

National Institute for Health and Clinical Excellence

**Multiple Sclerosis
Stakeholder Comments – Draft scope**

<p>Please enter the name of your registered stakeholder organisation below.</p> <p>NICE is unable to accept comments from non-registered organisation or individuals. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.</p>		
Stakeholder organisation:		Multiple Sclerosis Trust
Name of commentator:		Pam Macfarlane
Comment No.	Section number Indicate number or 'general' if your comment relates to the whole document. Do not refer to more than one section in the same cell.	Comments Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
Example	3.4.6	Our comments are as follows
Proformas that are not correctly submitted as detailed in the line above may be returned to you		
1	General	<p>The MS Trust welcomes the revision of the guideline. People with MS live a long time with an incurable disease that affects every aspect of their life. They deserve better services and the guideline is key to setting standards of service that can really make a difference for them.</p> <p>However in order to truly improve care for people with MS the guideline must come with the necessary levers to ensure full implementation. This will require leadership, collaboration and involvement from people who live with MS, their wider circle, and health professionals.</p>
2	3.1d	<p>This section currently understates the impact of the disease on the lives of people with MS and their families. In particular</p> <ul style="list-style-type: none"> • The relatively young age at which people are diagnosed (usually in their 20's and 30's), therefore they live with it for a long time. • The effect on the ability to work – a 2011 report by The Work Foundation suggested that on average people with MS miss out on 18 years of their working life.

3	3.2b	<p>MS is a complex and unpredictable condition that varies from person to person and does not follow a set pattern. It is important to note that it is not always possible to say at diagnosis what type of MS a person has, this may only become apparent over time.</p> <p>Secondary progressive MS is not defined - <i>people who start off with relapsing remitting MS may go on to develop a progressive form of the condition. The transition usually occurs somewhere between five to 20 years after diagnosis, but the change from relapsing remitting MS to secondary progressive MS can happen at any time. The severity and frequency of the relapses decrease, but disability slowly increases.</i></p>
4	3.2c	Symptoms should include bowel as well as bladder.
5	3.2e	<p>We assume the National Audit referred to is the one carried out in 2011 by the MS Trust in partnership with the Royal College of Physicians, which was also referenced in the National Audit Office Report on Services for People with Neurological Conditions. In particular the audit highlighted</p> <ul style="list-style-type: none"> • that there is huge variation in the quality and quantity of care provided for people with MS • none of the 6 recommendations in CG8 have been implemented widely or fully and the relevant quality requirements of the NSF for people with long-term conditions show an unacceptably low level of attainment <p>In responding to the audit people with MS emphasised:-</p> <ul style="list-style-type: none"> • problems in getting help quickly, as there is often no single point of contact • basic symptoms such as pain, fatigue and cognition are not well managed • the lack of access to treatments and therapies that can aid mobility, as well as physical aids and equipment • the lack of co-operation between health and social care • little evidence of involving them in decision making or service commissioning • poor access to rehabilitation generally and virtually no access to vocational rehabilitation • little support for their families or carers <p>It was disappointing to report that little has changed in the 3 audits we have undertaken since 2006.</p> <p>This guideline must seek to address these issues and ensure the necessary levers are put in place to ensure full implementation.</p>
6	4.1.1	<p>The guideline should cover anyone affected by MS regardless of age.</p> <p>It is not clear whether people between 16 and 18 are treated in adult services. The guideline may need to consider service arrangements for transition between paediatric and adult services.</p>
7	4.2	The MS Trust believes that it is vital to include social care as the interface between health and social care services is a key issue for people with MS.
8	4.3.1a	The inclusion of CIS and NMO is welcome. The guideline should also include a recommendation on how a diagnosis is given and the support to be offered at the time including referral to an MS specialist nurse.
9	4.3.1b	Structured holistic review is essential and this should be done regularly not just at diagnosis. Assessment should also cover key relationships and carers including their own wellbeing.

10	4.3.1c	High quality, accessible information must be available for people with MS, their families, friends, employers and the health professionals who work with them. This is essential for shared decision making at all stages of the disease course. However it may be useful to emphasise the key points when access to good information is vital for example at diagnosis, when considering disease modifying drugs, at transition between types of MS, and advanced decision making
11	4.3.1d	Should be expanded to include other lifestyle factors e.g. stress
12	4.3.1e	This section covers many of the issues people with MS highlighted in the audit. Access to all forms of rehabilitation is very important, as is the availability of mobility aids including FES, wheelchairs and all other equipment to aid daily living. This should cover therapies and equipment provided by both health and social services. Relapse management and rehabilitation should be included. Vocational rehabilitation is also important.
13	4.3.1f-k	Agreed. In addition sections should be included for the management of: <ul style="list-style-type: none"> • speech problems • swallowing problems • sexual dysfunction • bladder and bowel problems
14	4.3.1l	The availability of rehabilitation in all settings is key. In the audit less than 20% of people with MS could access rehabilitation at home.
15	4.3.1m	People with MS tell us how highly they value their MS specialist nurse, however there are still too few of them and not everyone with MS currently has access to this vital service. Understanding and articulating the content of their role over the disease course and the ensuing benefits for people with MS in this guideline will be welcome, and can inform the design, configuration and commissioning of services. The interface between specialist and generalist care should also be explored. We would request that the guideline should also add a section for MS specialist therapists as a multidisciplinary team approach is essential for people with MS. We provide professional development opportunities and resources for both nurses and therapists and continue to fund research to demonstrate the value of their services.
16	4.3.3	Whilst it is practical to reference other NICE guidelines, their use should not be an excuse to devolve accountability for care of a person with MS to other clinical areas. Poor management of key symptoms e.g. continence can have a huge impact on their life with MS and ultimately the MS specialist team should retain responsibility for their overall care.
17	4.3.3 c	Also needs to include reference to Health Service Circular 2002/004 and TA254 Fingolimod.
18	4.4	There are outcome measures for shared decision making and patient activation measures for self management which may be appropriate. It would be useful for the development group to co-opt someone with the necessary expertise to review all these measures to ensure they are comprehensive and genuinely measurable.

Please add extra rows as needed

Please email this form to: multiplesclerosis@nice.org.uk

Closing date: 5pm on 7 June 2012

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.