



Royal College
of Physicians



Setting higher standards

The national audit of services for people with multiple sclerosis 2011

September 2011

Executive Summary

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Preface

I feel I have to be in charge in my own care as little attempt is made to look at the whole picture or consider my entire situation, including my family, etc.

Person with MS

The aim of this audit is to improve care for people with MS

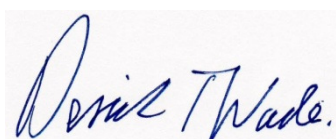
Multiple sclerosis (MS) is an incurable, unpredictable, life-long, challenging condition that affects every part of a person's life. It can have huge impact on family and social life, and lead to loss of work and independence. MS has an uncertain prognosis which can encompass anything from a relatively normal lifespan to severe disability.

MS is the most common neurological condition in young adults in the UK, affecting around 100,000 people. The disease onset usually occurs in young adults aged between 20-40, though there is often a prolonged period of symptoms before diagnosis. The range of clinical and functional problems it generates is vast and may involve almost any part of a healthcare service. Investigating how the NHS responds to the many and varied needs of people with MS at all stages of their illness should therefore allow a judgment of how well the NHS responds to patients with other long-term conditions.

This is the third audit of the NHS's performance in providing healthcare services to people with MS using six recommendations and a sentinel marker proposed by the National Institute of Health and Clinical Excellence (NICE) in *Management of multiple sclerosis in primary and secondary care* (2003).¹ In addition, we measured compliance with seven of the eleven *National Service Framework for Long-term Conditions* (2005) quality requirements that are particularly relevant to MS services.²

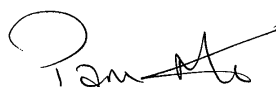
It is clear that there has been no major improvement in most areas studied since the first round of audit in 2006. We hope that the findings presented in this report will assist those who commission or provide services for people with MS to identify where services are deficient. We also hope that the data will be used to drive improvements in a time of organisational restructuring.

Finally, although we have focused on services for people with MS in this report, as an exemplar of many long-term conditions we hope that the findings will be useful to a much broader group of clinicians, commissioners and patients.



Professor Derick Wade

MS audit associate director and professor in neurological rehabilitation



Pam Macfarlane

Chief executive, MS Trust

Executive Summary

The national audit of services for people with multiple sclerosis 2011 is a clinically led audit of the organisation, resourcing and performance of NHS services for people with multiple sclerosis (MS) in England and Wales. The primary goal is to improve the care for all people with multiple sclerosis.

The audit, now in its third round, measures the NHS against the standards embedded in the NICE clinical guideline *Management of multiple sclerosis in primary and secondary care* (NICE CG8) and the *National Service Framework for Long-term Conditions* (NSF-LTC).^{1,2} Data were collected between 31 January 2011 and 29 April 2011, from six sources in order to provide a picture of service provision from different perspectives:

- People with multiple sclerosis – 704 service users.
- Acute NHS hospital trusts – 105 of 151 service providers (secondary care).
- Community-based services – 32 of 62 community service providers (primary-secondary care interface).
- General practice – 49 service providers (primary care).
- Primary care trusts and local health boards – 51 of 151 service commissioners.
- Strategic health authorities – 4 of 10 service performance managers.

This audit has two main components: the first concerns data provided by people with MS, the second concerns data provided by participating NHS organisations. Presented in this executive summary are the key findings and recommendations from the 2011 audit, along with key findings from the 2006 audit and the 2008 audit for historical context and comparison.

Aims of the audit

To improve care for all people with multiple sclerosis by:

- auditing the standard of healthcare services provided to people with MS in all settings and for all contacts against the primary recommendations of NICE CG8 and seven of the eleven quality requirements from the NSF-LTC.
- measuring the extent the recommendations made in *National audit of services for people with multiple sclerosis 2008* have been implemented
- producing a qualitative analysis of the informal spontaneous comments made about services by people with MS
- increasing awareness at the organisational level of the NHS of the national clinical guideline.

Key findings

This audit has found that some patients receive excellent care from the NHS. However, this is not universal, and the variation in both the quality and the quantity of care provided is notable.

Overarching findings

- There has been no major improvement in many aspects of service provision for people with MS that have been audited since 2006.
- None of the six key recommendations made by NICE in 2003 have been implemented widely or fully.
- The sentinel marker proposed by NICE, the prevalence of skin pressure ulcers, has dropped from 9% to 4% over five years, as reported by people with MS.
- Seven of the eleven quality requirements of the NSF-LTC are particularly relevant to people with MS: all showed a low level of attainment and they will not be achieved by the target date of 2015.
- One third of trusts have no plans to improve neurological services in the next year.

From people with multiple sclerosis

- 81% of people with MS indicated that specialist neurological services were available locally, but only 43% stated that as far as they knew, they had access to specialist neurological rehabilitation services.
- Most people (93%) stated that they had access to specialist MS nurses and 57% to specialist MS physiotherapists. There were many comments praising specialist nurses and therapists.
- Data from several questions suggests that pain is not well treated in people with MS; problems with fatigue and cognition are also not well controlled.
- Problems with mobility are very common and not all appear well managed: 79% of people reported a fall in the last year and 16% of these had fallen more than 20 times; and only 56% of people with MS stated they had been provided with all mobility equipment they needed, which is not only contrary to the NSF-LTC quality requirement but also contrary to the recommendations of the Audit Commission reports.^{3,4}
- Specialist vocational rehabilitation is not available or provided to most people in most areas.

From NHS organisations

- Only 22% of hospital providers have specialist neurological rehabilitation services that follow NICE CG8 or NSF-LTC standards – this is a reduction from 31% in 2008. We surveyed community trusts in 2011 for the first time and found that 38% are providing specialist neurological rehabilitation services in line with the NSF-LTC, but this still equates to inadequate service provision across the NHS.
- Whilst the commissioning of equipment services is almost universal, one-quarter of hospital providers cannot provide equipment or do not know if equipment can be provided. One third of GPs either do not know if it's possible, or cannot refer to organisations that assess, provide and train patients or others in the use of equipment / adaptations needed by people with MS.
- Fewer than 50% of providers require clinicians to use structured assessments of mood, cognition and daily activities as recommended by the NSF-LTC. Fewer commissioners are paying attention to assessments, and there is no increase in the use of structured assessment protocols.
- Organisations do not give much management priority or resource to services for people with MS. Specific managerial interest in services for people with MS and all related specialist services is generally less than 50%, and organisations rarely monitor whether the quantity of service provision is adequate.
- Services for people with MS are not well integrated, and the data show a decline in the quality of transfers between Health and Social Services.

Key Recommendations

<p>Department of Health</p>	<p>A system of commissioning and payment that facilitates integration between all healthcare providers and also between healthcare and Social Services needs to be developed and implemented.</p> <p>We recommend that a body such as NICE (through its quality improvement programme) or the Care Quality Commission be tasked with monitoring the extent of integration and collaboration among healthcare organisations and also with social services.</p>
<p>NHS organisations</p>	<p>All NHS organisations need to give more attention to rehabilitation services for people with long-term neurological conditions such as MS.</p> <p>We recommend that each NHS organisation should:</p> <ul style="list-style-type: none"> • review this report and their own performance at board level to improve the standards of care provided by them to people with MS • involve people with MS in the design and provision, or the commissioning of any services that are used by people with MS • start a five year project to improve the services within its remit for people with MS • foster links with other relevant organisations within and beyond the NHS i.e. Social Care, patient organisations • routinely record the frequency and extent of unmet need for equipment for people with MS, and commissioning organisations should then provide adequate resources for equipment.
<p>Clinical staff</p>	<p>All clinical staff need to pay more attention to the many and varied problems faced by people with MS.</p> <p>We recommend that clinical staff in primary and secondary care should:</p> <ul style="list-style-type: none"> • ask every patient if they are experiencing pain, and specialist pain management must be available to those with poor pain control. Non-specialist staff should use the NICE guideline <i>Neuropathic pain: The pharmacological management of neuropathic pain in adults in non-specialist settings</i> (CG96)⁵ • be asked to use structured assessments of mood, cognition and daily activities, to record the outcomes and to refer to specialist services as appropriate. The ‘review checklist’ in NICE CG8 (Table 2, page 60) is one possible template¹ • always consider the need for equipment and always refer for assessment and provision of equipment if necessary.

Historical context

This is the third national audit of NHS healthcare services for people with MS. To provide some historical context the key findings from the two previous audits have been reproduced below.

The 2006 audit⁶

The main finding of this audit was that the standards set by the seven key recommendations made in NICE CG8 for the management of MS were not being met, in that they were not being used by:

- service providers to guide service delivery
- service commissioners either to commission services or to monitor service delivery
- those responsible for managing health services to monitor that the healthcare needs of their population are being met.

A few organisations adhered partially to one or two recommendations, but most did not adhere to any. Furthermore, most organisations were not specifically planning to implement any of the recommendations.

We drew the following conclusions:

- The organisations within the NHS at all levels did not have the people, information or structures in place needed to develop and improve services for people with long-term neurologically-based disability.
- The triangulation method we used, obtaining data from several different perspectives, was a powerful and economic way of auditing services nationally.

The 2008 audit⁷

The main findings from the second audit were that:

- access to neurological rehabilitation was unacceptably low, with very limited commissioning and only slightly less limited actual provision
- access to specialist neurological services was generally good
- time between initial referral and final diagnosis remained long
- patient involvement both in the planning of individual personal care and in service provision and development was very poor
- assessments were perceived by people with MS generally to be carried out in a sensitive and thorough manner
- integration of care between health and social services was felt to be poor.

The 2011 audit

The third audit was undertaken to monitor service changes since 2008, and to determine the extent to which previous recommendations have influenced service commissioning and delivery. This audit has also collected data from general practice and community services for the first time. The intention is to assist all parts of the NHS to improve services: commissioning organisations, organisations that monitor standards of service provision, and providers of services in secondary care and in primary care and the community.

Final conclusions and recommendations from 2011

Observations	Conclusions	Recommendations
There has been no major improvement in most areas studied since 2006, and it is increasingly difficult to identify specific individuals with ongoing lead responsibility for long-term conditions.	One reason for the lack of change may be the lack of any sustained specific attention on services for people with long-term disabling conditions. This hinders any attempts to achieve the needed re-organisation of services.	All organisations in the NHS should be required to initiate a five year project with protected staff with the responsibility to re-organise services to achieve compliance with the standards put forward by the <i>National Service Framework for Long-term Conditions</i> and NICE CG8 on the management of people with multiple sclerosis. ^{1,2}
	A second, associated reason is that funding streams and mechanisms act to counter provision of integrated services to people with long-term problems.	The Department of Health should introduce a funding mechanism that encourages integration of services across organisations and over time; a form of 'condition management' would seem appropriate.
People with multiple sclerosis report poor care in two specific areas: control of pain and provision of equipment. At the same time services are not commissioned or provided on the basis of any quantification of need.	Services that are commissioned on a broad basis (i.e. without regard to the underlying conditions of the people using those services) are failing to provide adequate services to people with multiple sclerosis, and possibly clinical staff are failing to recognise clinical needs.	All clinical staff should routinely ask people with multiple sclerosis if they have pain and, if so whether it is adequately controlled. And all clinical staff should take responsibility for assessing the need for equipment. All patients needing additional service provision should be referred and service short-fall should be drawn to the attention of commissioners.
The questions on the seven (of eleven) quality requirements of the National Service Framework that were especially relevant to people with MS showed a low level of attainment in all areas.	Firstly, asking questions about the quality requirements in relation to a specific group, people with multiple sclerosis is a good way of monitoring the implementation of the NSF-LTC. Secondly, it will not be implemented within its ten year allocated timeframe.	All organisations in the NHS should be required to initiate a five year project with protected staff with the responsibility to re-organise services to achieve compliance with the NSF-LTC and NICE CG8 standards.
Services for people with multiple sclerosis are not well integrated, transfer of information between organisations is not good, and they do not receive specialist help when in hospital.	Some system needs to be developed so that people with multiple sclerosis receive specialist case management support (and/or support in self-management) throughout all of their encounters with Health (and other) services.	Provisions of specialist case management should be commissioned, and options include using existing specialist neurological rehabilitation and/or MS nurse services, or developing new specialist case management services which must be fully integrated with all relevant specialist services.

Appendix 1: References

- 1** National Institute of Health and Clinical Excellence. *Multiple sclerosis: management of multiple sclerosis in primary and secondary care* (CG8). London: NICE, 2003.
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- 5** National Institute of Health and Clinical Excellence. *Neuropathic pain: The pharmacological management of neuropathic pain in adults in non-specialist settings* (CG96). London: NICE, 2010.
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- 7** Royal College of Physicians and Multiple Sclerosis Trust. *National audit of services for people with multiple sclerosis 2008*. London: RCP and MS Trust, 2008.