



2018 surveillance of multiple sclerosis in adults: management (NICE guideline CG186)

Surveillance report

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Proposed surveillance decision

We propose to update the guideline on [multiple sclerosis in adults: management](#). The update will focus on multiple sclerosis (MS) diagnosis, symptom management and rehabilitation.

The following table gives an overview of how evidence identified in surveillance might affect each area of the guideline, including any proposed new areas.

Section of the guideline	New evidence identified	Impact
<u>1.1 Diagnosing MS</u>		
Diagnosing MS	Yes	Yes
Diagnosing optic neuritis and neuromyelitis optica	Yes	No
<u>1.2 Providing information and support</u>		
Providing information and support	Yes	Yes
<u>1.3 Coordination of care</u>		
Coordination of care	Yes	No
<u>1.4 Modifiable risk factors for relapse or progression of MS</u>		
Modifiable risk factors for relapse or progression of MS	No	No
<u>1.5 MS symptom management and rehabilitation</u>		
Fatigue	Yes	Yes
Mobility	Yes	Yes
Mobility and/or fatigue with balance problems	Yes	Yes
Treatment programmes for mobility and/or fatigue	Yes	No
Spasticity	Yes	Yes
Pain	Yes	Yes
Cognition including memory	Yes	Yes
Assessment	Yes	No
<u>1.6 Comprehensive review</u>		
Comprehensive review	Yes	No

<u>1.7 Relapse and exacerbation</u>		
Treating a relapse	Yes	No
<u>1.8 Other treatments</u>		
Vitamin D	Yes	No
Omega fatty acids compounds	No	No

Reasons for the decision

This section provides a summary of the areas that will be updated and the reasons for the decision to update.

Updated diagnostic criteria for MS will have an impact on recommendation 1.1. The implications of the changes in diagnostic criteria and MS classification on the information and support patients receive in recommendation 1.2 should be also be considered.

Recommendation 1.5 on MS symptom management and rehabilitation needs updating in the areas of pharmacological management of fatigue, mobility and spasticity and also for non-pharmacological management of fatigue, mobility, balance, pain and cognition. At present, the recommendation addresses each symptom separately, and has not considered how different interventions may address multiple symptoms, or the possible interactive effects of prescribing multiple pharmacotherapies for different symptoms. Therefore, a more integrated, patient-centred rehabilitation approach addressing multiple aspects of care should be considered when this recommendation is updated.

Pharmacological management of symptoms

- Recommendation 1.5.4 recommends offering amantadine to treat fatigue in people with MS, however new evidence indicates that amantadine may not be an effective treatment.
- Recommendation 1.5.10 recommends that fampridine is not a cost-effective treatment for lack of mobility in people with MS. While no cost-effectiveness studies were identified, there is new evidence concerning the effectiveness of fampridine on mobility in people with MS which indicates that fampridine significantly improves mobility when compared with placebo, but not when compared with gait training interventions. Given the new evidence on effectiveness, it is recommended that assessment of the cost effectiveness of fampridine for treating mobility in people with MS is considered for update.

- Recommendation 1.5.23 recommends that Sativex is not used as a treatment for spasticity as it was found to be not cost effective, however there is new cost-effectiveness evidence which indicates that it may be cost effective. Evidence was also identified that supports the use of botulinum toxin in treating spasticity; botulinum is not currently recommended, but is within scope.

Non-pharmacological management of symptoms

- Recommendation 1.5.5 recommends that mindfulness-based training, cognitive behavioural therapy or fatigue management are considered for treating MS-related fatigue. New evidence indicates that these interventions are effective in reducing fatigue in people with MS; and so an update could consider whether the strength of this recommendation could change to offering these interventions to people with MS (see [wording the recommendations](#) in developing NICE guidelines: the manual).
- New evidence was identified which indicates that falls management, balance rehabilitation and aquatic exercises can lead to improvements in balance for people with MS. This evidence should be considered in an update as currently only vestibular rehabilitation is recommended for managing balance problems in people with MS (recommendation 1.5.12).
- There are currently no recommendations concerning the non-pharmacological management of pain, however there is a small body of evidence which indicates that transcutaneous electrical nerve stimulation (TENS) is effective in relieving pain in people with MS and there is an ongoing Cochrane review on non-pharmacological interventions for chronic pain in people with MS (see [ongoing research](#)).
- There are currently no recommendations concerning interventions that may be beneficial for people with MS who experience cognitive problems, however there is new evidence which indicates that rehabilitation programmes can lead to improvements in memory in people with MS.
- New evidence was identified on mobility rehabilitation programmes for people with MS that addresses [research recommendation 2.3](#) on determining the optimal frequency, intensity and form of rehabilitation for mobility problems in people with MS.

Research recommendations

There is also new evidence that is relevant to the research recommendations on:

- [Cognitive rehabilitation](#): new evidence was identified which indicates that rehabilitation programmes can lead to improvements in memory in people with MS, evidence for which

- should be considered in the guideline update. However, as no cost-effectiveness studies were identified, the research recommendation is unlikely to be fully addressed in the update.
- Continued relapses: new evidence was identified which indicates that there is no difference in the clinical effectiveness of intravenous methylprednisolone when compared with oral methylprednisolone in the treatment of a relapse in people with MS; however as no cost-effectiveness studies were identified, the research recommendation is unlikely to be fully addressed in the update.
- Vitamin D: new evidence was identified which indicates that the use of vitamin D supplementation in people with MS provides no significant benefit in slowing the progression of disability in MS. This supports the content of recommendation 1.8.1 to not offer vitamin D solely for the purpose of treating MS.

For further details and a summary of all evidence identified in surveillance, see [appendix A](#).

Overview of 2018 surveillance methods

NICE's surveillance team checked whether recommendations in [multiple sclerosis in adults: management](#) (NICE guideline CG186) remain up to date.

The surveillance process consisted of:

- Initial feedback from topic experts via a questionnaire.
- Literature searches to identify relevant evidence.
- Assessing the new evidence against current recommendations and deciding whether or not to update sections of the guideline, or the whole guideline.
- Consulting on the decision with stakeholders (this document).

After consultation on the decision we will consider the comments received and make any necessary changes to the decision. We will then publish the final surveillance report containing the decision, the summary of the evidence used to reach the decision, and responses to comments received in consultation.

For further details about the process and the possible update decisions that are available, see [ensuring that published guidelines are current and accurate](#) in developing NICE guidelines: the manual.

Evidence considered in surveillance

Search and selection strategy

We searched for new evidence related to the whole guideline. The search strategy consisted of a main search designed to identify systematic reviews published between 4 February 2014 and 13 June 2018 relevant to the whole guideline; and to ensure that recently published evidence that may not be included in systematic reviews was captured. We also included randomised controlled trials (RCTs) published between 1 January 2017 and 13 June 2018 in the main search. In addition, focused searches looked for:

- cost-effectiveness evidence on Sativex in the treatment of spasticity and fampridine in the treatment of lack of mobility in people with MS (published between 4 February 2014 and 13 June 2018)

- systematic reviews, RCTs and qualitative research on the impact of MS nurses on the healthcare experiences of people with MS (published between 4 February 2014 and 13 June 2018).

We found 79 studies across the 3 searches.

We also included:

- Three studies identified through initial intelligence gathering.

From all sources, we considered 82 studies to be relevant to the guideline.

Selecting relevant studies

The standard surveillance review process of using RCTs, full economic evaluations and systematic reviews was used for this search. RCTs were only included if they assessed the effectiveness of pharmacological interventions in the management of symptoms associated with MS. An addition to the standard process was that qualitative studies addressing the perspectives and experiences of healthcare professionals and people with MS of UK healthcare services were also included.

Ongoing research

We checked for relevant ongoing research. Of the ongoing studies identified, 6 were assessed as having the potential to change recommendations. We plan to regularly check whether these studies have published results, and evaluate as quickly as possible, any impact of the results on current recommendations. These studies are:

- [Interventions for preventing falls in people with multiple sclerosis](#)
- [Changing physical activity behaviour in people with MS: the iStep-MS trial](#)
- [Non-pharmacological interventions for chronic pain in multiple sclerosis](#)
- [Rehabilitation for people with multiple sclerosis: an overview of Cochrane systematic reviews](#)
- [Cognitive Rehabilitation for Attention and Memory in people with Multiple Sclerosis \(MS\)](#)
- [An evaluation of an online mindfulness programme for people with multiple sclerosis](#)

Intelligence gathered during surveillance

Views of topic experts

We sent questionnaires to 8 topic experts and received 2 responses. The topic experts either:

- participated in the guideline committee who developed the guideline or
- were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty.

One topic expert said that the guideline should be updated. They noted that there is ongoing research looking at the added value of MS nurses, however no reference was provided. They also expressed concern that the current recommendations function as a list for managing symptoms rather than reflecting a 'rehabilitation approach' and therefore we are advising that a more integrated, patient-centred rehabilitation approach addressing multiple aspects of care is considered when NICE guideline CG186 is updated.

Implementation of the guideline

Feedback from the NICE implementation team highlighted that stakeholders have reported implementation challenges in the following areas:

- improving the understanding of relapse symptoms in people with MS
- ensuring people with MS are aware that they should contact an MS specialist nurse rather than their GP when they think they have had a relapse
- the accessibility and availability of specialist MS nurses.

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.

Other sources of information

We considered all other correspondence received since the guideline was published. We received external queries on whether cannabinoids (Sativex) should be recommended for managing spasticity in MS; a request for the guideline to recommend access to an MS specialist nurse for every individual with MS; and a request to look into guidance on neuromyelitis optica.

Evidence concerning all areas was included in the search strategy for this surveillance review:

- On the basis of the identified evidence it is recommended that the cost-effectiveness of Sativex be re-assessed as part of the update for NICE guideline CG186.
- We did not find any publicly accessible peer-reviewed published evidence that supports recommending access to an MS specialist nurse for every individual with MS. What appears to be key is the provision of support during diagnosis, continuity of care and patient-centred responsive care from people with expertise in MS.
- While evidence was identified concerning the diagnosis of neuromyelitis optica, this provided very specific details concerning diagnostic measurements, which are beyond the level of detail provided for diagnosing MS within NICE guideline CG186 and is therefore deemed unsuitable as an area for update of the multiple sclerosis in adults guideline. It is also noted that other guidance exists that provides diagnostics information.

Views of stakeholders

Stakeholders are consulted on all surveillance decisions except if the whole guideline will be updated and replaced. Because this surveillance decision was to update part of the guideline, we consulted on the decision.

Overall, 15 stakeholders commented. Stakeholders represented industry, professional bodies, Foundation Trusts and charities. Ten stakeholders agreed with the decision; 3 noted that they had no comments on the proposals, this included the Department of Health and Social Care and NHS England; 1 responded 'yes and no' to the proposal and 1 stakeholder responded 'no'. None of the stakeholders disagreed with the decision to update the guideline in relation to MS symptom management and rehabilitation, but the majority felt that other areas of the guideline should also be the focus of an update. Areas that stakeholders thought should be updated included:

- The impact of [Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria](#) on

- recommendations concerning the diagnosis and classification of MS and the information provided to patients when diagnosed. This feedback has informed the update proposal, with these areas recommended as a focus of the update of NICE guideline CG186.
- That follow-up MRIs should be conducted at least annually in patients with MS, and that this detail should be added to [recommendation 1.6](#) on comprehensive review. During the planned update of NICE guideline CG186 any implications on the rest of the guideline recommendations from changes in diagnostic criteria will be considered. However, the review of the McDonald criteria states 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 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.
- Making the role of the MS nurses more prominent in the guideline. While some grey literature and ongoing research was highlighted, no peer-reviewed journal publications were identified.
- Areas highlighted that are out of scope or beyond the remit of the guideline included comments requesting that recommendations are made: on disease modifying therapies (DMTs), on the use of cannabinoids for managing pain in people with MS, for children with MS, on digital care plans, and vocational rehabilitation.

See [appendix B](#) for full details of stakeholders' comments and our responses.

See [ensuring that published guidelines are current and accurate](#) in developing NICE guidelines: the manual for more details on our consultation processes.

Equalities

Feedback from implementation and stakeholders highlighted inequitable access to services for MS.

Editorial amendments

During surveillance of the guideline we identified the following points in the guideline that should be amended prior to update:

Recommendation 1.4.7 references the NICE public health guideline on smoking cessation services, this has since been replaced by the NICE guideline on [stop smoking interventions and services](#). The recommendation should be updated with the new guideline information.

Recommendation 1.5.18 should be amended with information that would cover concerns about stopping drug use, including abrupt withdrawal of baclofen. The recommendation should be edited to read:

1.5.18 Ensure that the person with MS:

- has tried the drug at an optimal dose, or the maximum dose they can tolerate
- stops the drug if there is no benefit at the maximum tolerated dose; but note any special precautions required when stopping specific drugs
- has their drug treatment reviewed at least annually once the optimal dose has been reached.

Recommendation 1.5.32 should reference the NICE guideline on [depression in adults with a chronic physical health problem](#). The recommendation should be edited to read:

1.5.32 Be aware that anxiety, depression (see the NICE guideline on [depression in adults with a chronic physical health problem](#)), difficulty in sleeping and fatigue can impact on cognitive problems. If a person with MS experiences these symptoms and has problems with memory and cognition, offer them an assessment and treatment.

The current footnote hyperlinks for the summary of product characteristics for [gabapentin](#) and [baclofen](#) are broken; these should be updated to those used in this paragraph.

Recommendation 1.6.5 should be amended with reference to the NICE guideline on medicines optimisation. The recommendation should be edited to read:

1.6.5 Ensure people with MS are offered a medication review in line with the NICE guidelines on [medicines adherence](#) and [medicines optimisation](#).

During surveillance of the guideline we identified that the following point should be amended at update:

Recommendation 1.1.7 references 'the revised 2010 McDonald criteria'. As this was revised again in 2017 the date should be changed in the recommendation to 2017; and the reference in footnote 2 should be changed to Thompson AJ, Banwell BL, Barkhof F et al. (2018) Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria. *Lancet Neurology* 17(2):162-173.

Overall decision

After considering all evidence and other intelligence and the impact on current recommendations, we decided that an update is necessary which will concentrate on diagnosis, pharmacological management and non-pharmacological management of symptoms in people with MS.

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