

MS Update Stakeholder Scoping Workshop

5th April 2012

Summary notes

The stakeholder scoping workshop is held in addition to the formal consultation on the scope which is taking place from the 17th April until the 15th May.

The objectives of the scoping workshop were to:

- Obtain feedback on the specified population and key clinical issues included in the first draft of the scope
- Seek views on the composition of the Guideline Development Group (GDG)
- Encourage applications for GDG membership

The scoping group (technical team, NICE and GDG Chair) presented a summary of the guideline development process, the role and importance of patient representatives, the process for GDG recruitment and proposed constituency for this group, and the scope. The stakeholders were then divided into 4 groups which included a facilitator and a scribe and each group had a structured discussion based around pre-defined questions relating to the draft scope. Comments received from each discussion group have been combined and summarised below.

Scope section	Comments
4.1 Population	<ul style="list-style-type: none"> • The group suggested that the population should potentially include children because of issues due to transitioning of care between child and adult services. • Children are mostly diagnosed around age 15-16 years and diagnosis and treatment does not differ to adults for this population • Potentially should include 16-18 year olds as PCTS may refuse to fund treatment for non-adults if the guidelines do not specifically refer to them. • It was suggested that the “investigated for MS” part of the population should not be included as this is different to “possible MS”. Many get investigated for MS who are extremely unlikely to have the disease.
4.3 Clinical Management 4.3.1 Key clinical issues that will be covered	
4.3.1 a) Diagnosis criteria for MS and possible MS including the revised McDonald criteria for MS, diagnostic criteria for neuromyelitis optica and the appropriate investigation for people with clinically isolated syndrome	<ul style="list-style-type: none"> • The group suggested that the McDonald criteria is mainly used for research. • Primary progressive and relapsing MS and how they are used should be included. • How the diagnosis is given plus the follow up contact was considered to be important • It was suggested that clinically isolated syndrome should be included and there should be an appropriate referral pathway, patients need quick access to MS specialists.

4.3.1 b)

The management of fatigue including Modafinil, Amantadine, B12 injections and exercise and fatigue management programmes

- Suggested additions to this list included:
 - Hyperbaric oxygen
 - Complementary therapies such as aromatherapy, massage, reflexology and acupuncture
 - SSRI's
 - Antidepressants – often depression and fatigue overlap
 - Patient education
 - Carer education
 - Group intervention
 - Relaxation

- The emphasis of this section should be on self management of fatigue
- Often fatigue is not due to MS and is due to other causes
- There are problems with access to physiotherapists for the management of fatigue in current practice

- The EMEA advises against using Modafinil, however the groups considered that the GDG should review this drug
- The group agreed that there was no strong evidence for the other listed drugs

<p>4.3.1 c)</p> <p>The pharmacological management of spasticity including baclofen, tizanidine, gabapentin, dantrolene, benzodiazepines, botulinum toxin and sativex</p>	<ul style="list-style-type: none"> • Sativex was considered important and should be included in the scope. It was suggested that Sativex is also useful for pain management. • The cost effectiveness of Intrathecal versus oral baclofen will need to be considered (intrathecal is more invasive and expensive). • Some group members expressed concern about adding gabapentin as a first line treatment • The group suggested that Non-pharmacological treatments should be addressed as well as pharmacological. • Seating, positioning, patient education and stretching were also considered important. • Should also look at functional outcomes, what does spasticity prevent you from doing. • Potential pathway considerations
<p>4.3.1 d)</p> <p>Donepezil and neuropsychological rehabilitation for memory and cognitive impairments</p>	<ul style="list-style-type: none"> • The groups recommended that Donepezil should be included in the scope. • Cognitive impairments was regarded as an important area as it can potentially reduce employability which will have knock on effects on societal costs. This issue should be given more emphasis in the scope, as provision for neuropsychological support is very limited.

<p>4.3.1 e)</p> <p>Exercise interventions and fampridine for mobility</p>	<ul style="list-style-type: none"> • Fampridine should be included in the scope and that there was encouraging data in terms of evidence. • Some concern was expressed that the cost effectiveness of fampridine will not be captured as a result of the failure to include benefits on societal costs. • Both exercise and pharmacological approaches were considered important in regards to mobility. • It was suggested that the scope should also look at self-management • The group raised the importance of access to physiotherapy • There is a Cochrane review on exercise interventions
<p>4.3.1 f)</p> <p>Route of administration of steroids (intravenous vs oral) for acute relapse</p>	<ul style="list-style-type: none"> • There was agreement that this question was relatively important as there is a variation in practice in steroid administration routes. • The group agreed that the scope should look at the dose and type of steroids and then the route. • It was suggested that home versus hospital provision could be explored especially as IV can now be administered at home. • One group felt there was no need to review this as no new evidence has emerged since 2003.
<p>4.3.1 g)</p> <p>Vitamin D for the management of MS</p>	<ul style="list-style-type: none"> • This is an important area to include. There are some small scale studies in this area and larger scale RCT's underway (as yet unpublished) • It was suggested that the focus of this area should be on dosage and the effects of relapse rates • Lifestyle/environmental factors including smoking should be looked at. • The group suggested that this could be a potential research recommendation.

<p>4.3.1 h)</p> <p>Current service delivery for example home vs hospital rehabilitation and specialist nurse care for people with MS</p>	<ul style="list-style-type: none"> • The issue of access to services is particularly relevant. An example was given of patients being discharged from 6 weeks of hospital inpatient treatment and then experiencing long waiting times to access services thereafter. • The following issues were discussed: <ul style="list-style-type: none"> ➤ Disability being a potential barrier to access of care ➤ Lack of OT/SLT/Physiotherapists that have specialist knowledge ➤ The importance of the role of specialist nurses ➤ Home vs hospital administration of IV steroids – there is variation in practice ➤ Advanced care planning e.g. informing patients about PEG options to enable them to make their own decisions ➤ The appropriate time to provide information to patients, at what stage of the condition ➤ Holistic care ➤ The importance of the role of carers
<p>4.3.2 Key clinical issues that will not be covered</p>	<ul style="list-style-type: none"> • The group agreed that this list was reasonable. They suggested the scope should be more specific about which issues are superseded by other guideline recommendations to avoid any confusion. • The group suggested including mental health. • The group indicated that treatment of early MS/clinically isolated syndrome has not been addressed and it is not covered elsewhere. • The group suggested that the stage at which disease-modifying-therapies is initiated should be covered. The suggestion was also made to highlight that risk-sharing schemes support the provision of MS services.

4.4 Main Outcomes

- Health related Quality of Life for example EQ-5D, SF-36
- Impact on carers
- Functional scales that quantify level of disability, such as:
 - Expanded Disability Status Scale (EDSS),
 - Multiple Sclerosis Functional Composite (MSFC),
 - Cambridge Multiple Sclerosis Basic Score (CAMBS) or
 - Functional Assessment of Multiple Sclerosis (FAMS)
- Cognitive functions: memory, concentration; Physical symptoms: fatigue, spasticity, spasms, bladder function, bowel symptoms (better, worse or no change).
[Assessed by validated and disease specific scales, questionnaire or similar instruments, for instance the Scripps Neurologic Rating scale (SNRS) or the Krupp Fatigue Severity Scale (FSS).]
- Psychological symptoms (better, worse or no change) assessed by validated and disease specific scales, questionnaire or similar instruments
- Adverse effects of treatment

- The group made the following suggestions:
 - Physical symptoms should be a separate bullet point
 - The importance of patients reported outcomes (PRO) versus physician reported outcomes should be highlighted – what clinicians think is important but may not be what is ultimately relevant to the patient (commissioning is highly dependant on PRO)
 - Pain outcomes should be included (no mention of trigeminal neuralgia)
 - National Fatigue Index (NFI MS) Mills RJ, Young CA, Pallant JF, Tennant A should be included as a functional scale that quantifies level of disability

Health Economic Issues

- The group discussed the following potential health economic issues:
 - Possible benefit of MS specialist nurses on reduction in hospital admission
 - Falls are common reason for admission, anything that would impact on falls would have high economic implications
 - IV versus oral steroid therapy
 - Home versus hospital steroid administration
 - Who delivers what intervention (e.g. physiotherapist)
 - Benefits of telecare for spasticity, however it was thought there would be a lack of evidence for this.
 - Poly-pharmacy – potentially money saving if medicines review was carried out regularly to stop unwanted prescribing.
 - Prescribing drugs without proper evidence base (e.g. donepezil)

General questions

We need to focus on:

- *What changes in practice will most improve patient and carer outcomes?*
- *Are there changes of practice that will substantially reduce resource use (cost savings)?*
- *Are there changes of practice that will improve patient outcomes but are likely to substantially increase resource use? (where cost-effectiveness would need to be analysed)*
- *Are there any equalities issues?*
- *How important is this issue for the service?*
- *Is there known variation in practice, poor unsafe practice or uncertainty?*
- *How many patients will it affect?*
- *Are we going to be changing clinical practice?*

- The group discussed equality issues such as loss of earnings and indicated that the RCP audit should highlight any equality issues.
- The group suggested the scope should address chronic pain as it affects a large population.

<p>GDG Constituency</p> <ul style="list-style-type: none"> • Neurologist with interest in MS • General neurologist • 3x Healthcare professionals with expertise in rehabilitation (e.g. physiotherapist, rehabilitation consultant, OT) • 2x MS Nurse specialist • Community/commissioning representative/GP • Neuropsychiatrist/neuropsychologist (Co-optee) • Pharmacist (Co-optee) • 2-3x patient/carer representative 	<ul style="list-style-type: none"> • The group were happy overall with the GDG constituency. The following suggestions were made: <ul style="list-style-type: none"> ➤ Possibly too many neurologists specified in the list, a general neurologist could be excluded if there was a need to reduce the GDG composition ➤ An SLT may be necessary if PEG is being addressed ➤ Possible inclusion of a dietician ➤ Include 2 MS nurses, one from acute and other from community ➤ Pain co-optee
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Attendees were informed of the scope consultation dates and process and that GDG recruitment would happen simultaneously. Further comments on the scope and applications for GDG membership were encouraged.

Appendix 1

Workshop Groups:

Each group will have a facilitator¹ and scribe².

Group 1	Norma O'Flynn ¹ Amy Kelsey ²	David Tyas Irwin Tran Chit Ko-Ko Bruno Gran David de Monteverde-Robb Pam Macfarlane Vicki Matthews Alison Bradford Martin Beyon Barbara Meredith
Group 2	Clifford Middleton ¹ Mark Perry ²	Andy Fenton Hetal Patel Huseyin Huseyin Waqar Rashid Annie Blayney Sajida Javaid Jason Wigham Hannah Johnson David Turner Prish Kandaswamy
Group 3	Sharon Swain ¹ Toni Tan ²	Arnas Berzanskis Mark Hill Barbara Franks Catherine Dunn Laura Weir

		<p>Helen Dawes Michael Dilley Ming Lim Rachel Griffiths Andrew Gyton</p>
<p>Group 4</p>	<p>Lina Gulhane¹ Lola Adedokun²</p>	<p>Stephen Wright Iain Lovelace Maryanne Harrison Alan Thompson Susan Hourihan Paul Nandi Jean Hannah Jackie Napier Siobhan Macauley Christine Carson</p>