

**Template for Multiple Sclerosis scope SH subgroup discussions**  
**Date: 12/12/19 Time: 10:00 – 13:00**

<p><b>3.1 Population:</b></p> <p><b>3.1.1 Groups that will be covered:</b></p> <ul style="list-style-type: none"> <li>• <b>Adults who have a diagnosis of MS or possible MS, or are being investigated for MS.</b></li> <li>• <b>No specific subgroups of people have been identified as needing specific consideration.</b></li> </ul> <p><b>3.1.2 Groups that will not be covered:</b></p> <ul style="list-style-type: none"> <li>• <b>Children and young people under the age of 18 years who have a diagnosis of MS or possible MS, or are being investigated for MS.</b></li> </ul>	<p>Is the population appropriate?</p> <ul style="list-style-type: none"> <li>○ Are there any specific subgroups that have not been mentioned? <ul style="list-style-type: none"> <li>• The group did not identify any subgroups to be included in the scope.</li> <li>• The group were fine with children not being included in the guideline.</li> </ul> </li> </ul>
<p><b>3.3.1 Key clinical issues that will be covered:</b></p> <ol style="list-style-type: none"> <li><b>1 Diagnosing MS and differential diagnosis.</b></li> <li><b>2 Providing information and support.</b></li> <li><b>3 MS symptom management and rehabilitation including MS nurse specialist.</b></li> </ol> <p><b>3.3.2 Key clinical issues that will not be covered:</b></p>	<p>These are the key areas of clinical management that we propose covering in the guideline. Do you think this is appropriate, acknowledging we must prioritise areas for inclusion?</p> <ul style="list-style-type: none"> <li>• Discussed that there should be some inclusion or reference to when or how DMTs are initiated in the guideline</li> <li>• There is a lot of monitoring involved when a person is on DMTs and this is a huge cost to the NHS and hospitals</li> </ul>

<p><b>1 Treatment of contractures at joints.</b></p> <p><b>2 Disease-modifying therapies covered by existing technology appraisals and Autologous haematopoietic stem cell transplantation (AHSCT).</b></p>	<ul style="list-style-type: none"> <li>• There is no current guidance on who should be monitoring people with MS and how often.</li> <li>• There is also a lack of information for people with MS and their families regarding how often they should be monitored.</li> <li>• Monitoring people with MS takes up most of the MS nurse time, which results in other important tasks not being undertaken by the MS nurse specialist.</li> </ul>
<p><b>Specific probes for key clinical issues:</b></p> <p><b>1. Diagnosis – We propose to update the recommendations based on the new McDonald criteria. Are you aware of any other diagnostic criteria that are used?</b></p> <p><b>2. Information and support - The new diagnostic criteria, which includes recommendations concerning determining the disease course, along with views that patients should have further information concerning the type of MS they have, indicate that this recommendation may require updating. Are there any other issues?</b></p> <p><b>3.</b></p> <p><b>a. Is the rehabilitation for people with MS specific to the condition?</b></p> <p><b>b. Symptom management and rehabilitation:</b></p> <p><b>Pharmacological management of spasticity, mobility (fampridine) and fatigue – Any new pharmacological agents?</b></p> <p><b>Agents included in previous guideline:</b></p> <ul style="list-style-type: none"> <li>- <b>Spasticity:</b></li> </ul>	<p><b>1. Diagnosis</b></p> <ul style="list-style-type: none"> <li>• The group agreed that the McDonald criteria is the most commonly used tool to diagnose MS</li> <li>• They mentioned the Lublin criteria is commonly used for active MS and that it poses issues with regards to when people start treatment, as they are often keen to know what type of MS they have</li> <li>• The group noted the time it takes to get a diagnosis and that it currently takes a very long time, and that GPs need more information regarding referring people.</li> </ul> <p><b>2. Info and support</b></p> <ul style="list-style-type: none"> <li>• The importance of having information about a treatment plan was discussed in detail – people feel anxious after having a diagnosis and usually want to know what the plan will be going forward. As they have short appointments with neurologists it is important to have a plan documented.</li> <li>• Contact details for MS services are important to have, especially having contact details for the MS nurse specialist</li> <li>• The importance of having information on diet was discussed</li> <li>• The way information is given was discussed, as some people</li> </ul>

- **Baclofen (oral) (Lioresal)**
- **Baclofen (intrathecal)**
- **Tizanidine (Zanaflex)**
- **Gabapentin (Neurontin)**
- **Dantrolene sodium (Dantrium)**
- **Benzodiazepines (Diazepam, clonazepam)**
- **Botulinum toxin (Azzalure, Bocouture, Botox, Dysport, Vistabel, Xeomin)**
- **Pregabalin (Lyrica)**
- **Sativex**
- **phenol Comparison**

- **Mobility**

- **Fampridine**

- **Fatigue:**

- **Amantadine**
- **SSRIs**
- **Aspirin**
- **Acupuncture**
- **Rehab based Rxs**
- **CBT**

**c. For adults with MS, what is the clinical evidence and cost effectiveness of pharmacological treatment with high dose statins for secondary progressive MS – Any other interventions to reduce progression?**

**d. Nonpharmacological management of memory and cognitive problems (neuropsychological rehabilitation), fatigue, spasticity, mobility, pain, ataxia or tremor – What interventions are you aware of?**

may have difficulty accessing certain types of information due to disability

**3. a) rehabilitation**

- rehabilitation is specific to the condition, and rehabilitation needs will be different for each person as they will be experiencing different symptoms
- rehabilitation should be conducted by specialists, for example, physiotherapists with expertise in MS
- discussed that rehabilitation needs to have a holistic approach

**b) symptom management and rehabilitation**

- agreed no new agents have become available
- there was a discussion about vitamin D not being looked at, but there have been recent results from two RCTs, SOLAR and CHOLINE. It was noted that this could be useful as a lot of people with MS ask about taking vitamin D.

**c) statins**

- some members of the group felt this was not a priority for the guideline and couldn't see the value of having this question
- some indicated that a lot of people are asking about taking statins, so it might be beneficial to see whether there is a point in administering them
- the group noted that there has been evidence of some benefit in a phase 2 trial and there is a phase 3 trial currently taking place in the UK (MS-STAT2)

**d) non-pharmacological management**

**e. MS nurse specialist – Are you aware of any evidence on clinical or cost effectiveness?**

**f. Are there any issues specific to people with pregnancy potential?**

- discussed the usefulness of self-management courses in group settings for fatigue
- computer based programmes can be helpful as people can undertake them from their home – although this isn't possible for everyone, especially if they have progressed
- mental health support/CBT/counselling – this should be available throughout the whole process, not only if someone is presenting with symptoms
- exercise therapy for mobility, importance of being able to deliver this in the community/at home

**e) MS nurse specialist**

- the group emphasised that having an MS nurse specialist should be standard care
- need to define their role within the pathway, a lot of their time is taken up with DMTs which has prevented them from doing important jobs such as coordinating people's care
- need to define what having an access to MS nurse means as this is variable across the country
- will need to use grey literature as there is no RCT evidence in this area
- MS nurse specialists save the NHS money, MS trust has a report looking at this

**f) pregnancy**

- the group agreed that pregnancy is an important area to cover, and that clear information regarding treatment for women who are pregnant or planning pregnancy needs to be considered.

<p><b>Any comments on guideline committee membership?</b></p> <ul style="list-style-type: none"> <li>○ Chair (neurologist)</li> <li>○ Topic adviser (neurologist)</li> <li>○ Neurologist (early GC member)</li> <li>○ General neurologist</li> <li>○ MS clinical nurse specialist (hospital-based, early GC member)</li> <li>○ MS clinical nurse specialist (community/district-based)</li> <li>○ Occupational therapist</li> <li>○ Physiotherapist with expertise in neurology</li> <li>○ Consultant or specialist in neurological rehabilitation</li> <li>○ GP</li> <li>○ Lay member x 2</li>   <li>○ Co-optee</li> <li>○ Clinical psychologist</li> <li>○ Pharmacist</li> </ul>	<ul style="list-style-type: none"> <li>● Pharmacist should be a full member of the committee as the guideline covers a lot of pharmacological aspects of treatment</li> <li>● Occupational therapist should have expertise in neurology</li> </ul>
<p><b>Further Questions:</b></p>	
<p>1. Are there any critical <b>clinical</b> issues that have been missed from the Scope that will make a difference to patient care?</p>	
<ul style="list-style-type: none"> <li>● Timelines in relation to when treatment is offered and initiated</li> <li>● Monitoring people when they are receiving DMTs</li> </ul>	
<p>2. Are there any areas currently in the Scope that are <b>irrelevant</b> and should be deleted?</p>	
<p>n/a</p>	
<p>3. Are there areas of <b>diverse or unsafe practice</b> or uncertainty that require address?</p>	
<p>n/a</p>	

4. Which area of the scope is likely to have the most marked or biggest health implications for patients?
n/a
5. Which practices will have the most marked/ <b>biggest cost</b> implications for the NHS?
<ul style="list-style-type: none"> <li>• Monitoring people on DMTs</li> <li>• Specialist MS nurse</li> </ul>
6. Are there any <b>new practices</b> that might <b>save the NHS money</b> compared to existing practice?
<ul style="list-style-type: none"> <li>• MS nurses save the NHS money – work done by MS trust looking at the savings associated with MS nurses</li> </ul>
7. If you had to delete (or de prioritise) two areas from the Scope what would they be?
<ul style="list-style-type: none"> <li>• Statins</li> </ul>
8. As a group, if you had to rank the issues in the Scope in order of importance what would be your areas be?
<p>The following areas were prioritised by the group:</p> <ul style="list-style-type: none"> <li>• Role of the MS nurse</li> <li>• Monitoring and management of DMTs</li> <li>• Managing people not on pharmacological treatment</li> </ul>

- Information and support
- Coordination of care

9. What are the top 5 outcomes?

n/a

10. Are there any areas that you think should be included for the purposes of the quality standard? Are there any service delivery or service configuration issues that you think are important?

n/a

11. Other issues raised during subgroup discussion for noting:

n/a