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

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| **3.1 Population:**<br>**3.1.1 Groups that will be covered:**<br>• **Adults who have a diagnosis of MS or possible MS, or are being investigated for MS.**<br>• **No specific subgroups of people have been identified as needing specific consideration.**<br>**3.1.2 Groups that will not be covered:**<br>• **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.** | Is the population appropriate?<br>○ Are there any specific subgroups that have not been mentioned?<br>• The group did not feel any subgroups were missing.<br>• The group thought that the voluntary sector should be added to the settings section of the scope.<br>• It was noted that children who are 16/17 are coming through adult services and are classed as adults. The jump from children to adult services is very different in different areas. |
| **3.3.1 Key clinical issues that will be covered:**<br>1 **Diagnosing MS and differential diagnosis.**<br>2 **Providing information and support.**<br>3 **MS symptom management and rehabilitation including MS nurse specialist.** | 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?<br>• The group agreed with the key clinical areas to be covered.<br>• The group felt there should be a note regarding how conversations |

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| **3.3.2 Key clinical issues that will not be covered:**<br>1 **Treatment of contractures at joints.**<br>2 **Disease-modifying therapies covered by existing technology appraisals and Autologous haematopoietic stem cell transplantation (AHSCT).** | around DMTs should happen (sensitively). There is currently a gap around this.<br>• The general management of DMTs has big impact on MS services. 60% of patients are no longer receiving the services they used to. The influx of drugs has an impact on services and this needs to be raised in the guideline to improve things for the future. |
| **Specific probes for key clinical issues:**<br>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?**<br>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?**<br>3.<br>a. **Is the rehabilitation for people with MS specific to the condition?**<br>b. **Symptom management and rehabilitation:**<br>**Pharmacological management of spasticity, mobility (fampradine) and fatigue – Any new pharmacological agents?**<br>**Agents included in previous guideline:** | Question 1: Diagnosis<br>• The McDonald criteria is the main one used for diagnosis. Whilst it does exclude other conditions, the percentage of misdiagnosis is high.<br>• In order to apply McDonald criteria, there needs to be a differential diagnosis to exclude other conditions e.g. HTLV has symptoms similar to MS.<br>Question 2: Information and support<br>• The contact details for MS services, nurses and access to local information is very important.<br>• Information on how MS will impact someone's particular lifestyle, how they live their life, their family etc is important.<br>• Advice on self-management.<br>• Advice on diet.<br>• Generalised information; not always possible to tell someone what type of MS they have, but they do need to know how to manage their symptoms.<br>• The system can be complicated and having someone to guide a person through it – a local contact – is helpful.<br>• Mental health perspective. It would be useful to have mental |

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| - **Spasticity:**<br>○ **Baclofen (oral) (Lioresal)**<br>○ **Baclofen (intrathecal)**<br>○ **Tizanidine (Zanaflex)**<br>○ **Gabapentin (Neurontin)**<br>○ **Dantrolene sodium (Dantrium)**<br>○ **Benzodiazepines (Diazepam, clonazepam)**<br>○ **Botulinum toxin (Azzalure, Bocouture, Botox, Dysport, Vistabel, Xeomin)**<br>○ **Pregabalin (Lyrica)**<br>○ **Sativex**<br>○ **phenol Comparison**<br>- **Mobility**<br>○ **Fampradine**<br>- **Fatigue:**<br>○ **Amantadine**<br>○ **SSRIs**<br>○ **Aspirin**<br>○ **Acupuncture**<br>○ **Rehab based Rxs**<br>○ **CBT**<br><br>**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?**<br><br>**d. Nonpharmacological management of memory and cognitive problems (neuropsychological rehabilitation), fatigue, spasticity, mobility, pain, ataxia or tremor – What** | health support from the beginning (from diagnosis).<br><br><u>Question 3a.</u><br>• Rehabilitation is individual to regions. Some meet individual need and is not focused on MS per se because each patient presents differently.<br>• Specialists in MS providing rehabilitation would be better.<br>• There needs to be a clear distinction between physical and neurological rehabilitation, as well as wellbeing rehabilitation.<br><br><u>Question 3b.</u><br>• Intrathecal Baclofen needs to be a separate/bigger section otherwise it can be missed. Research shows the significant impact it can have on quality of life.<br>• Fampradine – there is one study compared with FES. A combination of both came out as strongest option. Fampradine is poorly prescribed and often prescribed too late.<br>• Acupuncture is used in Fatigue.<br><br><u>Question 3c.</u><br><br>• The group were unsure if statins should be there. People are put on statins very easily without looking at the long term effect. Is there enough evidence that shows statins are useful?<br>• Other agents to be looked at: Biotin, cannabis, CBD oil, Sativex.<br><br><u>Question 3d.</u><br>• Health professionals should question how much of memory problems etc is caused by pharmaceuticals in the first place, rather than assuming it is MS.<br>• Need to define what psychological rehabilitation is: OTs work on |

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| **interventions are you aware of?**<br>**e. MS nurse specialist – Are you aware of any evidence on clinical or cost effectiveness?**<br>**f. Are there any issues specific to people with pregnancy potential?** | memory/cognitive problems as well as traumatic brain injury teams. Vocational rehabilitation important in higher education as there are patients giving up university due to diagnosis. There is an economic impact on younger people who are unable to work.<br>• Self-management programmes – Facets (for fatigue), getting to grips (newly diagnosed MS patients), living well programme.<br>• Reducing the consequences of symptoms is important; e.g. can't reduce fatigue but could reduce consequences of it.<br>• Guidance on FES CG186 should be updated as ten years out of date and the majority of research on MS has been done in the last decade.<br>Question 3e.<br>• The MS nurse role is important but a broader remit would capture all health care professionals e.g. MS therapist.<br>• The key thing is there being a point of contact, not necessarily having an MS nurse specifically.<br>• MS nurse needs to be embedded in an multi-disciplinary team so patient has access to an MDT, rather than only a nurse.<br>• There should be a one-person link to MDT and to navigate patient through the services, but it doesn't necessarily have to be a nurse. However, nursing background is beneficial because it needs to be someone with advanced skills e.g. nurse or advanced practitioner.<br>• The key worker, single point of access, is a flexible role but a must. It may change depending on individual patient needs.<br>• Role of GP for MS patients needs to be clearer (after a patient has been diagnosed).<br>Question 3f. |

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| | • Yes. It is around DMTs and prescribing of treatments. Needs to be a key link for that person e.g. midwife.<br>• Advice on breastfeeding, MRI scans.<br>• Number of ethical issues.<br>• People trying to get pregnant and having difficulties, and their access to other services that could help them. They are severely affected by having a long-term condition e.g. they may not be referred as quickly due to negative attitudes.<br>• People with pregnancy potential are a specific group that requires a recommendation. |
| **Any comments on guideline committee membership?**<br>○ **Chair (neurologist)**<br>○ **Topic adviser (neurologist)**<br>○ **Neurologist (early GC member)**<br>○ **General neurologist**<br>○ **MS clinical nurse specialist (hospital-based, early GC member)**<br>○ **MS clinical nurse specialist (community/district-based)**<br>○ **Occupational therapist**<br>○ **Physiotherapist with expertise in neurology**<br>○ **Consultant or specialist in neurological rehabilitation**<br>○ **GP**<br>○ **Lay member x 2**<br><br>○ **Co-optee**<br>○ **Clinical psychologist**<br>○ **Pharmacist** | • There should be both a district and community MS nurse specialist. As services provided in community are very different, a district nurse might need to be a separate role.<br>• Co-opteed workers – social worker, a speech & language therapist and a representative from therapy centre to help in rehabilitation section.<br>• Community pharmacist should be a full member. Pharmacy is quite wide and contributes to lots of aspects.<br>• Maybe more lay members? E.g. three roles. Younger, condition at earlier and later stage. Someone from charity trust?<br>• Medics are not the prominent part of MS journey – the prominent part is not medic-based. All of pathway needs to be well represented.<br>• Carers need to be represented.<br>• Potentially a need for focus groups, particularly as the guideline is looking at self-management. Patients need to be able to understand the guideline to assist with their own self-management.<br>• Should have a general rehabilitation consultant. |

**Further Questions:**

1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to patient care?

Missing outcomes:

- Walking speed
- Activity monitoring
- Wellbeing scales (including carer wellbeing)
- Pain

2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?

No.

3. Are there areas of **diverse or unsafe practice** or uncertainty that require address?

Diverse services:

- Rehabilitation services
- Wheelchair services
- Access to equipment

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/**biggest cost** implications for the NHS?

- DMTs: monitoring & everything around them
- Specialist nurse & HCP costs
- Keeping people in work
- Unplanned admissions
- Carers / young carers

6. Are there any **new practices** that might **save the NHS money** compared to existing practice?

- HCP specialists
- Timely diagnosis
- Relapse management

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

n/a

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

n/a

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?

- Access to lead care coordinator
- Continuation of care
- Planned structure of medication review

11. Other issues raised during subgroup discussion for noting:

- How information should be given.
- Timings of follow-up.
- A potential link to secretion management (NICE guidance)
- End of life journey is a gap. There are specific issues to MS (outside of EOLC general guideline) – increase in symptoms, spasticity. Palliative care would need to be specific to MS and can be quite complex. Advanced care planning is important.