

**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><b>Is the population appropriate?</b></p> <ul style="list-style-type: none"> <li>○ <b>Are there any specific subgroups that have not been mentioned?</b></li> </ul> <p>The group agreed with the population as identified in the scope.</p> <p>A discussion was had about how to capture home-based patients who are less likely to come to clinic in hospital and therefore have the potential to be missed by the current clinical pathway. Attention was also given to how to capture pre-diagnosis patients i.e. people with suspected MS. These discussions did not lead to a conclusion of creating subgroups.</p> <p>There was also discussion about whether there should be a subgrouping based on disease stage; i.e. early stage MS patients vs late stage MS patients. Parts of the group thought that special attention should be given to patients in the later stages of the disease. However, the counter-argument to this was that the disease stage usually doesn't affect how a patient is treated in practical terms, as focus is on treating individual symptoms, not overall disease stage.</p> <p>The group also agreed that the different MS subtypes (e.g. relapsing remitting, primary progressive, etc.) should not be individual subgroups as they are likely less distinct than this classification system would suggest. This might have an impact on grouping of subtypes when assessing clinical evidence and making recommendations.</p>
<p><b>3.3.1 Key clinical issues that will be covered:</b></p>	<p><b>These are the key areas of clinical management that we propose covering in the guideline. Do you think this is appropriate, acknowledging we must</b></p>

- 1 Diagnosing MS and differential diagnosis.
- 2 Providing information and support.
- 3 MS symptom management and rehabilitation including MS nurse specialist.

**3.3.2 Key clinical issues that will not be covered:**

- 1 Treatment of contractures at joints.
- 2 Disease-modifying therapies covered by existing technology appraisals and Autologous haematopoietic stem cell transplantation (AHSCT).

**prioritise areas for inclusion?**

**Diagnosis**

- The group agreed that the McDonald criteria should be used.
- There was also agreement that there needs to be additional focus on diagnosis and clinical management of radiologically isolated syndromes (RIS) as this is not covered by the McDonald criteria.
- In particular there is need for guidance on timeline for diagnosis, i.e. when to refer, which patients need to be seen more urgently.
- Part of the group suggested that a review of blood tests/pre-diagnosis screening tests should be added to the scope, suggesting that they are not necessary and subject patients to unnecessary testing (and unnecessary expense for health system).

Co-ordination of services was a focus of discussion. The whole group agreed that co-ordination should be included and reviewed in this guideline update. This is because there is currently a danger of people with MS 'getting lost' in between care. It will be important to give consideration to how the clinical pathway can keep people with MS engaged with services. The group specifically identified the following list of groups missing from the 'Coordination of care' section of the previous guideline version: pharmacists, neurologists, neuro-rehab, social workers, non-trained/non-specialist care coordinators, palliative care (see also below), relapse treatment/coordination (particularly important is the link between GP and neurologist), neuropsychologists (although it was acknowledged that psychologists were included in the coordination section of the previous guideline).

The group indicated that a focus of the guideline should be palliative care, given that the condition is physically complex and needs to be treated

	<p>differently.</p> <p>End of life planning was also discussed, including care planning and power of attorney, as well as 'life management' e.g. how and when children of people with MS should be taken care of.</p> <p>The group suggested that there should be a review of monitoring of DMDs, which also ties in with coordination and how to link up monitoring between services.</p>
<p><b>Specific probes for key clinical issues:</b></p> <ol style="list-style-type: none"> <li><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></li> <li><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></li> <li><b>3.</b> <ol style="list-style-type: none"> <li><b>a. Is the rehabilitation for people with MS specific to the condition?</b></li> <li><b>b. Symptom management and rehabilitation:</b> <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> </li> </ol> </li> </ol>	<p>The majority of the group thought that the guideline area 1.4 'Modifiable risk factors for relapse or progression' should be reviewed in this update. Their argument for this was that the current risk factor recommendations were not up to date and clinical practice doesn't align with the statements in the previous guideline. This in particular referred to the recommendations on vaccination, pregnancy and exercise. There was a suggestion that there is new evidence that could modify these recommendations but this clinical evidence was not specified.</p> <p><b>Information</b></p> <p>When discussing information for people with MS, the primary focus was on the timing of information delivery, with the group stressing the importance of well-timed or early sharing of information and the positive effect it can have on the clinical pathway. The group referenced in particular reviews done by the Department of Health and Social Care and NHS England on the effect of early information and the health economics surrounding it.</p> <p>Other important aspects of information delivery identified were the method of delivery e.g. IT/online accessibility, availability of information at all points of care, and health literacy (i.e. how to make information accessible for all).</p> <p>The group indicated that rehabilitation of people with MS should be done by</p>

<ul style="list-style-type: none"> <li>○ Baclofen (oral) (Lioresal)</li> <li>○ Baclofen (intrathecal)</li> <li>○ Tizanidine (Zanaflex)</li> <li>○ Gabapentin (Neurontin)</li> <li>○ Dantrolene sodium (Dantrium)</li> <li>○ Benzodiazepines (Diazepam, clonazepam)</li> <li>○ Botulinum toxin (Azzalure, Bocouture, Botox, Dysport, Vistabel, Xeomin)</li> <li>○ Pregabalin (Lyrica)</li> <li>○ Sativex</li> <li>○ phenol Comparison</li> </ul> <p>- <b>Mobility</b></p> <ul style="list-style-type: none"> <li>○ Fampridine</li> </ul> <p>- <b>Fatigue:</b></p> <ul style="list-style-type: none"> <li>○ Amantadine</li> <li>○ SSRIs</li> <li>○ Aspirin</li> <li>○ Acupuncture</li> <li>○ Rehab based Rx's</li> <li>○ CBT</li> </ul> <p>c. <b>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?</b></p> <p>d. <b>Nonpharmacological management of memory and cognitive problems (neuropsychological rehabilitation), fatigue, spasticity, mobility, pain, ataxia or tremor – What interventions are you aware of?</b></p>	<p>a practitioner with experience with rehabilitation of neurological conditions, however that MS rehabilitation could be treated similarly to other neurological conditions.</p> <p>The group suggested that MS-specific mental health conditions should be given consideration in the new guideline, e.g. cognitive effects, whereas only depression and anxiety were covered in the previous guideline.</p> <p><b>Symptom management</b></p> <p>The group suggested that the following symptom management interventions that weren't included in the previous review should be included:</p> <ul style="list-style-type: none"> <li>- Melatonin</li> <li>- Mindfulness and other psychological interventions (besides CBT which was included in the previous guideline)</li> <li>- Diet. The group agreed that guidance was needed to indicate to patients which diet strategies/decisions were useful and which were damaging or unhelpful e.g. keto, and to 'stop fad diets' (as opposed to introducing an MS-specific diet)</li> <li>- Self-management</li> <li>- Exercise programmes</li> <li>- Bowel/bladder symptoms</li> </ul> <p>The group thought that consideration should be given to the cost-effectiveness of training, qualifications and intervention-delivery by MS specialist nurses. This was seen particularly as a cost-effectiveness issue. Specific evidence was suggested from the MS trust, focussing on specialist nurses and forward planning, and from the UKMSSNA.</p> <p><b>Pregnancy</b></p>
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<p>e. <b>MS nurse specialist – Are you aware of any evidence on clinical or cost effectiveness?</b></p> <p>f. <b>Are there any issues specific to people with pregnancy potential?</b></p>	<p>Following on from discussion about 1.4 ‘Modifiable risk factors for relapse or progression’, the group believed that more guidance is required on people with MS who are pregnant or have pregnancy potential. They agreed that all issues surrounding pregnancy should be discussed. The discussion also ranged to consideration of effects of MS on male reproduction, for instance sexual dysfunction.</p> <p><b>Statins</b> The group all agreed that this was low priority, arguing that there are other treatments in the same stage of trial that would also need to be considered.</p>
<p><b>Any comments on guideline committee membership?</b></p> <ul style="list-style-type: none"> <li>○ <b>Chair (neurologist)</b></li> <li>○ <b>Topic adviser (neurologist)</b></li> <li>○ <b>Neurologist (early GC member)</b></li> <li>○ <b>General neurologist</b></li> <li>○ <b>MS clinical nurse specialist (hospital-based, early GC member)</b></li> <li>○ <b>MS clinical nurse specialist (community/district-based)</b></li> <li>○ <b>Occupational therapist</b></li> <li>○ <b>Physiotherapist with expertise in neurology</b></li> <li>○ <b>Consultant or specialist in neurological rehabilitation</b></li> <li>○ <b>GP</b></li> <li>○ <b>Lay member x 2</b></li>   <li>○ <b>Co-optee</b></li> <li>○ <b>Clinical psychologist</b></li> <li>○ <b>Pharmacist</b></li> </ul>	<p>The group suggested the following additions to the GC membership:</p> <ul style="list-style-type: none"> <li>- Care co-ordinator</li> <li>- MS specialist social worker</li> <li>- Palliative care professional</li> <li>- Dietician</li> <li>- Service manager (perhaps as a co-optee or expert witness)</li> <li>- Occupational therapist</li> <li>- Pharmacist</li> <li>- A third MS specialist nurse</li> <li>- Carer</li> <li>- Speech and language specialist (co-optee)</li> </ul> <p>The group indicated that representation from an MS specialist neurologist was a priority.</p> <p>The group agreed that the lay members of the committee should be people with MS at different stages of the disease progression.</p> <p>The group indicated that they thought the current co-optees (clinical</p>

	psychologist and pharmacist) should be full members.
<b>Further Questions:</b>	
1. Are there any critical <b>clinical</b> issues that have been missed from the Scope that will make a difference to patient care?	
See above.	
2. Are there any areas currently in the Scope that are <b>irrelevant</b> and should be deleted?	
Nil	
3. Are there areas of <b>diverse or unsafe practice</b> or uncertainty that require address?	
<p>The group agreed that the dangers of patients travelling abroad for stem cell treatments should be addressed in some way. For example, this could be included under information/advice for patients, including links to e.g. the MS society who provide information on this.</p> <p>It was argued that unsafe practice often stems from a lack of support in service, from e.g. MS specialist nurses, the access to which is currently limited/ monitoring of DMDs.</p> <p>The group also discussed self-medication with cannabis but accepted that this would be difficult to review due to lack of regulation. They agreed that the use of cannabis-based medicinal products is likely to be covered by the existing NICE guideline.</p>	
4. Which area of the scope is likely to have the most marked or biggest health implications for patients?	
<p>The group indicated the following areas as having the biggest potential for impact on patients:</p> <ul style="list-style-type: none"> <li>- Information for patients</li> <li>- Timing of referrals</li> <li>- Coordination of care</li> <li>- Palliative care</li> </ul>	
5. Which practices will have the most marked/ <b>biggest cost</b> implications for the NHS?	
Discussion focussed on where cost reductions could be made – see below.	
6. Are there any <b>new practices</b> that might <b>save the NHS money</b> compared to existing practice?	

- Coordination of care could lead to savings where work could be done by healthcare professionals who cost less than e.g. specialists, for example transferal of some aspects of care to nurses with appropriate training.
- Patient self-management, e.g. UTI self-testing, self-referral back to specialist services
- Timing of information

The group felt that patient self-management and timely delivery of information to patients could significantly reduce hospital admissions/healthcare resource use.

7. If you had to delete (or de prioritise) two areas from the Scope what would they be?

The group agreed that statins should be de-prioritised, arguing that other new treatments with limited evidence would need equal consideration.

8. As a group, if you had to rank the issues in the Scope in order of importance what would be your areas be?

The following areas were noted as of high importance (unranked):

- Timing of information delivery and referral
- Coordination of services
- Palliative care
- Guidance on vaccinations

9. What are the top 5 outcomes?

The following outcomes received focus during discussion (unranked):

- Morbidity
- Symptom improvement
- NEDA symptom scale

The committee noted that the stage of illness may change which measure/scale would be most appropriate, e.g. symptoms scales are less relevant at the start of the MS illness progression (see also discussion on subgrouping by illness stage).

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?

Nil

11. Other issues raised during subgroup discussion for noting:
Nil