1.5 – MS symptom management and rehabilitation**

Biogen would be happy to work with NHSEngland/NICE in assessing the cost-effectiveness of fampridine. However, it should be noted that the criteria have on the recommendation concerning the information and support patients receive.

The 2017 McDonald criteria recommends that ‘a provisional disease course should be specified as soon as the multiple sclerosis diagnosis is made, and periodically re-evaluated based on accumulated information.’ Recommendation 1.6 comprehensive review is in line with this guidance as it highlights the need to review MS disease course and relapse and recommends referring any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed.

**Section 1.3 Coordination of care**

In relation to recommendation 1.3, the list of professions with expertise is not meant to be exhaustive, but indicative that a variety of different professionals should be involved in co-ordinating the care of people with MS.

**Section 1.5 MS symptom management and rehabilitation**

Thank you for highlighting a reference to work evaluating the effectiveness of fampridine on walking ability in people with MS. We will share this reference with the developers of the guideline update. We have investigated why reference to this study was not retrieved via our literature search: we
indirect study comparing fampridine to gait speed quoted in the literature search concluded that there is insufficient evidence to conclude whether fampridine or gait training is superior for improving gait sleep in people with MS. In addition, it does not take into consideration other aspects of walking such as balance, as measured in the MSWS-12 tool. Biogen would also like to note that the systematic review for fampridine is missing pivotal studies such as the ENHANCE study (ClinicalTrials.gov Identifier: NCT02219932).

Section 1.6 – Comprehensive review
There is new evidence published by Magnims group, CMSC guidelines, and Joint EAN-ECTRIMS guidelines that should be incorporated within this guideline. It includes aspects such as monitoring disease via regular MRIs.

do not search clinicaltrials.gov.uk, but do search ISRCTN for trials, which does not have this study indexed. Publication of the study is not indexed in any of the Medline databases and while publication of the study is indexed in Embase, it is indexed as a conference abstract. We use a publication type filter in search strategies that excludes unwanted publication types, which includes conferences, and so it was automatically excluded. If the research is published as a full paper, it should be picked up in a search strategy for this guideline.

‘Aspects missing in the current guideline’
Please note that treatment with disease-modifying treatments (DMTs) is specifically outside of the scope of NICE guideline CG186. The overview page of the guideline provides a link to the technology appraisals on the multiple sclerosis page of the NICE website which provide details of DMTs.
Thank you for sharing these references, however, they do not meet the inclusion criteria for the surveillance review.
**Other aspects missing in the current guideline**

The guideline should have a section for treatment of MS and include a link to the NHSE algorithm. More importantly, there needs to be a consistent approach of initiating DMTs considering the diagnosis criteria for MS have been updated (e.g. dimethyl fumarate requires 2 relapses in 2 years to initiate treatment whereas alemtuzumab requires one relapse only).

The “Brain health – Time matters in multiple sclerosis” report published by Prof Giovannoni et al (recently updated this year) highlights the following key aspects which are missing in this guideline, and thus justifies a full update:

1. Speed and referral of diagnosis of MS
2. Early intervention to maximise lifelong brain health – intervention should aim to maximise brain health and physical function. Evidence supports early intervention with a DMT.
3. Monitor disease activity and treat to a target – MRI is being recognised an important tool to monitor disease activity (e.g. subclinical) and should be recognised in this guideline.
4. Act swiftly on evidence of disease activity – the current guideline only refers to acute...
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<tr>
<th>Stakeholder</th>
<th>Response</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Novartis Pharmaceuticals UK Limited</td>
<td>Yes</td>
<td>Looking at the online guideline re: Diagnosing MS we can only see comments back to the 2010 McDonald Criteria – we could not see if NICE has considered updating this to the 2017 revisions. Thank you for your comment. We have recommended updating NICE guideline CG186 with reference to the McDonald 2017 criteria (please see the editorial amendments section of the surveillance report and details are provided in Appendix A in the section for recommendation 1.1 on diagnosing MS).</td>
</tr>
<tr>
<td>The Royal College of Physicians</td>
<td>Not answered</td>
<td>No comments provided</td>
</tr>
<tr>
<td>NTW Foundation Trust</td>
<td>Yes</td>
<td>Section 1.3.1 Coordination of care section does not include Rehabilitation Medicine Consultants. Other areas of document refer to need for rehabilitation and therefore adding the Rehabilitation Medicine consultant to this list should be considered. In addition Nurse with expertise in MS would be more appropriate than MS nurse and in line with other comments in the Guidance. (In our geographical area, RM Consultants are part of the rehab team, working in a non acute setting, liaising with the neurologists, working closely with nurses and AHP’s with expertise in MS.) Thank you for your comments and information on your area. In relation to recommendation 1.3, the list of professions with expertise is not meant to be exhaustive, but indicative that a variety of different professionals should be involved in co-ordinating the care of people with MS. Wording concerning the description of nurses as MS nurse or Nurse with expertise in MS may be considered by the committee when they update the guideline.</td>
</tr>
</tbody>
</table>

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Appendix B: stakeholder consultation comments table for 2018 surveillance of Multiple sclerosis in adults: management (2014)
### Do you have any comments on equalities issues?

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Overall response</th>
<th>Comments</th>
<th>NICE response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coloplast Limited</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Pernicious Anaemia Society</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Therapists in multiple sclerosis (TiMS)</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Department of Health and Social Care</td>
<td>Not answered</td>
<td>No comments provided</td>
<td></td>
</tr>
<tr>
<td>Teva UK Limited</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Salford Royal NHS Foundation Trust</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Organization</th>
<th>Response</th>
<th>Comments Provided</th>
<th>Response to Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom Multiple Sclerosis Specialist Nurse</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Association (UKMSSNA)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Royal College of Nursing</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Associations British Neurologists</td>
<td></td>
<td>Need for palliative care and care at home in the most disabled.</td>
<td>Thank you for your comment. The co-ordination of care and palliative care is addressed in the guidelines in recommendations 1.6.9 and 1.6.10.</td>
</tr>
<tr>
<td>NHS England</td>
<td>Not answered</td>
<td>No comments provided</td>
<td></td>
</tr>
<tr>
<td>Medtronic Ltd</td>
<td>Yes</td>
<td>It is clear from the surveillance report that there is inequitable access to MS services. We suggest that this should be addressed in the updated guideline.</td>
<td>Thank you for your comment. We have noted that there is inequitable access to services, and we will ensure that the developers of the updated NICE guideline CG186 have this information.</td>
</tr>
<tr>
<td>MS Society</td>
<td>Yes</td>
<td>When considering the cost effectiveness of different symptom management options, NICE guidelines should consider that the treatments within the</td>
<td>Thank you for your comments.</td>
</tr>
</tbody>
</table>

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current guidelines are not suitable for all. As with a NICE appraisal it is important to consult with people with MS and identify any potential subgroups of people who may be in greater need of particular treatment, care or support. Later this year the MS Society will be publishing a landscape review on equality in MS, plus analysis of access and experience of different groups based on the MS Register.

NICE has processes in place to ensure that cost-effectiveness considers different population sub-groups, where evidence exists to support this analysis.

There are several ways in which people with MS are able to engage directly with the guideline development: all committees must have at least 2 lay members (people with personal experience of using health or care services, or from a community affected by the guideline), so there is opportunity via membership of the committee developing the updated guideline to be involved; and people with MS can communicate via a registered stakeholder organisation on the draft guideline when it is out for consultation (see chapter 10 on the validation process for draft guidelines, and dealing with stakeholder comments in the NICE guidelines: the manual).

Thank you for highlighting the work you are undertaking.

<table>
<thead>
<tr>
<th>Company</th>
<th>Response</th>
<th>Comments Provided</th>
<th>Thank you for your response.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roche Products Ltd</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>Biogen Idec</td>
<td>Yes</td>
<td>The “MS treatment in England: is access still a lottery” publication has been quoted in section 1.3 on the proposal suggesting only 56% of those who could potentially benefit from taking a DMT are doing so. Although Biogen agree that this in an implementation problem and will not change</td>
<td>Thank you for your comment. We have noted that people with MS who would benefit from a DMT do not always receive such treatment and we</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Answer Type</th>
<th>Comments Provided</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Novartis Pharmaceuticals UK Limited</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your response.</td>
</tr>
<tr>
<td>The Royal College of Physicians</td>
<td>Not answered</td>
<td>No comments provided</td>
<td></td>
</tr>
<tr>
<td>NTW Foundation Trust</td>
<td>No</td>
<td>No comments provided</td>
<td></td>
</tr>
</tbody>
</table>

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