Template for Multiple Sclerosis scope SH subgroup discussions **Date: 12/12/19 Time: 10:00 – 13:00**	
3.1 Population: **3.1.1 Groups that will be covered:** • **Adults who have a diagnosis of MS or possible MS, or are being investigated for MS.** • **No specific subgroups of people have been identified as needing specific consideration.** **3.1.2 Groups that will not be covered:** • **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? o Are there any specific subgroups that have not been mentioned? • Question around age ranges for differentiating 'adult', 16 / 17 year olds seen in adult services. • Population could be anyone seen by adult services • Clinically isolated syndrome - managed differently so could need specific consideration.
3.3.1 Key clinical issues that will be covered: **1 Diagnosing MS and differential diagnosis.**	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?

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).**	• Group agreed these are the key clinical issues, emphasising information and support and speedy diagnosis being key. • One member suggested pernicious anaemia as a differential diagnosis. • Important that the guideline is relevant to general neurologist.
Specific probes for key clinical issues: **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?** **2. Information and support - The new diagnostic criteria, which includes**	1. Group agreed that McDonald criteria is standard. Importance of referral to specialist emphasised, the timing of this is important for diagnosis. Group discussed the importance of diagnosing specific subtypes of MS and defining those subtypes. Surveillance using imaging is important for this step.

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? **3.** **a. Is the rehabilitation for people with MS specific to the condition?** **b. Symptom management and rehabilitation:** **Pharmacological management of spasticity, mobility (fampradine) and fatigue – Any new pharmacological agents?** **Agents included in previous guideline:** - **Spasticity:** o **Baclofen (oral) (Lioresal)** o **Baclofen (intrathecal)** o **Tizanidine (Zanaflex)** o **Gabapentin (Neurontin)** o **Dantrolene sodium (Dantrium)** o **Benzodiazepines (Diazepam, clonazepam)** o **Botulinum toxin (Azzalure, Bocouture, Botox, Dysport, Vistabel, Xeomin)** o **Pregabalin (Lyrica)** o **Sativex** o **phenol Comparison** - **Mobility** o **Fampradine** - **Fatigue:** o **Amantadine**	2. Group outlined the importance of info and support, especially information surrounding self-management. 3. **A**. Rehabilitation is not specific to MS, normal OTs and physios. Access to the rehabilitation is the problem.The group mentioned symptoms: Pain, Spasticity, Spasms, sexual dysfunction, Oscillopsia. **B**. Pharma – Modafanil is still sometimes prescribed. **C**. Statins – There is one phase II trial currently recruiting, won't be usable during development time of guideline. Statins are being prescribed by neurologists at the table. The group discussed the importance of talking about Biotin and Vit D, as these are queried by patients regularly. D. Group discussed how an assessment of neuro strengths and weaknesses is important as well as cognitive rehabilitation. Group highlighted self-management as a key issue. Group discussed easy access to counselling and public groups, physical or virtual, to deal with some cognitive problems. E. Consensus on importance of nurse specialist and how it should be standard care. Difficult with evidence as the nurse specialist role varies widely. Group not aware of any RCT evidence. F. The group briefly discussed this and mentioned the ABN guideline on pregnancy and MS.

○ **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?** **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?**	

Any comments on guideline committee membership? ○ **Chair (neurologist)** ○ **Topic adviser (neurologist)** ○ **Neurologist (early GC member)** ○ **General neurologist** ○ **MS clinical nurse specialist (hospital-based, early GC member)** ○ **MS clinical nurse specialist (community/district-based)** ○ **Occupational therapist** ○ **Physiotherapist with expertise in neurology** ○ **Consultant or specialist in neurological rehabilitation** ○ **GP** ○ **Lay member x 2** ○ **Co-optee** ○ **Clinical psychologist** ○ **Pharmacist**	• Neuroradiologist as a co-opted member.
Further Questions:	
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to patient care?	
n/a	
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	

n/a
3. Are there areas of **diverse or unsafe practice** or uncertainty that require address?
n/a
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?
n/a
6. Are there any **new practices** that might **save the NHS money** compared to existing practice?
n/a
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?
n/a
11. Other issues raised during subgroup discussion for noting:
n/a