



Royal College
of Physicians



Setting higher standards

The national audit of services for people with multiple sclerosis 2011

September 2011

National Report

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Glossary

Trust	Acute hospital trust
DH	Department of Health
LHB	Local health boards
MS	Multiple sclerosis
MS Trust	Multiple Sclerosis Trust
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NSF-LTC	<i>National Service Framework for Long-term Conditions (2005)</i>
NICE CG8	<i>NICE Clinical Guideline 8: Management of multiple sclerosis in primary and secondary care (2003)</i>
PwMS	People with multiple sclerosis
PCT	Primary care trust
QR	Quality requirement
RCP	Royal College of Physicians
SHA	Strategic health authority

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

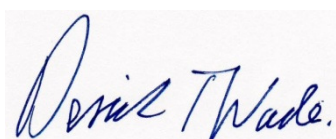
Multiple sclerosis (MS) is an incurable, unpredictable, life-long, challenging condition that affects every part of a person's life. It can have huge impact on family and social life, and lead to loss of work and independence. MS has an uncertain prognosis which can encompass anything from a relatively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

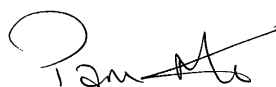
It is clear that there has been no major improvement in most areas studied since the first round of audit in 2006. We hope that the findings presented in this report will assist those who commission or provide services for people with MS to identify where services are deficient. We also hope that the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

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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 report has two main sections: the first concerns information from people with MS, the second concerns data from NHS organisations about performance against NICE CG8 and NSF-LTC standards and is compared with data from previous rounds of audit where possible. Local data is also available to facilitate local improvements in services for people with MS.

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; only 56% of people with MS stated they had been provided with all the 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.

Introduction

Multiple sclerosis (MS) is a particularly relevant condition to use as an exemplar of many long-term conditions in assessing services for patients:

- It is relatively common, affecting about 1.2/1000 of the UK general population.⁶
- The range of clinical and functional problems it generates is vast and may involve almost any part of any healthcare service.
- It often starts in young adulthood (20-40 years of age) but most patients have a nearly normal lifespan.
- In an individual patient the course of the condition is unpredictable but can range from a few minor, short-lived problems to a large number of severe and continuing problems.

Investigating how the health service responds to the many and varied needs of people with MS throughout their illness should therefore be representative of how well the service responds to patients with other long-term conditions. Undertaking such an investigation is a huge challenge because patients are not managed exclusively or even primarily within a single specific service; indeed, most interactions between the patient and healthcare services are **not** with specific MS or neurology services.

In the 21st century, health services will be judged on their ability to provide healthcare to people with long-term conditions. Acute care, diagnosis and treatment of disease have improved greatly since the second World War. Although improvements are still needed and occurring, the greatest challenge facing most healthcare systems is to provide services to people with long-term needs in an efficient and effective way.

This challenge was recognised by the Department of Health (DH) when it initiated two pieces of work:

- The national clinical guideline entitled *Management of multiple sclerosis in primary and secondary care* (NICE CG8) which was published in November 2003.¹ This was the first national clinical guideline published by NICE to consider a common long-term disabling condition.
- The Department of Health led *National Service Framework for Long-term Conditions* (NSF-LTC) published in March 2005.²

These two documents drew on a holistic, biopsychosocial model of illness similar to that used by the World Health Organization in its International Classification of Functioning.⁷ Thus both covered the whole spectrum of clinical needs of patients with long-term conditions. These needs cover diagnosing and managing:

- the disease process itself
- the resultant symptoms and signs
- the functional losses that occur, manifesting as limitations on the activities that a person can undertake
- the social consequences of the illness.

Furthermore, the model emphasises the importance of the patient's physical and social environments, and their own expectations and wishes. Finally, in its most recent form, the model recognises that quality of life is important.

Both documents developed recommendations (NICE CG8) and quality requirements (NSF-LTC) applicable to services for people with MS. They encompass both primary and secondary healthcare, and also care provided by other statutory services such as Housing and Social Services and the voluntary sector. The broad scope of the published recommendations and quality requirements illustrates the range of needs of people with long-term conditions, but it also provides a challenge to a healthcare system which has traditionally focused on acute, often hospital-based care rather than continued care, mostly delivered in the community.

The current plans to reorganise health services with an increased focus upon primary care and community care offers a great opportunity to improve services for all people with long-term conditions because the majority of disabled people spend the majority of their time in the community. This audit should provide data of great interest to any new commissioning organisations, illustrating areas that need specific attention.

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.

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 audit⁸

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, 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 audit⁹

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.

Method

This audit was jointly funded and organised by the RCP and the MS Trust. It was supervised by an overarching multidisciplinary steering group, whilst a smaller working group met regularly to provide day-to-day direction and support. The audit was managed by the Clinical Effectiveness and Evaluation Unit (CEEU) at the RCP.

Scope and aims of this audit

This audit aimed to study the totality of NHS services received by people with MS. While this does include the initial diagnosis of the disease and the giving of specific disease modifying treatments, it is not confined to processes directly related to the underlying pathology. It is intended to cover all interactions between the NHS and the person with MS on the assumptions that most of these arise directly or indirectly from the MS and that most other interactions will be influenced by the presence of MS and its sequelae.

Thus this audit considers the NHS from the perspective of a person with problems that arise directly or indirectly from the disease, and it considers all these problems. This is not an audit of services that are specific to MS (and have an MS label attached) nor is it restricted to specific neurological services. It includes **all services** used by people with MS anywhere in the NHS.

The aim is to measure how well the NHS responds to all the healthcare needs of people with MS, whether or not the patient is seen in a service that specialises in seeing people with MS or neurological conditions.

What's new in 2011?

Whilst the audit methodology was similar to that used in 2006 and 2008, there were key differences. These were incorporated following the second audit in an effort to provide a detailed and comprehensive examination of all services. The main differences were:

- a further seven standards of service provision derived from the NSF-LTC were added
 - Data from both previous audits made it clear that many organisations were more aware of the NSF-LTC than the NICE CG8, and that the NSF-LTC was often used to guide commissioning and service provision. Consequently, for this third audit we have extended the scope to include questions directly related to the NSF-LTC. Nonetheless, the questions still focus on the provisions of services for people with MS.
- data were collected specifically from community services and from a sample of general practices
 - The first two audits did not collect any data concerning services in the community; they exclusively collected data from hospitals. In this third audit cycle we have tried to identify which trusts were primarily providing services in the community either in community hospitals or directly at home. We have also, for the first time, collected data from general practices as service providers.
- a qualitative analysis of service user comments was undertaken within the audit itself.
 - Although data collection methods in all three audits have included the ability of respondents to make comments, these have not been formally analysed and reported within the audit. The comments from patients in 2006 have been analysed and reported elsewhere and patients comments in the second 2008 audit are now being analysed for eventual publication. In this audit report we include an analysis of the comments made by people with MS.

General outline

The audit covered England and Wales, and collected data from different perspectives in order to gain a full picture of services provided:

- People with MS – service users.
- Acute NHS hospital trusts – service providers (secondary care).
- Community-based services – service providers (primary-secondary care interface).
- General practice – service providers (primary care).
- Primary care trusts (PCTs) and local health boards (LHBs) – service commissioners.
- Strategic health authorities (SHAs) – service performance managers.

The audit data collection period was from the 31 January 2011 – 29 April 2011. Participating sites were asked to consider their current organisation of services and their plans for the next 12 months. People with MS were asked to consider their experience of NHS services over the preceding 12 months (i.e. 2010). Organisational data were collected and submitted by healthcare professionals and audit department staff within the various organisations. No clinical data derived from patient case notes were collected; the data concerned service organisation and delivery rather than actual clinical practice with individual patients. The only individual patient data were from the patients themselves.

Standards

The audit was based on the standards in the NICE clinical guideline 8 *Management of multiple sclerosis in primary and secondary care* published in 2003 (NICE CG8) and the *National Service Framework for Long-term Conditions* published in 2005 (NSF-LTC).^{1,2}

Data collection was via a bespoke web-based tool. The seven NICE CG8 standards were the six recommendations and one sentinel marker, and the seven NSF-LTC standards were from seven of the eleven quality requirements. The original recommendations and quality standards and the questions derived from each are shown in Appendix 2 and Appendix 3.

In summary, the service qualities measured were provision of:

- specialised services: neurology and neurological rehabilitation (NICE recommendation one)
- rapid initial diagnosis (NICE recommendation two)
- seamless services within Health and between Health and Social Services (NICE recommendation three)
- services that were centred on individual patient needs and wishes (NICE recommendation four)
- assessments when first seen that were sensitive but thorough (NICE recommendation five)
- services that accepted self-referral back when needed (NICE recommendation six)
- auditing of skin pressure ulcers, incidence and causes (NICE sentinel marker)
- integration of services around the patient's needs, with support for self-management (NSF-LTC QR one)
- access to the full range of services needed (NSF-LTC QR five)
- vocational rehabilitation service (NSF-LTC QR six)
- equipment needed when needed (NSF-LTC QR seven)
- palliation of symptoms (NSF-LTC QR nine)
- support services for families and carers (NSF-LTC QR ten)
- expert, specialist input when admitted to any hospital for any reason (NSF-LTC QR eleven).

The audit focused on services received by or provided for people with MS. In questions to provider organisations, this referred to how people with MS were managed within the organisation. In questions to organisations responsible for commissioning or performance management, the questions were adapted to reflect MS-specific aspects of commissioning or performance management. For the direct patient survey, we simply accepted the patient's diagnosis as given. The audit focused on services

provided for any problem that the person with MS might present with, whether or not it was a direct result of the disease, or an indirect result of the disease or indeed completely unrelated to the disease.

Organisations – identification and data collection

The MS audit steering group first convened in September 2010. It was agreed that some of the NSF-LTC quality requirements would be incorporated into the 2011 audit. Minor amendments were made to the questions used in the 2008 audit. In November 2010, the web-based data collection tool was used to pilot the audit questions, test the functionality of the tool itself and assess the feasibility of the proposed methodology. Participants included two acute hospital trusts, one community provider, two PCTs, one SHA, five general practices and six service users, ensuring that all variations of the proforma were tested.

NHS organisations were identified using the Binley's Database (v9). This database contained contact information on all NHS organisations, with the exception of general practices. In this round of audit mental health trusts and specialist trusts were not approached. Because of the evolving organisational landscape some PCTs had split responsibilities between commissioning and provider 'arms'. Community services were therefore not only identified through Binley's, but also through PCTs, which informed us of the name of their previous provider arm.

General practice contact information was obtained from the Internet and sorted by PCT (in England).^{10,11} A medical statistician randomly selected eight general practices per PCT (15% of 8110 English general practices identified). To maintain a balanced coverage in Wales, 15 general practices were randomly selected from each local health board (15% of the 700 Welsh general practices identified).

People holding the following roles in organisations were invited to participate in the audit:

- chief executive
- medical director
- consultant neurologists
- MS specialist nurses
- MS therapists
- leads for long-term conditions
- managers for clinical governance, effectiveness or audit
- public health directors
- head of commissioning
- general practice managers and senior general practice partner.

In addition neurologists, MS specialist nurses and therapists known to anyone involved in the audit were asked if they could identify and, if possible, contact named individuals working within organisations in their locality who might be willing to help.

The questions and the answer options developed were identical for each organisation as far as this was practical, so that direct comparisons could be made. The answer options were hierarchical, with one end indicating specific use of the NICE CG8 recommendation and the other indicating that nothing was done. In between we specifically included an option on using the NSF-LTC because many organisations used this to guide their work.

Thus the audit asked for the reply to indicate the greatest level of specificity employed when performance monitoring, commissioning or providing services. The following options were available:

- Services specifically for people with MS
- Service in line with NSF-LTC
- Service for neurology as a whole (including neurological rehabilitation)
- Generic services, at a broader level than neurology
- No
- Not known (or not applicable if appropriate)

Audit leads could complete the questionnaire by accessing the MS audit webtool using the site code and password they were sent upon registering. Data could be entered at any point during the data collection period (31 January 2011 – 29 April 2011). For each question, the respondent could access a help note or add additional explanatory information (or make any other comments).

A helpdesk service was provided by the CEEU to resolve queries and provide direction. Various documents were also produced and made available as PDF downloads from the webtool to provide additional support. These included help notes, a quick start guide, a downloadable version of the proforma, a frequently asked questions document and an information sheet (see link below). Newsletters were sent to all registered participants on a monthly basis to provide the latest updates, tips for using the webtool, solutions for commonly raised queries and a motivational message from the MS audit steering group. All newsletters were made available as a download from the webtool. Shorter updates and reminders were also sent regularly by email to all leads.

The final questionnaires used are available on the audit website: <https://audit.rcplondon.ac.uk/ms/>.

People with MS: sample selection and data collection

People with MS from England and Wales were recruited in several ways. The intention was to ensure a sample that covered the whole geographic area, people diagnosed within the last 12 months and the full range of disabilities seen.

The audit was displayed prominently on the website of the MS Trust, and all supporters were notified via newsletter. MS Therapy Centres and a number of residential care homes, both charity-owned and private, were notified. Notices also were posted on all websites, and in discussion groups known to be used by people with MS, including Jooly's Joint and the MS Resource Centre. Invitation cards were distributed via MS specialist neurologists, nurses and therapists. Letters were sent to the editors of regional and local newspapers advertising the audit.

People with MS were asked to provide data in one of two ways. The first option was to complete a form electronically on the web-based data collection tool hosted by the RCP, for which anyone could register. Alternatively, people with MS could contact the MS Trust to request a paper form which they could complete and return to the MS Trust. Paper-based returns were entered onto the web-based tool by MS Trust staff and subsequently posted to the RCP, where entries would be checked by the MS audit project team. Allowance was made for up to 500 paper forms to be completed.

The survey stressed that the respondent should fulfil the following criteria:

- Have MS. The person with MS could ask someone else to complete the form, provided the information came from and related to the person with MS. No check on diagnosis was made.
- Have used or wanted to use an NHS service (including primary care) over the preceding 12 months usually in relation to their MS. No independent check was made.

Within the data collection process any person could make additional comments on the services they had received.

The questions asked of people with MS fell into three groups:

1. The first group focused on the seven standards from NICE CG8 and the seven selected NSF-LTC quality requirements and asked related questions about the person's experience as set against each recommendation.
2. The second group were contextual, asking for information specifically about the respondent's experience with MS. This enabled some estimate to be made about how representative the sample was. In addition it would enable some cross-validation of answers.
3. The third group asked about satisfaction with NHS services.

Each person was also asked what they considered their most important problem was, and whether it had been satisfactorily handled by the NHS. The survey used is available on the audit website: <https://audit.rcplondon.ac.uk/ms/>.

People with MS qualitative data: collection and analysis

In the questions for people with MS there were three questions where the respondent could provide free-text information:

(1&2) Over all, considering your experiences over the last 12 months, how **dissatisfied** were you with the services received from the NHS:

- Comments on anything that went **well** or was **good**
- Comments on anything that went **badly** or was **not good**

(3) What gives you the greatest problem with your MS – in terms of a particular symptom or difficulty?

The comments made in relation to the first two of these questions have been analysed. This was achieved by importing the responses into a single database, sorting them alphabetically, and then allocating them sequentially to the 15 members of the steering group. Thus each steering group member received one fifteenth of the total number of comments. Although responses from some participants were much longer than others, this method distributed the workload fairly and without bias.

Each recipient was asked to:

- a) read the whole set through once
- b) write down their first overall impression as a series of bullet points, preferably no more than 5-6 themes at most
- c) read through the set again, more slowly, refining the bullet points, adding or subtracting themes, and choosing illustrative quotes (1-3 per theme)
- d) review their list
- e) read through the set a last time to
 - i. allocate each quote to one (or more) themes
 - ii. double check themes
 - iii. note comments which have not been used

The steering group member was then asked to return:

- a) The chosen themes, each with between one and three illustrative quotes
- b) The comments which could not be allocated to a theme
- c) Possibly the whole set, showing which theme or themes each comment had been considered to contribute to

The themes and the unallocated comments were then read by one member of the working group and a composite set of themes were generated, aiming for no more than 12. These were then returned, with at least two quotations to illustrate each one, to working group members for further consideration. The returned comments and adjustments were again used to reach a final analysis of themes which were circulated for agreement.

The data are presented as the themes with explanatory comments and illustrative quotations.

Data handling

All data were collected, directly or indirectly, using the web-based collection tool. Data passed into an initial database and they were then imported into SPSS version 19 and analysed. The primary analysis was descriptive.

For organisations, the data for each question are set out for the five organisations (i.e. general practice, community provider, secondary care provider, commissioner, performance management) to allow direct comparison. Within each set of questions, selected data from 2008 are given within summary statements where available to provide a temporal comparison.

As in previous audits, there were some secondary care organisations that stated some or most of their work was undertaken by another organisation on their behalf. We asked all organisations to reply about the service people within their organisation would receive, regardless of who actually provided the service within the organisation. A separate question asked about shared services.

Presentation of results

People with MS data

Data from people with MS are presented first so that the reader can set the organisational results in the context of reported experience. Tables are presented in shades of red.

NHS organisational data

Organisational data have been presented question by question, contrasting data from those responsible for monitoring (SHAs), service commissioning (PCTs/LHBs) and service provision (hospitals, community services, general practice). Each section starts with the key findings identified including a comparison with the 2008 data, where relevant. Following this, the numerical data are presented in tables, with comments at the end if further discussion was appropriate. Tables are presented in shades of blue.

Categorical data are summarised as percentages with numerator and denominator shown. Numerical results are summarised by the median and inter-quartile range (IQR). Denominators will vary according to how much missing data there is. In all data summarisation we have assumed that 'not known' should be interpreted as 'no', and so when giving the percentage of people or organisations who 'do not have' or 'do not do' something, this percentage will include all 'no' and all 'not known' answers. This may inflate the frequency of negative responses if there are a large number of 'not known' responses.

Table column headings:

- 'n =' should be read as 'number'.
- 'NK' should be read as 'not known'.
- 'NA' should be read as 'not applicable'.
- 'GP' should be read as 'general practice'

National results: people with multiple sclerosis

Key findings:

- Analysed data came from 704 people with MS (671 in England, 33 in Wales).
- Data represents 1.1% of the whole population of people with MS in England and Wales

Comparison with previous audits:

- In 2008, a total of 1300 people with MS responded to the survey.
- There was a drop in participation of 46% compared to the 2008 audit (see Discussion for explanation).

950 people with MS accessed the web tool. Of these 218 entered only a user name and went no further. Three patients answered 'No' to question one (i.e. they had not been in contact with the NHS about their MS over the past 12 months). Ten patients did not continue much further than question one and were excluded. Fifteen of the remaining 719 persons were also excluded as they were not living in England or Wales: 11 lived in Scotland, three in Northern Ireland and one person's area of residence was unknown.

Therefore the detailed results that follow are for 704 persons with MS, 671 living in England and 33 in Wales. Given a population in England and Wales of 54 million and an estimated prevalence rate of 1.2/1000 then approximately 64,000 people with MS live in England and Wales, making the sample approximately 1.1% of the whole population of people with MS.⁶

Demographic context

Key findings:

- The median age was 48 years at the time of survey. The median age at diagnosis was 37 years, suggesting a sample diagnosed at a slightly older age of onset than usual.
- The median duration of disease was 7 years.
- Two thirds (72%) were women.
- Eighty four people (12%) had been diagnosed within the last 12 months. A higher proportion than expected (4%) which reflected the emphasis on obtaining information about the process of diagnosis.
- Most people felt that MS had a major (38%) or moderate (43%) affect on their life with only 1% saying there was no impact; this level of impact would be expected given the requirement that the person should have used the NHS within the last year.

Comparison with previous audits:

- Respondents in this audit seemed less severely affected by their disease compared with 2008 when 48% felt severely affected, compared with 38% in 2011.

Table 1: Geographical Coverage

	Audit sample 2011		Audit sample 2008		Proportion/number of national population aged 15 and over	
	%	n =	%	n=	%	000,s
SHA (England):						
East of England	15.3	108	9.1	118	10.4	4601.8
East Midlands	6.7	47	5.4	70	8.2	3604.1
London	11.1	78	7.8	102	13.9	6152.3
North East	5.4	38	4.2	54	4.8	2120.6
North West	7.2	51	9.8	128	12.7	5626.9
South Central	10.4	73	11.7	152	7.4	3271.4
South East Coast	8.2	58	8.8	114	7.9	3494.3
South West	10.9	77	13.2	172	9.7	4268.5
West Midlands	10.4	73	11.2	146	9.9	4383.8
Yorkshire & the Humber	9.7	68	12.6	164	9.6	4232.7
Wales	4.7	33	6.2	80	5.5	2445.0
Total	100.0	704	100.0	1300	100	44201.5

Mid 2006 estimates of resident population aged 15 and over

*(SHA) <http://www.statistics.gov.uk/STATBASE/ssdataset.asp?vlnk=9739&More=Y>

*(Wales)<http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=9661&More=Y>

Gender

Women comprised 72% (508) and men 28% (196) of the responders. In the 2008 audit, 73% were women, 27% men.

Table 2: Duration with MS since diagnosis

		Female	Male
Age	Median	47	53
	Inter-quartile range	39-54	43-60
	Number of persons	508	196
	<i>2008 audit Median</i>	50	54
Age at diagnosis	Median	37	39
	Inter-quartile range	30-45	33-48
	Number of persons	505	194
	<i>2008 audit Median</i>	38	39
Years with MS	Median	7	8
	Inter-quartile range	3-13	4-17
	Number of persons	505	194
	<i>2008 audit Median</i>	8	11

Table 3: How your MS affects you			
Overall, how much impact does your MS have upon your life now?*			
	% Yes (2011)	n =	%Yes (2008)
None	1	8	1
Slight	18	125	14
Moderate	43	300	37
Major	38	263	48

* 8 persons did not give an answer

General experience of services for problems related to MS

<p>Key findings:</p> <ul style="list-style-type: none"> • 81% of people with MS indicated that specialist neurological services were available but only 43% thought that they had access to specialist neurological rehabilitation services. • Most people (93%) said they had access to specialist MS nurses and 57% to specialist MS physiotherapists. • When asked about satisfaction with NHS services, 7% were not at all satisfied and 30% were very satisfied. • When asked about dissatisfaction, 7% were very dissatisfied and 39% were not at all dissatisfied. • The most frequently reported 'most major concern' related to fatigue and mobility. • When asked how the NHS had helped with their self-defined greatest problem, 10% thought that the NHS had done well but 18% were very unsatisfied, agreeing that the NHS "had not really tried". <p>Comparison with previous audits:</p> <ul style="list-style-type: none"> • Generally there was little difference from previous audits, except that many more patients reported that their most important problem was with cognitive deficits.

This group of questions aimed to obtain general information about the use of NHS services by people with MS in the sample; they are not related to the NICE guidance and simply help establish a context. They relate to the **perception** of the respondent.

Table 4: Specialist Services					
As far as you know, are there specialist services for people with MS in your area:					
	% Yes (2011)	Yes	No	NK	% Yes (2008)
Specialist MS neurological services?*	81	570	34	100	78
Specialist neurological rehabilitation services?***	43	304	51	349	40
Specialist MS nursing?	93	652	17	35	82
Specialist MS physiotherapy?	57	399	76	129	58

***specialist neurology service:** services for diagnosis of MS and any later symptoms, and for provision of specific drug treatments, especially disease modifying drugs

*****specialist neurological rehabilitation service:** services providing an integrated rehabilitation programme through a multidisciplinary team when there are complex problems, aiming to help the person live as independently as possible

Table 5: Overall satisfaction with services			
Over the last year, how satisfied were you in general with the standard of service received from the NHS (mark one)*:			
	% Yes (2011)	n =	%Yes (2008)
Not at all satisfied	7	48	10
Somewhat satisfied; the NHS could do better	25	174	30
Moderately satisfied; the NHS did as well as I expected	39	273	37
Very satisfied; the NHS did better than I expected	30	208	23

* 1 person did not give an answer

Table 6: Dissatisfaction			
Overall considering your experiences over the last 12 months, how dissatisfied were you with the services received from the NHS?*			
	% Yes (2011)	n =	%Yes (2008)
Not at all dissatisfied; no complaints	39	268	40
A little dissatisfied; there were some things that could have been done better	38	262	39
Dissatisfied; many things could have been better, but some were OK	17	117	15
Very dissatisfied; nothing much was helpful or useful	7	49	7

* 8 persons did not give an answer

Table 7: Pain (n = 694 responses)			
	% Yes (2011)	n =	%Yes (2008)
Do you have any problems with pain from your MS?	67	462/694	67
Is this pain present every day?	78	355/458	72
Do you take medication every day for this pain?	64	293/459	59
Is the pain controlled to your satisfaction?	55	254/458	57

The results suggest that between a quarter and a third of people felt that the NHS could have helped them more. The proportion of people with pain is surprisingly high with two thirds having pain. Moreover, only just over half of these people feel that the pain is satisfactorily controlled, a depressingly low percentage.

The very high rate of access to specialist MS nurses is probably not representative of the overall population, because specialist MS nurses were active in publicising the survey to people with MS.

Most major concern

People with MS were asked to describe (in free-text) what was the greatest problem they had with their MS – in terms of a particular symptom or difficulty. They were also asked how successful they thought the NHS had been in helping with this problem. The table below lists their major concerns. The table has sorted the top twelve by frequency in 2011, and the next 12 show the figures for 2008 sorted by frequency in 2008.

Table 8: Most major concern		
Symptoms	Persons (2011)	Persons (2008)
Fatigue	137	193
Mobility, walking	93	161
Mobility, other	80	160
Pain	73	99
Bladder & continence	31	49
Balance	28	45
spasticity/spasms	21	34
Cognitive loss/function	21	9
Visual	18	39
Motor control general	16	33
Sensory disturbance (not pain)	13	30
variability/uncertainty	10	18
Being dependent on others		27
Motor control, leg		26
Acceptance/adjustment		19
Bowel control/function	6	13
Work		13
Frustration	1	12
Altered abilities		12
"Everything"	5	10
Motor control, arm	6	9
Emotional problems	3	9
Health service availability		8
Vertigo/dizziness	9	6

Table 9: Most major concern – NHS success (n = 679 responses)			
How successful do you think that the NHS has been in helping you with this problem?			
	% Yes (2011)	n =	%Yes (2008)
Very successful	10	70	10
Moderately; there may not be much more that can be done	45	307	46
Slightly; they did at least try something	26	179	28
Not at all; they have not really tried	18	123	16

Key recommendation one: specialised services

Specialised neurological and neurological rehabilitation services should be available to every person with MS when they need them usually when they develop any new symptom, sign, limitation on their activities or other problem, or when their circumstances change.¹

Key findings:

- About three quarters of people with MS thought that they could be seen by a specialist neurologist if needed.
- Only one third of people with MS thought that they could be seen by a specialist neurological rehabilitation service if needed.

Comparison with previous audits:

- These figures are almost identical to 2008, with no improvement in access to specialist rehabilitation

These questions concerned the first NICE CG8 recommendation and focused on the beliefs and expectations of respondents. We expected the answers to be derived either from personal experience or through other people with MS locally.

Table 10: Specialist neurology service

If you or your GP thought you needed to be seen in a specialist neurology service (Services for diagnosis of MS and subsequent symptoms, and provision of specific drug treatments, especially disease modifying drugs):

	% Yes (2011)	Yes	No	NK	NA	%Yes (2008)
Could you be referred to a specialist neurology service?	73	512	11	162	19	73

Table 11: Specialist neurological rehabilitation service

If you or your GP thought you needed to be seen in a specialist neurological rehabilitation service (Services providing an integrated rehabilitation programme through a multidisciplinary team when there are complex problems, aiming to help the person live independently):

	% Yes (2011)	Yes	No	NK	NA	%Yes (2008)
Could you be referred to a specialist rehabilitation service?	36	252	25	388	39	36

Key recommendation two: rapid diagnosis

An individual who is suspected of having MS should be referred to a specialist neurology service and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time).¹

Key findings:

- Over half (58%) of all 84 newly diagnosed patients were seen by a neurologist within 6 weeks, and 61% had all tests completed within six weeks of first seeing a neurologist.
- The median (IQR) time between initial referral and final diagnosis was 25 (8-46) weeks; this implies that half of all people took more than 25 weeks in total to achieve final diagnosis (against a NICE standard of 12 weeks).
- Nearly two-thirds of people were given written information about the disease and were given information about national support organisations after diagnosis, and 70% were given contact details about a specialist neurologist or specialist nurse.
- Only 29% were given information on specialist therapists and 23% an opportunity to attend an educational course and only 42% were given information about local support groups.

Comparison with previous audits:

- Generally people received more support after diagnosis in 2011.
- The information on speed is contradictory: more people had tests completed within six weeks, but the overall delay from referral to diagnosis was longer.

These questions only applied to those diagnosed in the last 12 months. There were 12% (84/704) who had been diagnosed in the last 12 months. Four of these did not answer the rest of the questions. Therefore **the data are from 84 people**.

Table 12: Referral to specialist service

	% Yes (2011)	Yes	No	NK	%Yes (2008)
Were you seen by a neurologist within 6 weeks of referral by the GP?	58	49	30	5	58
After the first consultation with the neurologist, were all tests carried out within 6 weeks?	61	51	28	5	48

Table 13: Time to diagnosis

	Median	Interquartile range	80 th centile range	Number of persons
How many weeks passed from first seeing your GP to final confirmation of the diagnosis	25	8-46	4-107	84
<i>2008 audit:</i>	20	7-38	2-63	116

Table 14: Information about MS

During or immediately after diagnosis were you given any of the following:

	% Yes (2011)	Yes	No	NK	%Yes (2008)
Written information about MS?	64	54	29	1	54
Contact details for a specialist neurologist?	70	59	23	2	62
Contact details for a specialist MS nurse?	70	59	25	-	67
Contact details for a specialist MS therapist?	29	24	55	5	16
Information on local MS support groups?	42	35	48	1	36
Information on national MS organisations?	61	51	32	1	47
An opportunity to attend an educational programme?	23	19	59	6	16

Key recommendation three: seamless services

Every health commissioning organisation should ensure that all organisations in a local health area agree and publish protocols for sharing and transferring responsibility for and information about people with MS, so as to make the service seamless from the individual's perspective.¹

Key findings:

- 64% of people with MS reported that the sharing of information between health organisations made the transfer of care easy.
- Only 29% percent of people felt that information sharing from Health to Social Services made transfer of care easy.

Comparison with previous audits:

- There was a marked worsening in the perceived transfer of information from health to social services (good dropping from 41% to 29%) between 2008 and 2011.
- The overall trend was for less seamless services.

Only people who had been referred between organisations could answer this question. Three hundred and sixty six (52%) people had been referred between different health or social care organisations. In 2008, the percentage was the same.

Table 15: Information regarding transfer

Did you feel that the referring person and the new organisation shared sufficient information to make the transfer easy for you:

	% Yes (2011)	Yes	No	NK	NA	%Yes (2008)
From one hospital service to another e.g. physiotherapy to urology	64	235	63	30	38	67
From GP (or other local health professional) to hospital	67	247	49	21	49	73
From hospital or GP to Social Services	29	105	60	38	163	41
From hospital or GP to any other service	48	176	52	36	102	52

Key recommendation four: involvement in clinical decisions

*All services and service personnel within the healthcare sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be actively involved in all decisions and actions.*¹

Key findings:

- Just over half (59%) of people felt that they had been involved in clinical decision making as much as they wanted.

Comparison with previous audits:

- The trend is for more involvement of patients, but the change is small.

This question investigates whether people with MS felt that NHS staff had involved them in clinical decisions on diagnosis and treatment.

Table 16: Involvement in decisions

During your contact with NHS services, were you involved in decisions on tests, assessments, referrals, and treatments?*

	% Yes (2011)	n =	%Yes (2008)
Not at all / Less than I would have liked	41	290	47
As much as I wanted	59	413	53

*1 person did not give an answer

Key recommendation five: sensitive but thorough assessment

*Health professionals in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control.*¹

Key findings:

- 69% of people with MS thought that their initial assessment had been thorough, and the same proportion thought it had been carried out sensitively.

Comparison with previous audits:

- There has been little change.

These questions aimed to establish whether health professionals undertook thorough assessments in a sensitive manner.

Table 17: Sensitive but thorough assessment

Considering when you were first seen about a problem relating to your MS:

	% Yes (2011)	Yes	No	NK	%Yes (2008)
Did the person or team do a thorough assessment, covering all the important areas?	69	488	154	62	66
Was the assessment carried out sensitively?	69	488	155	61	67

Key recommendation six: self-referral

Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate.¹

Key findings:

- Two thirds of people with MS felt able to refer themselves back to specialist neurology services, but only one third (30%) felt that this was possible for specialist neurological rehabilitation services.

Comparison with previous audits:

- There has been a slight increase in ability to refer oneself back to neurology, but no change in the low rate for rehabilitation.

These question whether people with MS who had been discharged (i.e. when no more appointments or admissions were planned) from a specialist service could refer themselves back to the specialist services.

Table 18: Self-referral

If you need to, are you able to make contact directly with someone in the specialist service about a new problem:

	% Yes (2011)	Yes	No	NK	%Yes (2008)
Specialist neurology service	72	509	54	141	67
Specialist neurological rehabilitation service	30	214	98	392	30

Sentinel marker: skin pressure ulcers

The commissioning health organisation should require all healthcare services including community services: to report every pressure ulcer occurring in a person with MS, to undertake and report an investigation into what could have been done to avoid its occurrence, to agree actions that should reduce the risk of the same situation leading to a pressure ulcer.¹

Key findings:

- 27 people (4%) developed a skin pressure ulcer over the year preceding this survey; only 16 were investigated by the NHS (as far as the person knew).

Comparison with previous audits:

- The rate of skin pressure ulcers was lower in 2011 but the sample is less disabled which may account for this.
- Four percent is still a high figure, but is reduced from 9% in 2006 and 6% in 2008.

These questions related to the 'sentinel marker' of good services, namely that the NHS should investigate every new pressure ulcer, in order to reduce the number occurring.

Table 19: Skin pressure ulcers

	% Yes (2011)	Yes	No	NK	%Yes (2008)
Have you developed any skin pressure ulcers (pressure sores) over the last 12 months?	4	27	673	4	6
Was the cause investigated by someone from the healthcare team?	59	16	9	2	55

National Service Framework for Long-term Conditions: quality requirements

The next seven questions are derived from the *National Service Framework for Long-term Conditions* quality requirements numbers 1-13. This is the first time these questions have been used, and so there are no historical comparison data.

Key Findings:

- Only a small minority (12%-16%) of patients had received specific assistance in integrating the services received or in learning about self-management.
- The question on quality requirement four confirms that specialist neurological rehabilitation is rarely available with the highest rate being for one third on an outpatient basis.
- Vocational rehabilitation is notable by its absence; only 11% of 168 people unable to return to work and 15% of 265 people with problems at work had any vocational rehabilitation support.
- Equipment supply is very poor: only 47% of people needing equipment received all the equipment they needed and only 56% of people needing mobility aids received them.
- Palliative control of pain is poor: only 14% of people with uncontrolled pain received specialist palliative care input.
- Support to families and carers is very poor: only 9%-12% received specific help and support including respite care.
- Only 18% of people admitted to a non-neurological ward with a problem were seen by a specialist neurological and/or rehabilitation service during their admission.
- The results of this first audit of compliance with the NSF-LTC in people with MS would suggest that an audit against the quality requirements are another useful and valid measure of the quality of NHS services for people with long-term conditions.

Quality requirement one

The NHS is supposed to ensure integrated services that cover both health and social needs, and that facilitate people with MS to learn self-management of their condition.²

Table 20: Case-management and self-management

	% Yes (2011)	Yes	No	NK
Have you been put in contact with a case-management service that integrates all services across Health and Social Services?	12	86	511	107
Have you been put in contact with a case-management service that helps you learn how to manage problems for yourself?	16	116	491	97

Quality requirement four

The NHS is supposed to provide the whole range of specialist neurological rehabilitation to people with MS.²

Table 21: Access to specialist neurological rehabilitation				
	% Yes (2011)	Yes	No	NK
Can you receive inpatient specialist rehabilitation if needed?	21	145	55	504
Can you receive outpatient specialist rehabilitation if needed?	37	263	37	404
Can you receive specialist rehabilitation at home if needed?	19	134	44	526
If you are in a nursing home, can you receive specialist rehabilitation if needed?	3	18	58	628

It should be noted that the answer options for the last question on nursing homes did **not** include 'not applicable' and it is unclear whether the people who replied 'Yes' or 'No' were all in nursing homes or were referring to expectation or actual knowledge from other sources. Future audits should establish whether the person answering was in a nursing home or had direct knowledge from some specific source.

Quality requirement six

The NHS is supposed to supply specialist vocational rehabilitation for people with difficulties at work.²

Table 22: Access to specialist vocational rehabilitation					
	% Yes (2011)	Yes	No	NK	NA
If you had problems at work due to your MS in the last year (including stopping work), did you receive any specialist help from the NHS?	15	41	197	27	439
If you were unable to work due to your MS but asked to return to work, did you receive any specialist help from the NHS?	11	19	128	21	536

The general perception is that few NHS hospitals provide any specialist vocational rehabilitation and so it is surprising that 15% of patient with problems at work received 'specialist help'. It is possible that this was advice and help from an occupational therapist who was interested and future surveys could ask more to establish whether an identified specialist **vocational rehabilitation service** was involved.

Quality requirement seven

The NHS is supposed to provide all assistive technology, equipment and adaptations needed to support people with MS in living independently at home.²

Table 23: Provision of equipment needed					
	% Yes (2011)	Yes	No	NK	NA
Did the NHS provide you with all the equipment and adaptations you needed over the last year	47	189	169	41	305
Were you provided with all mobility equipment needed (stick, frame, wheelchair, hoist etc)	56	249	168	28	259

This question reveals a low level of equipment provision, not only contrary to the NSF-LTC quality requirement but also contrary to the strong and repeated recommendations of the Audit Commission reports.^{3,4} Only half of all people needing equipment had been provided with it and even allowing for some possible unrealistic expectations, this is a low figure.

Quality requirement nine

The NHS is supposed to provide people with multiple sclerosis with all palliative care services needed to control symptoms.²

Table 24: Control of pain					
	% Yes (2011)	Yes	No	NK	NA
If you had uncontrolled pain in the last year, were you seen by a specialist palliative care service?	14	32	177	34	461

It is distressing that only 14% of people with uncontrolled pain were seen by a specialist palliative care service. It is obviously arguable that both a specialist neurological rehabilitation service and indeed a specialist neurology service should have the specialist skills needed to alleviate pain in people with MS. Moreover most parts of the country have specialist pain services as well.

Interestingly 204 people answered an earlier question stating that they had pain that was not controlled satisfactorily, and in this question 202 people have stated that they had uncontrolled pain. Of these 202 people 177 who were presumably in contact with some part of the NHS nonetheless felt that they had not seen a specialist service. This failure to use the best service possible to control the pain needs urgent action. It is unacceptable that so many people are in pain and are not having it treated by a specialist service.

Quality requirement ten

The NHS is supposed to support the families and unpaid carers of people with multiple sclerosis in their own right.²

Table 25: Support to families and carers					
	% Yes (2011)	Yes	No	NK	NA
Over the last year were any family or friends providing care offered an assessment of their needs (by Social services)	9	39	362	31	272
If needed and wanted by you and your family, were you able to obtain respite care in a place where the staff understood about multiple sclerosis and met your particular care needs	12	24	85	98	497
Were family and friends who provide care offered the emotional, practical or informational support that they needed	10	41	303	61	299

It is striking that social services appear to have failed in their statutory duty to assess the needs of carers in 90% of relevant cases. While obviously Social services may not have the resource to provide the support needs identified, they should have the resource to assess need. The lack of suitable respite placements with relevant expertise is less surprising, because nursing home and residential placements for younger people are often unavailable. Nonetheless 85 (78%) of 109 people who wanted respite care and knew what was available could not access any suitable place. And even relatively cheap support was only provided to 41 (12%) of 344 people who definitely wanted it.

The inescapable conclusion is that this quality requirement is not being met in most parts of England and Wales; carers are being ignored.

Quality requirement eleven

The NHS is supposed to ensure that any person with multiple sclerosis admitted to hospital in a non-neurological ward nonetheless receives input from a specialist neurological service to ensure that their needs are identified and met appropriately.²

Table 26: Specialist support when admitted to hospital					
	% Yes (2011)	Yes	No	NK	NA
If you were admitted to a non-neurological ward last year, were you assessed by a person or team specialising in multiple sclerosis early in the admission	18	29	100	28	547
If assessed, were your specific care needs met	83	24	3	2	-

One of the recurrent complaints made by people with MS is that when they are admitted to hospital with an incidental illness under the care of a general medical service (rather than being admitted with a specific neurological problem needing admission to a specialist neurological ward), their needs are not met. They report that non-neurological wards have difficulty managing the disability, and any symptoms arising from the MS.

The response to this question shows that less than one fifth of people admitted to non-neurological wards are seen by anyone with specialist knowledge of MS. But, interestingly, when patients were seen their specific needs were usually met.

This question highlights the failure of hospitals to ensure that **all** the needs of patients under their care are met.

Optional information

Key findings:

- Fatigue was troublesome to 91% of respondents, and affected daily activities for 1-2 hours each day in 70%.
- Walking difficulties were experienced by 83%; 77% used aids or support while walking.
- Transferring from bed to chair was possible independently in 85%.
- 16% used wheelchairs indoors on a daily basis.
- Falling was common: 79% of people had fallen in the last year, 16% more than 20 times and 14% of people had attended hospital with a fall.
- 70% of people had some bladder problems, with 54% experiencing incontinence and 8% using a catheter.
- 67% of people had problems with pain and 78% of these had daily pain and 64% took daily analgesia (successfully in 55%).
- 18% of people felt that the NHS had not really tried to help with their most important problem whereas 10% felt the NHS had been very successful at help with their most severe problem.

Comparison with previous audits:

- The figures are very similar to those in 2008.

The questions in this section were aimed at obtaining more clinical information about respondents in order to set the survey in a general context. Answering was optional but over 90% responded. The questions concerned:

- Fatigue
- Mobility
 - Falls
- Bladder
- Pain

Table 27: Fatigue (n = 695)			
	% Yes (2011)	n =	%Yes (2008)
Do you have any problems with fatigue (tiredness) from your MS?	91	639/695	92
Has fatigue affected your daily activities over the last four weeks?	90	572/638	89
Has fatigue prevented you from doing things for more than 1-2 hours without a rest each day over the last four weeks?	70	446/637	69

Table 18: Mobility (n = 697)			
	% Yes (2011)	n =	%Yes (2008)
Do you have any problems with walking?	83	581/697	86
Do you use a walking aid (e.g. stick, frame) or a person or furniture and walls to help you walk on a regular basis?	77	449/580	75
Do you use a wheelchair or scooter outdoors?	43	252/580	59
Do you use a wheelchair indoors on a daily basis?	16	94/580	25
Can you get out of bed into a chair on your own?	85	494/579	83
Can you get about your home without help - by whatever means?	83	478/578	77
Did you attend hospital as a result of a fall over the last year?	14	65/472*	Not asked

*denominator comprises 65 saying 'yes' and 407 saying 'no'; 97 said 'not applicable'

Reduced mobility is one of the commonest limitations on activities experienced by people with MS. The figures are broadly similar to those in 2008. However the rate of falling leading to hospital attendance was recorded for the first time in this round, and the rate of 14% of those people who could fall is high, and warrants further investigation: is this due to lack of equipment, lack of assessment and therapy, lack of awareness by the person, or perseverance in trying to remain mobile?

Falls

In addition to asking about hospital attendance after a fall, on this occasion we asked how many falls the respondent had had over the last twelve months. There were 565 responses. Seventy-nine percent (449/565) had fallen over the last 12 months and of these 16% (71/449) had fallen 20 or more times and 6% (26/449) had fallen 50 or more times. (Fifty was the maximum number allowed in the webtool). Overall for the 581 people with walking problems, there had been a median 4 and IQR 1-8 falls in the last year and for the 449 people who had fallen, a median of 5 and IQR 2-10 falls in the last year. These data suggest that services may need to ask about falls and to take action to reduce the risk of falling without over-ruling the person's autonomy.

Table 28: Bladder (n = 692)			
	% Yes (2011)	n =	%Yes (2008)
Do you have any problems with your bladder?	70	487/692	72
Have you had any problem with incontinence (wetting yourself) over the last four weeks?	54	261/484	56
Do you have a catheter in place permanently to empty your bladder?	8	41/485	13

National results: qualitative analysis

Key findings:

- The most easily identified domains or areas of interest encompassed in the comments included:
 - Quality of care; both positive and negative comments.
 - Administrative errors causing distress; no positive comments.
 - Availability of resources; generally about the lack of therapies, drugs, time etc.
 - Communication and integration between professional staff, and organisations; generally highlighting difficulties.
 - Responsiveness; responding quickly and appropriately to new needs. Both positive and negative experiences reported.
 - Level of knowledge of GPs about MS and its problems; comments generally critical but often recognition that it cannot necessarily be expected.
 - Attitude of nurses and doctors; generally critical comments about attitude or ability to communicate.
 - Fear about future quality and quantity of services; decline in services expected.
 - Specialist MS nurses and therapists; generally very positive experiences, but not always.
 - Clinical issues; comments on failures to diagnose or treat specific problems correctly or promptly.
 - Provision of information; both positive and negative experiences.
 - Support including respite care; good and bad experiences.
- A significant number of comments named particular places, services or people.
- The experiences were very varied, ranging from totally excellent to totally poor with many people being positive about something and negative about something else.

Most of the people with MS who completed the survey made comments about the services received. Some comments were brief and general, whereas others were long, detailed and very specific. They varied from the very positive to the very negative, and some implied that formal complaint or legal procedures were being followed. In almost all theme areas identified below it was possible to find both positive and negative statements.

One general feature that stood out was that experiences were very varied. Some people clearly had received a service that they considered excellent and comprehensive, whereas other clearly felt the opposite. Many commented on both good and bad experiences, and a few noted how patchy services were either through comparison with other people living elsewhere or after a move.

The themes identified here reflect the area of interest. It would have been possible to divide the comments into positive and negative – almost all took a positive or negative view – but this would not be informative. Thus we have extracted the domain of concern.

The results are given as a **domain of interest** which is the heading in bold type, followed by a brief explanation and then a series of textual quotations in italics. The text shown is only minimally edited. Firstly, any specific named information has been removed – names of staff or hospitals have been taken out. Secondly, some simple spelling mistakes have been corrected. Otherwise the text is simply as it was entered.

Quality of care

There were many comments concerning the general quality of care received from healthcare professionals. Some of the comments were very positive but equally some were very negative.

- *Both of the consultant neurologists who I have seen [named place] have provided my wife and me with clear information about my MS and the treatment that I will be having in a sensitive manner*
- *The service I have received at [named place] has been excellent. This includes my neurologist, MS specialist doctor and MS nurse. __ My GP has also been very supportive, as has the Rehab Team at [named place]*
- *The ms nurse showing me how to use the betaferon device didn't know how to use it.*
- *I only had my first major relapse in Sept 2010. The care and attention i have received has been exceptional and I can't believe how much backup is available. My ms nurse is fantastic!!! I work in the NHS and have been exceptionally impressed as you only ever hear the bad side!!!!*

Administration

There were several comments on the administration of the services within organisations, usually recounting failures.

- *mislabelled my file with wrong address for 4 years*
- *My initial tests were carried out in 2005/2006 but I wasn't told the results officially until 2008 because they had been 'lost' in the system.*
- *The short-notice (you're only informed about 3 weeks before an appointment making forward planning for the patient difficult) appointment system the NHS have in place for Neurology (and probably other specialisms) is counter productive and risks your missing your one and only annual appointment (I do have a life outside MS).*
- *My appointments with my consultant are regularly cancelled and made for another 3 to 6 months later*
- *I was not followed up after my diagnosis and had to ring the hospital to find I was meant to be seen two months previously but was told "for some reason the computer did not flag it up". So had I not phoned how much longer would it have been????"*

Availability of resources (therapy, drugs etc)

Many comments were concerned with the lack of access to a treatment or therapy that the person considered appropriate or necessary. These covered everything from specific treatments to a lack of respite care.

- *The real problem for me is the lack of physiotherapists.*
- *Not enough appointments with the neurologist*
- *there is a gap of 16 months between seeing the neurologist responsible for my case*
- *I was having respite care 3x yearly for 5x years for PPMS, I was then cut to 2x yearly,*
- *PCT cancelled the palliative physiotherapy care 6 years ago and replaced it with NOTHING*

Communication/integration between professionals and services

The failure of individual professionals and/or organisations and departments to communicate and to transfer care smoothly was often mentioned. This was separate from the specific aspects of communication between a person with MS and an individual therapist.

- *"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" (3)*
- *"I only discovered the MS nurse in my area in 2010. I worked with a colleague of hers who put me in touch because my vertigo/balance was deteriorating again, Although my GP confirmed my diagnosis in 1992 (and I have had MS since mid 1982) he has never mentioned this service to me. The MS nurse has referred me to physio for vestibular rehab. If I had started this physio in 2003 when the first episode of this type occurred, I may be far less disabled now." (40)*
- *"No contact between consultants, which delayed treatment with DMT by several months."*
- *The last relapse I had was in 2010 & there was a lack of joining up between the Hospital & my GP. I had switched GP Surgery at least 2 years ago & informed the Hospital Administration staff at the time, but this failed to get onto my file - therefore all the letters about my treatment from the*

hospital were being sent to the incorrect GP Surgery. This caused a problem when I went to my GP requesting a course of steroids for the relapse I was having & they weren't able to fulfil the request as they'd received no updated information from the Hospital. This meant I had to go back to the GP a few days later when they had got hold of my MS Nurse & got the information, thus causing a delay in the start of the steroid course for which I was not happy. The above is one of the reasons I don't tend to involve my GP in my MS treatment because (a) I have more of a clue about my illness & treatment than they do & (b) I tend to get a better response from my MS Nurse, even though she is based more than 50 miles away from my home

- Very little integrated support especially follow up for carer and sufferer who are basically left to try and cope'
- communication between general medical staff and neuro staff is very poor, little practical info given upon diagnosis, never sure what to do when experiencing symptoms, not sure how to use MS nurse service or what they really do

Responsiveness of service

The ability (sometimes) or the inability (more often) of services to respond quickly to a new problem was commented on quite frequently.

- No urgency sometimes which when I have a problem it's hard to get an answer
- Unable to get hold of any MS nurse over the Christmas period, so by the time I got to see my specialist it was too late to take steroids for my relapse
- I still feel that I have to explain the need for prompt treatment of UTIs to GP every time in order to make sure I don't suffer related relapses. My MS nurse is very busy, I don't have as much contact as I would like but she does her best within time constraints and is very empathetic.

Low level of knowledge/expertise in general practice

Many people commented on the difficulty their GP faced having little experience or expertise, and most were not critical.

- The local GP could be better knowledgeable in MS to give the confidence I feel I need after only being diagnosed for 6 months.
- GPs know barely anything about what is happening in MS, how to help with symptoms, and frankly what MS is properly.
- GP said to me "you are the first person I have ever seen with MS "
- think my GPs understand enough about MS and/or the relevant specialist MS services and treatments available to me. The best support I have had is through my MS nurse and the 2 neurologists I have seen in the last year. I really feel that GPs should know and understand more than they do and be more proactive in offering their patients support, guidance and info re relevant drugs and treatments available. I am quite shocked at their lack of knowledge regarding MS and will always contact my MS nurse first for advice as my GPs seem to know so little

Attitude towards patient, usually of doctors and nurses

There were quite critical comments about the attitude of doctors and other healthcare professionals.

- The contact I have had with an MS nurse has been appalling, she got very aggressive and confrontational with me on the phone so I have not contacted her again
- "Extremely insensitive nursing and medical staff. No help offered just told to 'live with it'....I could go on but have decided to get on with my life using my own strategies and GP"
- "My last appointment left me feeling like a naughty school child. I felt I was being lectured by the consultant, who didn't want to see or hear the records I'd kept of my condition since starting beta-interferon...attend an appointment once a year and I dread it....it's a conveyor belt system"

Fear of future access to services

There were several comments expressing concern about the likely reduction in service quality or quantity.

- *I have been referred to all the services I need and am only concerned that government cuts might mean that this support system is put under pressure and not be able to deliver such a good service in future*
- *Extremely worried that physio facilities at [named place] are being cut back so much and the lack of information for the future. Also having been assessed and tested for a wheelchair the waiting period and again information relating to delivery is not at all good. _ Of course the closure of [named place] is the worst news of all and the uncertainty of being unable to get good and save respite care is an ongoing concern._*

Value of specialist nurses/therapists

There were very many comments extolling the virtue of specialist nurses and therapists, often named.

- *MS Nurse is amazing!! She is great and helps with anything, if it weren't for her I do not know what would be happening to me*
- *My local MS nurse has been an absolute (sic) godsend, I could not imagine coping without her*
- *The MS specialist nurse that I saw is fantastic. She gave me lots of advice, listened to my concerns and made sure that I was put in touch with the correct services.*
- *Physiotherapy team is good, extra staff meant I finally got to see someone and was told they are now making provisions to make sure anyone who suffers a relapse is seen for rehab within 6 weeks*

Clinical issues

Many comments referred to the difficulty and perceived failure of clinical practice such as making the diagnosis and giving correct treatments.

- *GP's misdiagnosis of a relapse*
- *One thing that really frustrates me is that I seem to have to come up with suggestions for discomfort, pain or difficulties to the neurologist, who will then go through my suggestions to exclude or include some of them. I feel the suggestions never come from him!*
- *I am disappointed that this has never been picked up by my GP before.*
- *I was given morphine by the pain nurse at the hospital which my GP refused to renew which left me with little or no pain relief since November last year. I personally feel the NHS is the worst ever and badly lets me and others with mS down_ Despite my 25 years of soldiering I have nothing to depend on*

Provision of information

There are many comments on information provision, generally positive.

- *The National's Neuro Direct telephone advice service is brilliant - hugely helpful to patients. Needs to be set up in other areas too to help patients there*
- *Received virtually no written information or advice other than that which my family have found for me via the internet*

General support, including respite

Many comments referred generally to support, which seemed to cover practical issues, emotional support and generally being helpful or not.

- *The assistance offered at diagnosis which was not needed at the time, was difficult to discover and access some years later when I needed it*
- *My MS nurse is supportive and helpful and it's nice to know there's someone I can call if I need to*
- *Excellent support and clarity from the consultant that diagnosed me*
- *I have always been provided by a good array of information and advice to help me.*
- *The MS specialist nurse I was allocated is a great source of support.*
- *Nobody cares. I have been written off a long time ago.*
- *MS nurse prepared to talk in general about my condition but not prepared to support me during incapacity hearing*

Full national results: NHS organisational audit

Key findings:

- The response rate from Wales (n = 4) and strategic health authorities (n = 4) was too low to allow separate analysis; data from Wales was added to the English dataset.

Comparison with previous audits:

- The number of organisations providing data has reduced since 2008. However this audit included 32 providers of community services, a group that was not previously studied.

Table OA1 shows the number of organisations approached and the number who provided usable data. Some organisations registered but then did not complete the questionnaire. Some of the trusts initially approached made it obvious that they would not normally see anyone with MS (e.g. a hospital specialising in cardiac surgery), and they have not been included.

Because of the low response rate from Wales as a whole, we have amalgamated data from Wales with the data from England. And because of the low response rate from the strategic health authorities in England we have not drawn any conclusions from their data.

Table OA1: Participating sites

	SHA	PCT / LHB	Acute trust	Community trust	GP
Approached	(n = 10)	(n = 151)	(n = 151)	(n = 62)	(n = 1265)
Analysed	(n = 4; 40%)	(n = 51; 34%)*	(n = 105; 70%)**	(n = 32; 52%)	(n = 49; 4%)

*49/144 eligible PCTs and 2/7 LHBs

**103/144 eligible acute trusts and 2/7 LHBs

A significant minority of organisations did not provide data. We excluded as far as we could specialist trusts that exclusively admitted non-neurological patients (e.g. specialist chest hospitals) on the grounds that very few people with MS were likely to be admitted or seen.

Fewer organisations replied in 2011 compared with 2008, possibly because the NHS was undergoing even more organisational change than usual. Also there may have been mergers between organisations, reducing the total number. On the other hand, we did recruit 32 community providers; some of these may have been included with hospital trusts previously.

Managerial responsibility for services for people with MS and specialist clinical time contracted for multiple sclerosis

Key findings:

- Specific managerial interest in service for people with MS and in all related specialist services is generally less than 50%, with the primary exception being a high interest in long-term conditions in commissioning organisations.
- Clinical input into commissioning remains low, at about 50%.

Comparison with previous audits:

- The amount of specialist management has reduced since 2008, but there has been little change in the amount of advisory clinical time contracted in organisations.

These questions were asked to ascertain the level of interest the organisation had in MS specifically and in long-term neurological conditions in general. The answers may indicate, to a minor extent, the likely validity of information provided; organisations without a specialised lead would be less likely to have readily available relevant information.

Table OA2: Cross-tabulations MS & NSF-LTC responsibilities in trusts	Long-term conditions NSF: Does your trust / provider unit have someone with managerial responsibility (i.e. within their job description or title) for services			
	No	NK	Yes	
Multiple sclerosis: Does your trust / provider unit have someone with managerial responsibility (i.e. within their job description or title) for services	No	40	12	4
	NK	-	9	-
	Yes	5	9	26

Table OA3: Managerial responsibilities within trusts														
Does your organisation have someone with managerial responsibility (i.e. within their job description or title) for services in the following areas														
	SHA		PCT / LHB				Acute trust				Community trust			
	%	n =	%	yes	no	NK	%	yes	no	NK	%	yes	no	NK
Multiple sclerosis	0	0/4	18	9	40	2	38	40	56	9	38	12	16	4
Specialist neurology	0	0/4	29	15	32	4	59	62	31	12	16	5	24	3
Specialist neurological rehabilitation	25	1/4	31	16	31	4	46	48	46	11	63	20	6	6
Long-term conditions NSF	100	4/4	71	36	13	2	29	30	45	30	41	13	10	9

* No and Not Known responses included in denominators

Table OA4: WTE of those with managerial responsibility					
WTE	SHA		PCT / LHB		
	Median	n =	Median	IQR	n =
Multiple sclerosis	-	0	0.50	na	8
Specialist neurology	-	0	0.50	0.25-1.00	12
Specialist neurological rehabilitation	-	0	1.00	0.50-1.00	13
Long-term conditions NSF	1.25	4	1.00	0.50-1.00	33

Table OA5: WTE of those with managerial responsibility

WTE	Acute trust			Community trust		
	Median	IQR	n =	Median	IQR	n =
Multiple sclerosis	0.50	0.25-1.00	37	1.00	0.50-1.00	10
Specialist neurology	1.00	0.50-1.20	56	1.20	na	4
Specialist neurological rehabilitation	1.00	0.50-1.00	43	1.00	0.25-1.00	19
Long-term conditions NSF	1.00	0.25-1.00	27	1.00	0.25-1.00	11

Tables OA6-7 concern clinical time contracted for MS. The majority of contractually specified clinical commitment applies to doctors, nurses and physiotherapists.

Table OA6: Clinical time devoted to multiple sclerosis

Does your SHA have formal mechanisms in place to obtain specialist clinical input (defined in description of the committee or agreement) concerning services for people with multiple sclerosis.

All four strategic health authorities answered 'No' to this question, which is concerning because without specialist clinical input the organisation cannot ask informed and useful questions of commissioners, nor can they make clinically appropriate suggestions or requests.

Table OA7: Clinical time devoted to multiple sclerosis

Specialised clinical input (defined in job plan or description) devoted to services for people with multiple sclerosis

WTE	PCT / LHB				Acute trust				Community trust			
	% Yes*	yes	no	NK	% Yes*	yes	no	NK	% Yes*	yes	no	NK
Medical (doctors)	25	13	29	9	68	71	31	3	19	6	22	4
Clinical Nurse specialists					78	82	22	1	69	22	9	1
Physiotherapists					36	38	58	9	31	10	18	4
Other health professionals	53	27	21	3	26	27	65	13	25	8	18	6

* No and Not Known responses included in denominators

Table OA8: WTE of those with specialised clinical input

WTE of those with specialised clinical input (defined in job plan or description) devoted to services for people with multiple sclerosis

WTE	PCT / LHB			Acute trust			Community trust		
	Median	IQR	n =	Median	IQR	n =	Median	IQR	n =
Medical (doctors)	1.00	0.25-2.00	11	0.80	0.33-1.10	65	0.25	na	6
Clinical Nurse specialists				1.50	1.00-2.00	78	1.200	1.00-1.60	21
Physiotherapists				1.00	1.00-1.50	33	2.00	1.00-2.50	10
Other health professionals	1.00	1.00-2.00	26	1.00	0.50-1.00	25	2.00	na	8

Process of performance monitoring/commissioning services

Key findings:

- The commissioning and provision of services is rarely guided by any formal needs assessment.
- About half of providers involve patients with MS in developing services for people with MS, but commissioners only do so for broader services.
- About half of providers have collected data to audit MS services, but commissioners rarely use or request data on services for people with MS.
- Needs for specialist urological services are reasonably well met, mostly with contracts at a general level, but spasticity services are not commissioned by 20% of commissioners and are not available in 40% of providers.

Comparison with previous audits (commissioners only):

- There has been little improvement in the use of needs assessment or in the collection and use of data to monitor services at a broader level.
- There is a marked contrast between the stated intention in 2008 to use a needs assessment in the following year (31%) and the observed change in the use of a needs assessment from 21% to 28%, at the level of the NSF-LTC or better.

This set of questions was asked to understand how the type of and number of services commissioned or provided were determined by organisations. It was expected some form of independent assessment of need might be used, and that people with MS might be involved in service development.

Table OA9: Formal needs assessment

	SHA		PCT / LHB		Acute trust		Community trust	
	Have you used a formal needs assessment (i.e. based on a set of data) for your population when monitoring PCTs/LHBs?		Have you used a formal needs assessment (i.e. based on a set of data) for your population when commissioning services?		Have you used a formal needs assessment (i.e. based on a set of data) for your population when providing services?		Have you used a formal needs assessment (i.e. based on a set of data) for your population when providing services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	12	6	21	22	22	7
In line with the NSF-LTC	25	1	16	8	10	10	6	2
For neurology as a whole	25	1	25	13	15	16	19	6
At a broader level	25	1	31	16	4	4	13	4
No	25	1	12	6	34	36	22	7
Not known	-	-	4	2	16	17	19	6

Table OA9: Plans to use formal needs assessment next year

	SHA		PCT / LHB		Acute trust		Community trust	
	Have you plans to use a formal needs assessment based on a data-set when monitoring PCTs/LHBs next year?		Have you plans to use a formal needs assessment based on a data-set when commissioning services next year?		Have you plans to use a formal needs assessment based on a data-set when providing services next year?		Have you plans to use a formal needs assessment based on a data-set when providing services next year?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	18	19	9	3
In line with the NSF-LTC	25	1	18	9	12	13	6	2
For neurology as a whole	25	1	27	14	12	13	19	6
At a broader level	25	1	29	15	3	3	6	2
No	25	1	16	8	36	38	31	10
Not known	-	-	6	3	18	19	28	9

Table OA10: Patient involvement

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs / LHBs involve patients in the process of commissioning services?		Do you involve patients in the process of commissioning services?		Do you involve people with multiple sclerosis when designing or improving services?		Do you involve people with multiple sclerosis when designing or improving services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	14	7	44	46	47	15
In line with the NSF-LTC	50	2	25	13	9	9	13	4
For neurology as a whole	-	-	27	14	15	16	9	3
At a broader level	50	2	25	13	7	7	3	1
No	-	-	8	4	16	17	22	7
Not known	-	-	-	-	10	10	6	2

We also investigated to what extent organisations used data on service process or outcome to monitor and improve service quality (next tables).

Table OA11: Undertaken any audits

	SHA		PCT / LHB		Acute trust		Community trust	
	Have you requested or commissioned any audits of services commissioned?		Have you requested or commissioned any audits of services provided?		Have you undertaken any audits of services for people with multiple sclerosis?		Have you undertaken any audits of services for people with multiple sclerosis?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	16	8	61	64	53	17
In line with the NSF-LTC	50	2	16	8	3	3	3	1
For neurology as a whole	-	-	29	15	9	9	16	5
At a broader level	25	1	16	8	-	-	3	1
No	25	1	18	9	26	27	16	5
Not known	-	-	6	3	2	2	9	3

Table OA12: Data based reports

	SHA		PCT / LHB		Acute trust		Community trust	
	Have you requested or commissioned any data-based reports on services commissioned?		Have you requested or commissioned any data-based reports on services provided?		Have you produced any data-based reports on services for people with multiple sclerosis?		Have you produced any data-based reports on services for people with multiple sclerosis?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	42	44	28	9
In line with the NSF-LTC	25	1	10	5	2	2	6	2
For neurology as a whole	-	-	33	17	7	7	9	3
At a broader level	25	1	20	10	-	-	6	2
No	50	2	24	13	46	48	38	12
Not known	-	-	2	1	4	4	13	4

Table OA13: Return of data on patient outcome

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs use service specifications to require the provision of data on patient outcome		Do your service specifications require any return of data on patient outcome:		Do your service specifications require any return of data on patient outcome:		Do your service specifications require any return of data on patient outcome:	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	16	17	16	5
In line with the NSF-LTC	50	2	18	9	5	5	9	3
For neurology as a whole	-	-	20	10	15	16	22	7
At a broader level	25	1	24	12	11	12	19	6
No	-	-	33	17	40	42	28	9
Not known	25	1	-	-	12	13	6	2

Table OA14: Return of data on patient process

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs use service specification to specify return of data on patient process (e.g. waiting time, CQUINS):		Do your service specifications require any return of data on patient process (e.g. waiting time):		Do your service specifications require any return of data on patient process (e.g. waiting time):		Do your service specifications require any return of data on patient process (e.g. waiting time):	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	13	14	16	5
In line with the NSF-LTC	-	-	16	8	7	7	6	2
For neurology as a whole	-	-	45	23	39	41	31	10
At a broader level	75	3	16	8	17	18	22	7
No	-	-	20	10	15	16	19	6
Not known	25	1	-	-	9	9	6	2

Table OA15 (SHA only):

Do you monitor whether PCTs/LHBs use service specifications to encourage and monitor the involvement of patients in supported research projects (SHA).

3 SHAs responded 'No' and 1 SHA responded 'Not known'.

In this round of the audit we added a question on specialist services because many people with MS need access to one or more of the specialist services shown in the table. This table also shows the perceptions of general practitioners about access to specialist services.

Table OA16: Commissioning of specialist services often needed by people with MS

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether PCTs/LHBs specifically commission		Do you commission specifically:		Are you specifically commissioned to provide any of the following specialist services:		Are you specifically commissioned to provide any of the following specialist services:		Which of the following specialist services relevant to people with multiple sclerosis are available to you, as far as you know:	
Spasticity management										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	8	4	14	15	3	1	33	16
In line with the NSF-LTC	-	-	12	6	10	10	3	1	8	4
For neurology as a whole	-	-	35	18	35	37	38	12	24	12
At a broader level	-	-	12	6	1	1	13	4	16	8
No	75	3	18	9	39	41	38	12	6	3
Not known	25	1	16	8	1	1	6	2	12	6
Specialist equipment for disabled										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	6	6	3	1	6	3
In line with the NSF-LTC	50	2	16	8	10	10	6	2	8	4
For neurology as a whole	-	-	27	14	29	30	25	8	33	16
At a broader level	-	-	43	22	14	15	44	14	35	17
No	25	1	4	2	34	36	19	6	6	3
Not known	25	1	4	2	8	8	3	1	12	6
Vocational rehabilitation										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	12	13	3	1	6	3
In line with the NSF-LTC	50	2	4	2	3	3	9	3	6	3
For neurology as a whole	-	-	24	12	18	19	25	8	31	15
At a broader level	-	-	29	15	8	8	22	7	20	10
No	25	1	29	15	53	56	34	11	10	5
Not known	25	1	10	5	6	6	6	2	27	13
Urological / continence services										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	8	4	11	12	6	2	24	12
In line with the NSF-LTC	25	1	12	6	6	6	6	2	6	3
For neurology as a whole	-	-	10	5	18	19	22	7	18	9
At a broader level	25	1	71	36	46	48	56	18	45	22
No	25	1	-	-	16	17	6	2	-	-
Not known	25	1	-	-	3	3	3	1	6	3
Clinical specialist case managers (nurse/Therapist)										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	47	24	39	41	38	12	51	26
In line with the NSF-LTC	50	2	12	6	5	5	16	5	8	4
For neurology as a whole	-	-	20	10	10	10	13	4	18	9
At a broader level	-	-	12	6	8	8	13	4	8	4
No	25	1	6	3	31	33	19	6	6	3
Not known	25	1	4	2	8	8	3	1	6	3
Disease modifying treatment clinics										
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	25	1	49	25	64	67	44	14	37	18
In line with the NSF-LTC	25	1	6	3	3	3	-	-	6	3
For neurology as a whole	-	-	14	7	3	3	3	1	37	18
At a broader level	-	-	16	8	3	3	6	2	4	2
No	25	1	10	5	26	27	44	14	8	4
Not known	25	1	6	3	2	2	3	1	8	4

The data suggest a reasonable level both of commissioning and of provision of specialist nurses for people with MS.

Several results were surprising. We expected all commissioners to commission specialist disease-modifying clinics, because these are a national requirement. In fact only 49% did so (the other answers are difficult to interpret). The fact that 44% of community providers were commissioned to provide disease modifying clinics was also surprising, because generally such clinics are run in neurology departments in hospitals. Third, the level of specialist vocational rehabilitation that is reported to be commissioned and provided is surprising.

Provider trust and GP services

Key findings:

- Only a minority (35%-40%) of acute hospital trusts provided all necessary services from within their own organisation.
- About one third of community trusts provide specialist neurological rehabilitation.
- There are no specialist inpatient beds available to people with MS needing neurology or neurological rehabilitation in over half of all trusts.
- 20% of trusts do not provide any inpatient or outpatient neurological rehabilitation services.
- Most (84%) general practices had a disease register, and a median of 14 people with MS were registered in each practice, equivalent to a prevalence of 2:1000 people.
- Few (12%) general practices had disability registers.

Comparison with previous audits:

- Most of the data are new.
- The data on services provided within organisations are unchanged.

A series of questions was asked to establish the extent to which a trust provided services itself, and the extent to which other providers took on responsibility for service provision on behalf of or with the trust.

Specialist services available/provided

Service provision at the level of hospitals is actually very complex, with some trusts providing all services from within their own resources, some trusts providing services located within their hospital but staffed by employees of another organisation, and others transferring or referring patients to other providers, especially for specialist neurological rehabilitation. The data below show that community services rarely provide specialist neurology services alone, as one would expect, but about one third do provide specialist neurological rehabilitation. The data from acute trusts are similar to 2008.

Table OA17: Specialist services available/provided: Acute trust providers

	How do people attending your trust with neurological problems receive:			
	Specialist neurological services		Specialist neurological rehabilitation services	
	% Yes	n =	% Yes	n =
• Totally from within trust provided services, inpatients and outpatients	40	42	35	37
• Initially from within trust services, but also transferring patients to a tertiary centre	42	44	44	46
• From a visiting neurology (rehabilitation) service, with at least daily attendance	3	3	1	1
• From a visiting neurology (rehabilitation) service, at least weekly attendance	11	12	1	1
• By referral to another service or centre	4	4	19	20

Table OA18: Specialist services available/provided: Community trust providers

	How do people attending your trust with neurological problems receive:			
	Specialist neurological services		Specialist neurological rehabilitation services	
	% Yes	n =	% Yes	n =
• Totally from within trust provided services, inpatients and outpatients	9	3	31	10
• Initially from within trust services, but also transferring patients to a tertiary centre	50	16	44	14
• From a visiting neurology (rehabilitation) service, with at least daily attendance	3	1	-	-
• From a visiting neurology (rehabilitation) service, at least weekly attendance	16	5	6	2
• By referral to another service or centre	22	7	19	6

Table OA19: Designated specialist beds and clinics: Acute trust providers

	Specialist neurological services			Specialist neurological rehabilitation services		
	Median	IQR	n =	Median	IQR	n =
Inpatient beds	0	0-14	103	0	0-15	104
	40% (41) with at least 1 bed			45% (47) with at least 1 bed		
Outpatient clinics per week	11	4-19	101	0	0-2	102
	91% (92) with at least 1 clinic			49% (50) with at least 1 clinic		

Table OA20: Designated specialist beds and clinics: Community trust providers

	Specialist neurological services			Specialist neurological rehabilitation services		
	Median	IQR	n =	Median	IQR	n =
Inpatient beds	0	0-0	32	0	0-14	34
	6% (2) with at least 1 bed			44% (14) with at least 1 bed		
Outpatient clinics per week	0	0-3	32	0	0-3	32
	41% (13) with at least 1 clinic			47% (15) with at least 1 clinic		

General practice sector specific results

The great majority (84%) of general practices who participated had a register that allowed identification of people with MS, and in those practices a median of 14 people had MS (in a median population of about 7,000). This suggests a high prevalence (2:1000) which is difficult to interpret, but the data provided by general practice disease registers are likely to be reasonably accurate. However only 12% of practices had a register of disabled people, and these practices had a median of 40 people registered with a disability, a median of three having MS.

Table OA21

	Summary statistics
How many whole time equivalent (WTE) general practitioners work in your practice?	Median 4.0, IQR 2.5-6.0 N=49
How many people are covered by your practice, to the nearest 100?	Median 6900, IQR 4500-10750, N=48
Number of people in practice per WTE GP	Median 1800, IQR 1651-2055, N=49
Do you have a register that allows you to identify people with multiple sclerosis?	Yes 84% (41), No 14% (7), Other 2% (1)
If so, how many people are registered with this diagnosis?	Median 14, IQR 9-25, N=41
Do you have a register that identifies people with a disability (however defined)?	Yes 12% (6), No 73% (36), Other 14% (7)
If so, what number of disabled people do you have?	Median 40, range 1-200, n=8
How many of the disabled people have multiple sclerosis?	Median 3, range 1-17, n=7

Key recommendation one: specialised services

Specialised neurological and neurological rehabilitation services should be available to every person with MS when they need them usually when they develop any new symptom, sign, limitation on their activities or other problem, or when their circumstances change.¹

This recommendation has two components, the provision of services specialising in **neurology** (the diagnosis/assessment and treatment of the disease) and the provision of services specialising in **neurological rehabilitation** (the assessment/diagnosis and management of disability and symptoms). The questions relating to specialist neurological services are covered first.

Specialist neurological services

Key findings:

- 58% of service providers do provide a specialist service for people with MS, 28% provide a service for neurological problems, and 51% of general practices could refer to a specialist MS neurology service.
- Commissioning usually focuses on neurology (55%) not MS (24%).
- Organisations rarely monitor whether the quantity of service provision is adequate.
- One third of trusts have no plans to improve neurological services in the next year.
- Commissioners rarely (6%) monitor the performance of neurology service providers in relation to people with MS.

Comparison with previous audits:

- There is a reduction in the number of organisations planning improvements, from 69% to 57%.

These questions were asked because without expert neurological services the quality of diagnosis and disease management (for example using disease modifying drugs) will be suboptimal. In principle every commissioning organisation should be commissioning a specialist MS service if only to deliver disease modifying drugs through the Department of Health's 'Risk Sharing Scheme'.

Table OA22: Commissioning & provision

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you specifically monitor whether PCTs/LHBs commission specialist neurological services?		Do you commission specialist neurological services?		Do you provide specialist neurological services?		Do you provide specialist neurological services?		Can you refer a patient to a specialist neurological service?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	24	12	58	61	38	12	51	25
In line with the NSF-LTC	50	2	14	7	5	5	6	2	6	3
For neurology as a whole	-	-	55	28	28	29	25	8	37	18
At a broader level	25	1	4	2	1	1	3	1	2	1
No	25	1	4	2	9	9	28	9	2	1
Not known	-	-	-	-	-	-	-	-	2	1

Table OA23: Adequacy of service*

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you consider the adequacy of the specialist neurological services that PCTs/LHBs commission (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological services that you commission (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological services that you provide (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological services that you provide (e.g. against needs assessment, waiting lists etc)?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	29	28	26	6
In line with the NSF-LTC	33	1	12	6	6	6	-	-
For neurology as a whole	-	-	57	28	40	38	39	9
At a broader level	33	1	4	2	4	4	-	-
No	33	1	14	7	15	14	17	4
Not known	-	-	2	1	6	6	17	4

*Excludes those who do not monitor, commission or provide a service and those for whom this is not known.

Table OA24: Plans to improve services in the next year

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs have documented plans to improve the commissioning of specialist neurological services in the next year?		Do you have documented plans to improve the commissioning of specialist neurological services in the next year?		Do you have documented plans to improve the provision of specialist neurological services in the next year?		Do you have documented plans to improve the provision of specialist neurological services in the next year?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	25	26	13	4
In line with the NSF-LTC	25	1	10	5	9	9	3	1
For neurology as a whole	25	1	31	16	21	22	28	9
At a broader level	25	1	10	5	2	2	-	-
No	25	1	27	14	30	31	41	13
Not known	-	-	16	8	14	15	16	5

Table OA25: Performance of providers*

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs monitor the performance of providers of specialist neurological services?		Do you monitor the performance of providers of specialist neurological services?		Do you document and report the performance of specialist neurological services?		Do you document and report the performance of specialist neurological services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	27	26	35	8
In line with the NSF-LTC	33	1	12	6	3	3	-	-
For neurology as a whole	-	-	61	30	29	28	39	9
At a broader level	33	1	12	6	6	6	-	-
No	33	1	6	3	22	21	13	3
Not known	-	-	2	1	13	12	13	3

* Excludes those who do not monitor, commission or provide a service and those for whom this is not known.

Specialist neurological rehabilitation services

Key findings:

- Only 22% of hospital providers and 38% of community trusts have neurological rehabilitation services that follow NICE CG8 or NSF-LTC standards.
- A minority (24%) of commissioners commission specialist neurological rehabilitation services at the national standards (NICE CG8/NSF-LTC).
- A small minority of providers (21% community trusts, 10% hospital trusts) and commissioners (2%) check that rehabilitation services are adequate for people with MS.
- 57% of commissioners and 40-53% of providers have some plans either to improve general neurological rehabilitation services or to be in line with the NSF-LTC.
- One quarter of general practices could not refer to any rehabilitation services and only one quarter could refer to a specialist rehabilitation service.

Comparison with previous audits:

- Fewer hospital trusts now provide specialist rehabilitation services, but 38% of community trusts do. Otherwise the data are not changed much.

The majority of the healthcare needed by people with MS over their lifetime will be for symptoms and disabilities that arise from the disease. This aspect of their care requires a specialised neurological rehabilitation service; these needs cannot be met effectively by non-specialist rehabilitation services or by neurology services. These questions aimed to investigate the provision of this resource.

Table OA26: Commissioning and provision of neurological rehabilitation services

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you specifically monitor whether PCTs/LHBs commission specialist neurological rehabilitation services?		Do you specifically commission specialist neurological rehabilitation services?		Do you specifically provide specialist neurological rehabilitation services?		Do you specifically provide specialist neurological rehabilitation services?		Can you refer a patient to a specialist neurological rehabilitation service?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	12	13	25	8	18	9
In line with the NSF-LTC	50	2	18	9	10	11	13	4	8	4
For neurology as a whole	25	1	57	29	38	40	41	13	45	22
At a broader level	25	1	8	4	7	7	13	4	16	8
No	-	-	8	4	32	34	9	3	6	3
Not known	-	-	4	2	-	-	-	-	6	3

Table OA27: Adequacy of service*

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you consider the adequacy of the specialist neurological rehabilitation services that PCTs/LHBs commission (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological rehabilitation services that you commission (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological rehabilitation services that you provide (e.g. against needs assessment, waiting lists etc)?		Do you monitor the adequacy of the specialist neurological rehabilitation services that you provide (e.g. against needs assessment, waiting lists etc)?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	10	7	21	6
In line with the NSF-LTC	25	1	16	7	14	10	7	2
For neurology as a whole	25	1	67	30	42	30	48	14
At a broader level	25	1	11	5	4	3	-	-
No	25	1	4	2	11	8	10	3
Not known	-	-	-	-	18	13	14	4

*Excludes those who do not monitor, commission or provide a service and those for whom this is not known

Table OA28: Plans to improve services in the next year

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs have documented plans to improve the commissioning of specialist neurological rehabilitation services in the next year?		Do you have specific plans to improve the commissioning of specialist neurological rehabilitation services in the next year?		Do you have specific plans to improve the provision of specialist neurological rehabilitation services in the next year?		Do you have specific plans to improve the provision of specialist neurological rehabilitation services in the next year?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	7	7	19	6
In line with the NSF-LTC	50	2	14	7	8	8	6	2
For neurology as a whole	-	-	41	21	25	26	25	8
At a broader level	25	1	8	4	1	1	3	1
No	25	1	22	11	36	38	19	6
Not known	-	-	14	7	24	25	28	9

Table OA29: Performance of providers*

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs monitor the performance of providers of specialist neurological rehabilitation services?		Do you monitor the performance of providers of specialist neurological rehabilitation services?		Do you document and report the performance of provision of specialist neurological rehabilitation services?		Do you document and report the performance of provision of specialist neurological rehabilitation services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	8	6	14	4
In line with the NSF-LTC	-	-	24	11	10	7	10	3
For neurology as a whole	25	1	60	27	28	20	45	13
At a broader level	50	2	11	5	4	3	-	-
No	25	1	2	1	23	16	3	1
Not known	-	-	-	-	27	19	28	8

*Excludes those who do not commission a service and those for whom this is not known.

Key recommendation two: rapid diagnosis

An individual who is suspected of having MS should be referred to a specialist neurology service and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time).¹

Key findings:

- Only 25-30% of trusts and 6% of commissioners specifically consider the speed of finalising a diagnosis of MS.
- Planning for improvement is absent in over half of organisations.
- Although few general practices have guidance, most (71%) expect a patient with suspected MS to be seen within six weeks.

Comparison with previous audits:

- There is a slight increase in the number of hospitals providing rapid access to neurology for people with MS, to 30%.
- At the same time, more commissioners are not commissioning rapid access neurology services (41% now as compared to 24% in 2008).

These questions focus on the process of making the diagnosis. The recommendation concerns the delays between a general practitioner or patient first suspecting that a person has MS and the final confirmation of the diagnosis. The 18 week waiting targets will influence these delays, but NICE suggested that 12 weeks should be a maximum delay so the impact may be small.

Table OA30: Rapid access

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether PCTs/LHBs specifically commission rapid access (patient to be seen within 6 weeks) of new referrals to specialist neurology services?		Do you specifically commission rapid access (patient to be seen within 6 weeks) of new referrals to specialist neurology services?		Do you specifically provide rapid access (patient to be seen within 6 weeks) of new referrals to specialist neurology services?		Do you specifically provide rapid access (patient to be seen within 6 weeks) of new referrals to specialist neurology services?		Do you have guidance from your PCT or service providers on rapid referral of people to neurology services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	30	31	25	8	4	2
In line with the NSF-LTC	25	1	4	2	5	5	-	-	4	2
For neurology as a whole	25	1	20	10	37	39	16	5	14	7
At a broader level	-	-	14	7	7	7	3	1	8	4
No	25	1	41	21	18	19	44	14	45	22
Not known	25	1	16	8	4	4	13	4	24	12

Table OA31: Plans for increasing rapid access in next year*

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs have documented plans to increase commissioning of rapid access to specialist neurology services in the next year (if patients wait more than 6 weeks)		Do you have documented plans to increase commissioning of rapid access to specialist neurology services in the next year (if patients wait more than 6 weeks)		Do you have documented plans to increase provision of rapid access to specialist neurology services in the next year (if patients wait more than 6 weeks)		Do you have documented plans to increase provision of rapid access to specialist neurology services in the next year (if patients wait more than 6 weeks)	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	-	-	-	-	-	-
In line with the NSF-LTC	25	1	2	1	4	3	-	-
For neurology as a whole	25	1	8	4	20	15	8	2
At a broader level	-	-	8	4	3	2	4	1
No	25	1	58	28	61	45	54	13
Not known	25	1	23	11	12	9	33	8

*Those already with rapid access specifically for people with MS excluded

Table OA32: Team guidance for rapid referral

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs ensure that primary care teams have guidance on rapid referral of people to neurology services?		Do you ensure that primary care teams have guidance on rapid referral of people to neurology services?		Do you provide primary care teams with guidance on rapid referral of people to neurology services?		Do you provide primary care teams with guidance on rapid referral of people to neurology services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	29	30	22	7
In line with the NSF-LTC	-	-	2	1	4	4	-	-
For neurology as a whole	25	1	22	11	30	31	16	5
At a broader level	-	-	25	13	3	3	6	2
No	50	2	24	12	33	35	34	11
Not known	25	1	22	11	2	2	22	7

Table OA33: GP expectation

	% Yes	Yes	No	NK
Would you expect a patient with suspected multiple sclerosis to be seen within 6 weeks by the specialist neurology services?	71	35	9	5

Key recommendation three: seamless services

Every health commissioning organisation should ensure that all organisations in a local health area agree and publish protocols for sharing and transferring responsibility for and information about people with MS, so as to make the service seamless from the individual's perspective.¹

Key findings:

- Protocols for transferring responsibility from service providers to other Healthcare organisations were present in no more than 41% at least to the level of the NSF, and were lower for the Health-Social Services interface.
- Commissioners had less interest in transfers, and focused more generally rather than on MS or even neurology.
- General practitioners were rarely aware of protocols for liaison with Social Services (10%) and only 33% were aware of protocols for sharing with secondary care providers.
- The majority of existing protocols and planned changes were general, and not specific to MS.

Comparison with previous audits:

- There is an increase in reporting of intra-health protocols for sharing care between hospitals and primary care, particularly in MS-specific pathways (from 17% to 29%).
- There is a decrease in the proportion of hospitals with protocols for handover to Social Services, from 51% to 42%.

This recommendation concerns the transfer or sharing of responsibility across organisational boundaries, both within Health and between Health and other organisations especially Social Services. The questions focus on written protocols, because the presence of documented procedures indicates that organisations are committed to the process.

Table OA34: Co-ordinated care pathways across organisational boundaries (current situation)

	SHA Do you check whether your PCTs/LHBs monitor the existence of co-ordinated care pathways across organisational boundaries between:		PCT / LHB Do you monitor the existence of co-ordinated care pathways across organisational boundaries between:		Acute trust Do you have co-ordinated care pathways across organisational boundaries between:		Community trust Do you have co-ordinated care pathways across organisational boundaries between:	
1. Health and Social Services?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	12	13	19	6
In line with the NSF-LTC	25	1	4	2	7	7	9	3
For neurology as a whole	-	-	22	11	7	7	6	2
At a broader level	50	2	43	22	17	18	19	6
No	25	1	25	13	49	51	41	13
Not known	-	-	-	-	9	9	6	2
2. Different secondary care Health Organisations?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	-	-	24	25	19	6
In line with the NSF-LTC	-	-	6	3	9	9	6	2
For neurology as a whole	-	-	31	16	16	17	25	8
At a broader level	50	2	35	18	9	9	16	5
No	50	2	25	13	32	34	22	7
Not known	-	-	2	1	10	11	13	4
3. Primary/secondary healthcare?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	29	30	28	9
In line with the NSF-LTC	25	1	4	2	8	8	13	4
For neurology as a whole	-	-	27	14	16	17	19	6
At a broader level	50	2	39	20	18	19	16	5
No	25	1	24	12	21	22	25	8
Not known	-	-	4	2	9	9	-	-

Table OA35: Co-ordinated care pathways across organisational boundaries (future plans)

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs have documented plans to request or facilitate the development of care pathways across organisational boundaries over the next year between:		Do you have documented plans to request or facilitate the development of care pathways across organisational boundaries over the next year between:		Do you have documented plans to request or facilitate the development of care pathways across organisational boundaries over the next year between:		Do you have documented plans to request or facilitate the development of care pathways across organisational boundaries over the next year between:	
1. Health and Social Services?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	-	-	8	8	6	2
In line with the NSF-LTC	25	1	8	4	5	5	9	3
For neurology as a whole	-	-	24	12	9	9	6	2
At a broader level	50	2	37	19	9	9	16	5
No	25	1	29	15	45	47	28	9
Not known	-	-	2	1	26	27	34	11
2. Different secondary care Health Organisations?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	17	18	6	2
In line with the NSF-LTC	-	-	6	3	5	5	3	1
For neurology as a whole	-	-	31	16	14	15	22	7
At a broader level	50	2	31	16	7	7	9	3
No	50	2	24	12	36	38	25	8
Not known	-	-	4	2	21	22	34	11
3. Primary/secondary healthcare?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	22	23	13	4
In line with the NSF-LTC	-	-	6	3	4	4	3	1
For neurology as a whole	-	-	29	15	14	15	16	5
At a broader level	50	2	37	19	8	8	13	4
No	50	2	24	12	36	38	28	9
Not known	-	-	2	1	16	17	28	9

Table OA36: GP perception of presence of co-ordinated care pathways

In your areas are there co-ordinated care pathways applicable to people with multiple sclerosis across organisational boundaries between:				
	% Yes	Yes	No	NK
1. Health and Social Services?	10	5	18	26
2. Primary/secondary healthcare?	33	16	16	17

Key recommendation four: a responsive service

All services and service personnel within the healthcare sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be actively involved in all decisions and actions.¹

Key findings:

- A minority of providers (21-22%) provided and a small minority of commissioners (2%) considered the whole range of services available for people with MS.
- Only about one fifth of GPs could refer patients with MS to the full range of specialist services needed.
- 19%-25% of providers but only 6% of commissioners monitored the adequacy of services provided or commissioned for people with MS.
- 16%-23% of providers and 8% of commissioners had plans to reduce identified deficiencies in service provision for people with MS.
- Most (76%) general practices involved people with MS in clinical decisions, but no more than 25% of provider organisations had policies requiring this.
- People with MS were involved in service planning for their needs in a minority of organisations.
- The data are consistent across perspectives suggesting a gradual fragmentation of services needed by people with MS.

Comparison with previous audits:

- There is no great improvement. and if anything fewer trusts can now provide all specialist services needed by people with MS.

The questions asked here investigate whether organisations focus on all the problems experienced by a patient, or only those that fit within an organisation's services (i.e. is the organisation patient-centred or service-centred?). Written documents were asked about because they indicate commitment by the organisation.

Table OA37: Specialist services needed by people with MS

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you check whether your PCTs/LHBs commission the whole range of specialist services (e.g. spasticity services, specialist wheelchairs) needed by people with MS (e.g. against a needs assessment, or in other ways)?		Do you commission the whole range of specialist services (e.g. spasticity services, specialist wheelchairs) needed by people with MS (e.g. against a needs assessment, or in other ways)?		Do you provide the whole range of specialist services (e.g. spasticity services, specialist wheelchairs) needed by people with MS (e.g. against a needs assessment, or in other ways)?		Do you provide the whole range of specialist services (e.g. spasticity services, specialist wheelchairs) needed by people with MS (e.g. against a needs assessment, or in other ways)?		Is the whole range of specialist services (e.g. spasticity services, specialist wheelchairs) needed by people with MS available to you?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	21	22	22	7	14	7
In line with the NSF-LTC	25	1	18	9	9	9	9	3	4	2
For neurology as a whole	-	-	41	21	33	35	34	11	31	15
At a broader level	50	2	24	13	10	11	19	6	27	13
No	25	1	12	6	26	27	16	5	10	5
Not known	-	-	2	1	1	1	-	-	14	7

Table OA38: Adequacy of services needed by people with MS

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor, directly or through your PCTs/LHBs, the adequacy (range and quantity) of services needed by people with MS?		Do you monitor the adequacy (range and quantity) of services needed by people with MS?		Do you monitor the adequacy (range and quantity) of services needed by people with MS?		Do you monitor the adequacy (range and quantity) of services needed by people with MS?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	19	20	25	8
In line with the NSF-LTC	25	1	16	8	10	10	9	3
For neurology as a whole	-	-	35	18	17	18	22	7
At a broader level	50	2	29	15	7	7	6	2
No	25	1	10	5	37	39	31	10
Not known	-	-	4	2	10	11	6	2

Table OA39: Plans to improve range / availability of services, if deficient

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you check whether your PCTs/LHBs have documented plans in the next year to improve the range and/or availability of services (if deficiencies have been identified)?		Do you have documented plans in the next year to improve the range and/or availability of services (if deficiencies have been identified)?		Do you have documented plans in the next year to improve the range and/or availability of services (if deficiencies have been identified)?		Do you have documented plans in the next year to improve the range and/or availability of services (if deficiencies have been identified)?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	8	4	23	24	16	5
In line with the NSF-LTC	25	1	6	3	6	6	3	1
For neurology as a whole	-	-	24	12	14	15	16	5
At a broader level	50	2	24	12	6	6	6	2
No	25	1	27	14	37	39	28	9
Not known	-	-	12	6	14	15	31	10

Table OA40: Patient involvement in clinical decisions

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether PCTs/LHBs specify in commissioning contracts that service providers involve patients in clinical decisions?		In your commissioning contract do you require service providers to involve patients in clinical decisions?		Do you have written policies ensuring that clinical staff involve patients in clinical decisions?		Do you have written policies ensuring that clinical staff involve patients in clinical decisions?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	16	17	25	8
In line with the NSF-LTC	50	2	16	8	8	8	3	1
For neurology as a whole	-	-	24	12	14	15	28	9
At a broader level	50	2	41	21	18	19	22	7
No	-	-	6	3	31	33	6	2
Not known	-	-	4	2	12	13	16	5

Table OA41: GP patient involvement

	% Yes	Yes	Mostly	Rarely
Do you routinely involve people with multiple sclerosis in clinical decisions about their care	76	37	11	1

Table QA42: Formal mechanisms to involve people with MS in planned service developments

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs have formal mechanisms to involve people with MS in planned service developments undertaken through commissioning?		Do you have formal mechanisms to involve people with MS in planned service developments undertaken through commissioning?		Do you have formal mechanisms to involve people with MS in planned service developments?		Do you have formal mechanisms to involve people with MS in planned service developments?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	22	11	32	34	28	9
In line with the NSF-LTC	25	1	8	4	4	4	6	2
For neurology as a whole	-	-	18	9	8	8	13	4
At a broader level	75	3	25	13	8	8	16	5
No	-	-	20	10	39	41	25	8
Not known	-	-	8	4	10	10	13	4

Key recommendation five: sensitive but thorough problem assessment

Health professionals in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control.¹

Key findings:

- 55% of general practitioners use a structured assessment of mood.
- Less than 50% of service providers have policies to use structured assessments for mood, ADL, and cognition to at least the level of the NSF-LTC.
- Few organisations monitored use of assessments or had plans to increase their use.

Comparison with previous audits:

- Fewer commissioners are paying attention to assessments, and there is no increase in the use of structured assessment protocols.

The questions asked here investigate the organisational (cultural) approach to treating patients with respect while maintaining a high standard of care in terms of being thorough in their assessment, often a difficult balance.

Table OA43: Use of structured assessment protocols

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs require service providers to use structured assessment protocols to cover:		When commissioning services do you require service providers to use structured assessment protocols to cover:		Do you have policies for clinical staff to use structured assessment protocols to cover:		Do you have policies for clinical staff to use structured assessment protocols to cover:	
1. Personal activities of daily living (ADL)?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	29	30	34	11
In line with the NSF-LTC	-	-	10	5	6	6	13	4
For neurology as a whole	-	-	25	13	18	19	28	9
At a broader level	25	1	20	10	12	13	9	3
No	75	3	16	8	29	30	13	4
Not known	-	-	20	10	7	7	3	1
2. Cognitive functioning?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	23	24	34	11
In line with the NSF-LTC	-	-	10	5	10	10	13	4
For neurology as a whole	-	-	27	14	22	23	28	9
At a broader level	25	1	16	8	12	13	9	3
No	75	3	18	9	28	29	9	3
Not known	-	-	20	10	6	6	6	2
3. Mood disturbance?								
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	25	26	34	11
In line with the NSF-LTC	-	-	10	5	7	7	13	4
For neurology as a whole	-	-	20	10	19	20	25	8
At a broader level	25	1	22	11	11	12	9	3
No	75	3	16	8	32	34	13	4
Not known	-	-	24	12	6	6	6	2

Table OA44: Performance of structured assessment protocols

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs monitor performance of service providers in using structured assessments?		Do you monitor performance of service providers in using structured assessments?		Do you audit the use of structured assessments?		Do you audit the use of structured assessments?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	14	15	19	6
In line with the NSF-LTC	-	-	2	1	1	1	9	3
For neurology as a whole	-	-	20	10	9	9	19	6
At a broader level	25	1	12	6	9	9	6	2
No	75	3	45	23	56	59	31	10
Not known	-	-	16	8	11	12	15	5

Table OA45: Plans to increase use of structured assessments in next year

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs have documented plans for the next year to increase use of structured assessments by service providers?		Do you have documented plans for the next year to increase use of structured assessments by service providers?		Do you have documented plans for the next year to increase use of structured assessments by clinical staff?		Do you have documented plans for the next year to increase use of structured assessments by clinical staff?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	11	12	13	4
In line with the NSF-LTC	-	-	2	1	2	2	9	3
For neurology as a whole	-	-	12	6	10	10	19	6
At a broader level	50	2	6	3	5	5	9	3
No	50	2	55	28	56	59	31	10
Not known	-	-	20	10	16	17	19	6

Table OA46: GP use of structured assessments

When seeing a person with multiple sclerosis about a new problem, do you use structured assessment protocols to cover

	% Yes	Yes	No
Personal activities of daily living (ADL)	20	10	39
Cognitive disturbance	27	13	36
Mood disturbance	55	27	22

Key recommendation six: self-referral after discharge

Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate.¹

Key findings:

- Most commissioners (76%) and providers (80-94%) commissioned or allowed self referral back to specialist services.
- However only 31% (rehabilitation) to 45% (neurology) of general practices reported that this was available to their patients.
- Where auditing of actual performance did not occur or was not commissioned, no organisation had plans to change the current situation.

Comparison with previous audits:

- The situation has not changed significantly.

These questions investigate whether the policy of self-referral by a patient back to expert services occurs and whether it is encouraged or enabled by commissioners.

Table OA47: Documented plans for self-referral – Acute trusts

		Do you have documented plans in the next year to allow self-referral back to specialist services?					
		NK	No	At a broader level	For neurology as a whole	In line with the NSF-LTC	Specifically for people with MS
Do you provide services for people with MS in a way that allows a patient to self-refer back to your specialist service?	Specifically for people with MS	7	28	-	-	-	33
	In line with the NSF-LTC	1	2	-	-	1	-
	For neurology as a whole	1	5	-	3	-	-
	At a broader level	1	1	1	-	-	-
	No	2	19	-	-	-	-
	Not known	-	-	-	-	-	-

Table OA48: Documented plans for self-referral – Community trusts

		Do you have documented plans in the next year to allow self-referral back to specialist services?					
		NK	No	At a broader level	For neurology as a whole	In line with the NSF-LTC	Specifically for people with MS
Do you provide services for people with MS in a way that allows a patient to self-refer back to your specialist service?	Specifically for people with MS	1	5	-	-	-	11
	In line with the NSF-LTC	1	1	-	-	2	-
	For neurology as a whole	1	4	-	3	-	-
	At a broader level	-	-	1	-	-	-
	No	-	1	-	-	-	-
	Not known	1	-	-	-	-	-

Table OA49: Documented plans for self-referral – Commissioners							
		Do you have documented plans in the next year to allow self-referral back to specialist services within the commissioning process?					
		NK	No	At a broader level	For neurology as a whole	In line with the NSF-LTC	Specifically for people with MS
Do you commission services for people with MS in a way that allows a patient to self-refer back to your specialist service?	Specifically for people with MS	1	9	-	3	-	5
	In line with the NSF-LTC	2	2	1	-	2	-
	For neurology as a whole	2	4	1	4	-	-
	At a broader level	-	3	-	-	-	-
	No	-	7	-	-	-	-
	Not known	4	1	-	-	-	-

Table OA50: Self-referral back to specialist services								
	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs commission services for people with MS in a way that allows a patient to self-refer back to a specialist service?		Do you commission services for people with MS in a way that allows a patient to self-refer back to a specialist service?		Do you allow a patient to self-refer back to your specialist service?		Do you allow a patient to self-refer back to your specialist service?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	35	18	65	68	53	17
In line with the NSF-LTC	-	-	14	7	4	4	13	4
For neurology as a whole	-	-	22	11	9	9	25	8
At a broader level	-	-	6	3	3	3	3	1
No	100	4	14	7	20	21	3	1
Not known	-	-	10	5	-	-	3	1

Table OA51: Monitoring performance in responding to patient referral								
	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs monitor performance of service providers in responding to patient self-referral?		Do you monitor performance of service providers in responding to patient self-referral?		Do you audit rate of patient self-referral?		Do you audit rate of patient self-referral?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	15	16	13	4
In line with the NSF-LTC	-	-	2	1	2	2	6	2
For neurology as a whole	-	-	10	5	2	2	13	4
At a broader level	-	-	20	10	2	2	6	2
No	100	4	47	24	76	80	59	19
Not known	-	-	18	9	3	3	3	1

Table OA52: Plans to allow self-referral in next year

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs have documented plans in the next year to allow self-referral back to specialist services within the commissioning process?		Do you have documented plans in the next year to allow self-referral back to specialist services within the commissioning process?		Do you have documented plans in the next year to allow self-referral back to specialist services?		Do you have documented plans in the next year to allow self-referral back to specialist services?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	10	5	31	33	34	11
In line with the NSF-LTC	-	-	4	2	1	1	6	2
For neurology as a whole	-	-	14	7	3	3	9	3
At a broader level	-	-	4	2	1	1	3	1
No	100	4	51	26	52	55	34	11
Not known	-	-	18	9	11	12	13	4

Table OA53: GP

In your area are people with MS able to self-refer back to a:

	% Yes	Yes	No	NK
Specialist neurological service	45	22	13	14
Specialist neurological rehabilitation service	31	15	16	18

Sentinel marker: skin pressure ulcers

The commissioning health organisation should require all healthcare services including community services: to report every pressure ulcer occurring in a person with MS, to undertake and report an investigation into what could have been done to avoid its occurrence, to agree actions that should reduce the risk of the same situation leading to a pressure ulcer.¹

Key findings:

- The occurrence of skin pressure ulcers was rarely monitored at the level of people with MS (8%) and only 67-81% of providers monitored the occurrence of skin pressure ulcers at any level.
- 71% of commissioners did monitor the occurrence of skin pressure ulcers.
- One third (35%) of general practices were aware of the incidence of skin pressure ulceration, and 41% knew where to report a new case.
- A majority (68-88%) of organisations report monitoring the change in incidence rates of skin pressure ulcers at some level.
- 46% of hospital trusts had no known plans to improve performance.

Comparison with previous audits:

- There is a slight improvement in the recording of skin pressure ulcers in hospitals.
- The general reduction in the number of ulcers reported by patients noted earlier suggests a possible improvement in services.

This sentinel marker was intended to pick up systematic failures in care, and was chosen by NICE because NHS organisations have been supposed to monitor skin pressure ulceration for some years. The questions investigate the attention given to skin pressure ulceration in general and in relation to people with MS.

Table OA54: Incidence of skin pressure ulceration

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs commission or otherwise obtain reports on the incidence of skin pressure ulceration in your population?		Do you commission or otherwise obtain reports on the incidence of skin pressure ulceration in your population?		Do you audit the incidence of skin pressure ulceration in your population?		Do you audit the incidence of skin pressure ulceration in your population?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	9	9	9	3
In line with the NSF-LTC	-	-	6	3	3	3	13	4
For neurology as a whole	-	-	4	2	15	16	13	4
At a broader level	100	4	57	29	40	42	47	15
No	-	-	16	8	23	24	3	1
Not known	-	-	14	7	10	11	16	5

Table OA55: Response to changes in incidence of skin pressure ulcers

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs / LHBs actively monitor and respond to changes in incidence of skin pressure ulcers?		Do you actively monitor and respond to changes in incidence of skin pressure ulcers?		Do you actively monitor and respond to changes in incidence of skin pressure ulcers?		Do you actively monitor and respond to changes in incidence of skin pressure ulcers?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	11	12	19	6
In line with the NSF-LTC	-	-	6	3	4	4	16	5
For neurology as a whole	-	-	6	3	16	17	6	2
At a broader level	75	3	57	29	36	38	47	15
No	25	1	14	7	20	21	3	1
Not known	-	-	12	6	12	13	9	3

Table OA56: Plans to monitor and reduce incidence of skin pressure ulcers

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs have documented plans for the next year to monitor and reduce the incidence of skin pressure ulcers?		Do you have documented plans for the next year to monitor and reduce the incidence of skin pressure ulcers?		Do you have documented plans for the next year to monitor and reduce the incidence of skin pressure ulcers?		Do you have documented plans for the next year to monitor and reduce the incidence of skin pressure ulcers?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	7	7	6	2
In line with the NSF-LTC	-	-	2	1	4	4	9	3
For neurology as a whole	-	-	4	2	11	12	6	2
At a broader level	75	3	55	28	31	33	47	15
No	25	1	14	7	23	24	3	1
Not known	-	-	20	10	24	25	28	9

Table OA57: GP awareness of skin pressure ulceration

	% Yes	Yes	No
Are you aware of the incidence of skin pressure ulceration in your practice?	35	17	32
.....If so, do you know how many people with MS have had an episode of skin pressure ulceration in the last year?	53	9*	8

*Two people (2), 1 person (4), no persons (3) had such an episode – i.e. a total of 8 persons from these 9 GPs.

Table OA58: GP awareness of reporting of skin pressure ulcers

	% Yes	Yes	No, but I know that there is somewhere	No, and as far as I know there is nowhere
Do you know where to report any new incident of skin pressure ulceration occurring in one of your patients?	41	20	4	25

National Service Framework for Long-term Conditions: quality requirements

This section is new to this round of the audit, and covers answers to questions on seven of the eleven quality requirements proposed by the National Service Framework for Long-term Conditions.

Quality requirement one

People with longterm neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.²

Key findings:

- Although self-management services are commissioned by 78% of commissioners, only 75% of community providers and 30% of hospital trusts provided such services
- 78% of commissioner commission case management services but only 26% of hospitals and 69% of community providers report availability of case management services to facilitate integration of services.
- Only 59% of GPs could refer to case management services.

This quality requirement covers both an organisational matter – the integration of care for a patient - and clinical practice – the promotion and support of self-management by the patient.

Table OA59: integration of care across organisations

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs commission case-management services to promote integrated management between health and social services for individual patients:		Do you commission case-management services to promote integrated management between health and social services for individual patients:		Are you commissioned to provide case-management services to promote integrated management between health and social services for individual patients:		Are you commissioned to provide case-management services to promote integrated management between health and social services for individual patients:		Can you refer patients to specialist case-management services that promote integrated management between health and social services for individual patients:	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	6	3	13	14	28	9	18	9
In line with the NSF-LTC	50	2	14	7	4	4	6	2	6	3
For neurology as a whole	-	-	20	10	4	4	16	5	20	10
At a broader level	25	1	39	20	5	5	19	6	14	7
No	25	1	8	4	50	53	16	5	20	10
Not known	-	-	14	7	24	25	16	5	20	10

Table OA60: self-management by people with MS

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs commission case-management services to promote effective self-management by individual patients:		Do you commission case-management services to promote effective self-management by individual patients:		Are you commissioned to provide case-management services to promote effective self-management by individual patients:		Are you commissioned to provide case-management services to promote effective self-management by individual patients:		Can you refer patients to specialist case-management services that promote effective self-management by individual patients:	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	14	7	18	19	31	10	16	8
In line with the NSF-LTC	50	2	10	5	4	4	16	5	6	3
For neurology as a whole	-	-	16	8	4	4	16	5	24	12
At a broader level	25	1	39	20	5	5	13	4	12	6
No	25	1	8	4	45	47	9	3	14	7
Not known	-	-	14	7	25	26	16	5	27	13

Quality requirement five

People with longterm neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.²

Key findings:

- About one third of acute trust providers do not provide specialist multi-disciplinary neurological rehabilitation.
- Only 59% of general practitioners can access specialist inpatient rehabilitation, but 80% can access specialist outpatient services.

This quality requirement requires that patients can access comprehensive specialist neurological rehabilitation services whenever they need to, and this should ideally include inpatient, outpatient and outreach services including to patients in nursing homes delivered at the nursing home.

Table OA61: specialist multi-disciplinary neurological rehabilitation teams

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs commission specialist neurological rehabilitation delivered by a complete multi-disciplinary team :		Does your PCT commission specialist neurological rehabilitation delivered by a complete multi-disciplinary team :		Do you provide specialist neurological rehabilitation delivered by a complete multi-disciplinary team :		Do you provide specialist neurological rehabilitation delivered by a complete multi-disciplinary team :		Are you able to refer a patient with multiple sclerosis for specialist neurological rehabilitation delivered by a complete multi-disciplinary team :	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
1. On an inpatient basis										
Specifically for people with MS	-	-	10	5	8	8	6	2	14	7
In line with the NSF-LTC	50	2	20	10	13	14	6	2	2	1
For neurology as a whole	-	-	27	14	32	34	28	9	37	18
At a broader level	-	-	18	9	16	17	16	5	6	3
No	50	2	12	6	29	30	34	11	16	8
Not known	-	-	14	7	2	2	9	3	24	12
2. On an outpatient basis										
Specifically for people with MS	-	-	6	3	23	24	16	5	20	10
In line with the NSF-LTC	50	2	18	9	11	12	3	1	4	2
For neurology as a whole	-	-	41	21	24	25	41	13	39	19
At a broader level	-	-	14	7	10	11	22	7	16	8
No	50	2	8	4	29	30	13	4	6	3
Not known	-	-	14	7	3	3	6	2	14	7
3. On an outreach, domiciliary (delivered at home) basis,										
Specifically for people with MS	-	-	10	5	20	21	19	6	20	10
In line with the NSF-LTC	50	2	14	7	10	10	3	1	2	1
For neurology as a whole	-	-	37	19	19	20	44	14	20	10
At a broader level	-	-	18	9	8	8	22	7	27	13
No	50	2	6	3	37	38	9	3	10	5
Not known	-	-	16	8	8	8	3	1	20	10
4. To people in nursing homes or residential care?										
Specifically for people with MS	-	-	10	5	15	16	13	4	14	7
In line with the NSF-LTC	-	-	14	7	9	9	3	1	4	2
For neurology as a whole	-	-	31	16	16	17	50	16	22	11
At a broader level	-	-	16	8	10	10	22	7	20	10
No	100	4	8	4	42	44	6	2	10	5
Not known	-	-	22	11	9	9	6	2	29	14

Although nursing home residents can access specialist services, it is not clear if this requires the person to travel to the provider or if the service is delivered into the nursing home – the next audit should include a question to clarify this.

Quality requirement six

People with longterm neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.²

Key findings:

- Although a surprising 59% of commissioners answered that they did commission specialist vocational rehabilitation services, only 6%-15% of providers provided specialist vocational rehabilitation for people with MS and most commissioning is of generic vocational rehabilitation.
- About half of all GPs either could not access specialist vocational rehabilitation at all or they did not know.
- About half of acute trust providers did not deliver any specialist vocational rehabilitation for people with neurological disorders.

This requires the provision of specialist multidisciplinary vocational rehabilitation services that are aware of the many different problems people with MS may have, especially fatigue, and can thus help both the employer and the employee in managing the situation successfully. It is not simply referring to a single professional giving work advice.

Table OA62: Vocational rehabilitation services

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs commission specialist NHS vocational rehabilitation services to assist people with multiple sclerosis in maintaining or adapting work and/or in helping with training and education for new occupational activities?		Do you commission specialist NHS vocational rehabilitation services to assist people with multiple sclerosis in maintaining or adapting work and/or in helping with training and education for new occupational activities?		Do you provide specialist NHS vocational rehabilitation services to assist people with multiple sclerosis in maintaining or adapting work and/or in helping with training and education for new occupational activities?		Do you provide specialist NHS vocational rehabilitation services to assist people with multiple sclerosis in maintaining or adapting work and/or in helping with training and education for new occupational activities?		Are you able to refer patients to a specialist NHS vocational rehabilitation service to assist people with multiple sclerosis in maintaining or adapting work and/or in helping with training and education for new occupational activities?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	4	2	15	16	6	2	6	3
In line with the NSF-LTC	50	2	4	2	2	2	9	3	6	3
For neurology as a whole	-	-	27	14	19	20	25	8	18	9
At a broader level	-	-	24	12	10	10	25	8	16	8
No	50	2	27	14	50	53	28	9	18	9
Not known	-	-	14	7	4	4	6	2	35	17

Quality requirement seven

People with longterm neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.²

Key findings:

- Commissioning of equipment services is almost universal, but one-quarter of hospital providers cannot provide equipment needed or don't know if equipment can be provided and one third of GPs either cannot refer patients for equipment provision or they don't know if equipment can be provided.

This requirement echoes the strong recommendation made a decade ago by the Audit Commission.^{3,4}

Table OA63: Timely and appropriate provision of equipment

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs commission organisations to assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?		Do you commission organisations to assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?		Do you assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?		Do you assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?		Are you able to refer patients to organisations that assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	19	20	31	10	8	4
In line with the NSF-LTC	25	1	10	5	9	9	6	2	4	2
For neurology as a whole	-	-	25	13	28	29	28	9	16	8
At a broader level	25	1	53	27	19	20	28	9	35	17
No	50	2	6	3	20	21	-	-	18	9
Not known	-	-	4	2	6	6	6	2	18	9

Table OA64: Monitoring of equipment provision and use

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs commission organisations to monitor the functioning, the use and the safety of all equipment and adaptations provided to people with multiple sclerosis?		Do you monitor whether your PCTs/LHBs commission organisations to monitor the functioning, the use and the safety of all equipment and adaptations provided to people with multiple sclerosis?		Do you monitor the functioning, the use and the safety of all equipment and adaptations provided to people with multiple sclerosis?		Do you monitor the functioning, the use and the safety of all equipment and adaptations provided to people with multiple sclerosis?	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	-	-	15	16	28	9
In line with the NSF-LTC	-	-	6	3	8	8	6	2
For neurology as a whole	-	-	14	7	22	23	25	8
At a broader level	50	2	61	31	18	19	31	10
No	50	2	8	4	23	24	3	1
Not known	-	-	12	6	14	15	6	2

The answers to these questions do not indicate whether **sufficient** equipment is made available. The data from people with MS would suggest not.

Quality requirement nine

People in the later stages of longterm neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.²

Key findings:

- Most commissioners commission palliative care generically and do not specify provision specifically for patients with a neurological condition.
- Most GPs can access palliative care for their patients with MS, and about half of providers give palliative care at least for neurological patients.

This requirement is for patients to be given effective relief of symptoms including pain and distress by a service with appropriate expertise. When asking people with MS about this, we chose to focus on pain relief, being the easiest to ask about and being one that any humane healthcare service should achieve. Organisations were asked a more general question.

Table OA65: Palliative care

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs explicitly specify patient groups who should be able to access commissioned palliative care services:		Do you explicitly specify patient groups who should be able to access commissioned palliative care services:		Are people with multiple sclerosis able to access and use any palliative care services your organisation provides:		Are people with multiple sclerosis able to access and use any palliative care services your organisation provides:	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Specifically for people with MS	-	-	2	1	15	16	9	3
In line with the NSF-LTC	50	2	12	6	9	9	19	6
For neurology as a whole	-	-	14	7	22	23	19	6
At a broader level	50	2	53	27	34	36	44	14
No	-	-	16	8	4	4	-	-
Not known	-	-	4	2	16	17	9	3

Table OA66: GP access to palliative support

	% Yes	Yes	No	NK
Are you able to refer a person with multiple sclerosis to a palliative care service able and willing to provide appropriate palliative care?	90	44	2	3

These data are a marked contrast to the previously reported data indicating that many people with MS have uncontrolled pain and have not been referred to or seen by a service able and willing to provide appropriate palliative care.

Quality requirement ten

Carers of people with long term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.²

Key findings:

- Only 20% of acute hospital providers can access specific support for carers of people with MS with regard to respite care options and about one third either cannot access any service or don't know.
- One-quarter of commissioners either do not ensure that Social Services provide carer support or don't know.

This requirement is often translated by patients and families into an expectation of *respite care* and it is also often considered to be a service provided by the NHS.

Table OA67: support services – access through the NHS

	SHA		PCT / LHB		Acute trust		Community trust		GP		
	Do you monitor whether your PCTs/LHBs commission for the unpaid carers of people with multiple sclerosis including		Do you commission a range of specific services for the unpaid carers of people with multiple sclerosis including		Can your services access or refer the unpaid carers of people with multiple sclerosis to a range of specific services including:		Can your services access or refer the unpaid carers of people with multiple sclerosis to a range of specific services including:		Are you able to refer carers to a range of specific services for the unpaid carers of people with multiple sclerosis including:		
1. Respite care options that meet the particular needs of people with multiple sclerosis, specifically their young age (under 65 years) and their severe and complex neurological problems,											
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	
Specifically for people with MS	-	-	4	2	20	21	31	10	16	8	
In line with the NSF-LTC	25	1	4	2	10	11	6	2	4	2	
For neurology as a whole	-	-	8	4	19	20	6	2	12	6	
At a broader level	25	1	65	33	21	22	28	9	37	18	
No	50	2	10	5	18	19	16	5	10	5	
Not known	-	-	10	5	11	12	13	4	20	10	
2. Multiple sclerosis specific support for carers (i.e. information, and general emotional and practical support)?											
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	
Specifically for people with MS	-	-	14	7	52	55	47	15	31	15	
In line with the NSF-LTC	25	1	6	3	8	8	13	4	2	1	
For neurology as a whole	-	-	4	2	13	14	13	4	10	5	
At a broader level	50	2	51	26	10	10	16	5	29	14	
No	25	1	16	8	10	11	3	1	10	5	
Not known	-	-	10	5	7	7	9	3	18	9	

Table OA68: Social services – NHS expectations

	SHA		PCT / LHB		Acute trust		Community trust		GP	
	Do you monitor whether your PCTs/LHBs ensure that Social Services covering your area:		Do you ensure that Social Services covering your area:		Do Social Services covering your area:		Do Social Services covering your area:		Do Social Services covering your area:	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Organise and support financially respite care options that meet the particular needs of people with multiple sclerosis, specifically their young age (under 65 years) and their severe and complex neurological problems										
Specifically for people with MS	-	-	2	1	13	14	22	7	8	4
In line with the NSF-LTC	25	1	6	3	8	8	6	2	6	3
For neurology as a whole	-	-	12	6	11	12	16	5	6	3
At a broader level	25	1	55	28	28	29	28	9	29	14
No	50	2	14	7	13	14	6	2	12	6
Not known	-	-	12	6	27	28	22	7	39	19

Quality requirement eleven

People with long term neurological conditions are to have their specific neurological needs met while receiving care for other reasons in any health or social care setting.²

Key findings:

- 41% to 50% of providers do not provide specialist neurological support to patients with MS when under their care.

This quality requirement aims to ensure that when a patient is admitted to hospital their ongoing and long-term special needs related to their underlying neurological condition continue to be managed appropriately, whatever the specific reason for admission to the hospital.

Table OA69: specialist support to patients when admitted

	SHA		PCT / LHB		Acute trust		Community trust	
	Do you monitor whether your PCTs/LHBs ensure that all healthcare providers used are able to		Do your service commissioning specifications ensure that all healthcare providers used are able to		Are there services within your organisation able to		Are there services within your organisation able to	
	% Yes	n =	% Yes	n =	% Yes	n =	% Yes	n =
Recognise and respond to the specific needs of people with long-term neurological conditions when such a patient is being cared for								
Specifically for people with MS	-	-	2	1	23	24	19	6
In line with the NSF-LTC	25	1	12	6	13	14	9	3
For neurology as a whole	-	-	14	7	23	24	22	7
At a broader level	25	1	41	21	20	21	44	14
No	50	2	16	8	8	8	3	1
Not known	-	-	16	8	13	14	3	1

Table OA70: GP perception of specialist support in hospital

	% Yes	Yes	No	NK
In your experience, are the major secondary care healthcare providers in your area able to recognise and respond to the specific needs of people with long-term neurological conditions when such a patient is being cared for outside a specialist neurological service?	51	25	13	11

Discussion

This third national audit of the services provided to people with MS suggests that services for people with long-term neurological conditions have not improved significantly since 2006, and that neither the six main recommendations made in the 2003 NICE national clinical guideline 8, *Management of multiple sclerosis in primary and secondary care*, nor seven of the eleven quality requirements of the 2005 *National Service Framework for Long-term Conditions* are being implemented. The audits also suggest that one major reason may be the constant reorganisation within the NHS which prevents any sustained attention being given to improving these services.

This discussion will cover:

- Important new findings
- Changes from earlier audits
- Evaluation of recommendations made in 2008
- Qualitative data from people with MS
- Methodology – challenges?
- Methodology – changes
- Conclusion
- Final conclusions and recommendations from 2011
- Key Recommendations

Important new findings

The apparent failure to manage **pain** in a large number of patients is very striking, and very concerning. The data from several questions are all consistent, suggesting that about one quarter of all people with MS surveyed had pain that was uncontrolled.

Furthermore, responses from the people with pain suggest that they have not had specialist input. This is slightly difficult to interpret because several specialist services might be available – neurology, neurological rehabilitation, specialist pain services, and palliative care. As the only specific question related to palliative care, one cannot know whether in fact the person had been seen by an equally specialist service about the problem. Moreover, it is unfortunately true that in some instances pain can be difficult to control.

Nonetheless, the finding that 25% of people report uncontrolled pain is worthy of further attention, and commissioners, providers and most importantly clinical staff should pay particular attention to ensuring that:

- every patient is asked whether they are experiencing any pain, and
- full specialist help is made available when needed because the pain is not well controlled.

The recent NICE guideline *Neuropathic pain: The pharmacological management of neuropathic pain in adults in non-specialist settings* (CG96) should particularly be used.⁵

The high rates of **falls**, falling and attending hospital after falls are also significant new findings, arising from the inclusion of a specific question on falls – this suggestion came from patient representation. It is difficult to know how to interpret the observation, and the rate could simply reflect ‘gritty determination’ on the part of some people with MS.

The best management of falls in this group of patients is unknown, though risk factors have been identified.¹² At present, most available falls clinics are targeted at the elderly. Although many risk factors may be similar (drugs, sensory impairment, poor balance reactions, etc) it might nonetheless be appropriate to have clinics for younger people with neurological conditions such as cerebral palsy, MS, head injury and Huntington’s disease because the problems and solutions probably differ.

At present we suggest that this observation should:

- prompt clinical staff to ask all patients about falls, and to consider whether the risk can be reduced
- encourage commissioners to consider specific falls clinics for younger people with neurological disorders, to reduce the use of hospital services
- lead to more research into reducing the rate of falls

Changes from earlier audits

The most obvious and depressing observation is how little the quality of services for people with MS have improved since the first round of audit in 2006. The table below shows a summary of all noticeable changes. There were, however, some significant changes.

The reduction in the rate of skin pressure ulcers reported by people with MS is encouraging. There has been a consistent drop on each occasion from 9% in 2006 to 4% in 2011. Although there may have been small changes in the clinical characteristics of the people completing the survey, they are unlikely to have been large enough to account for this drop. Interestingly this improvement has occurred despite the apparent lack of significant change in the attention paid to skin pressure ulceration by organisations.

There also appears to have been an improvement in protocols for sharing information when transferring patients between healthcare organisations.

On the other hand there is an apparent decline in information sharing during transfers between health and social services.

We have also investigated the response to the recommendations made in 2008. The second table below shows the eight major recommendations made in 2008, and what this audit found.

For three recommendations made in 2008 we have no data to measure change. These three recommendations were general and not related to one specific set of data. One recommendation did not have relevant data collected in 2008 and so no comparison can be made. For one recommendation – that people with MS should be involved in all clinical decisions – there appears to have been a dramatic drop in the number of trusts requiring this in policy documents, but this probably reflects changes in the wording or interpretation of the question because the proportions of patients reporting adequate involvement is little changed. The other changes were small and were in both directions with a slight preponderance of improvements.

While one might take comfort from the trend towards improvement, the table also shows how far the NHS is from achieving the standards of service commissioning and delivery set out in national documents in 2003 and 2005. The intervening period covers half of the ten years allocated for full implementation of the NSF-LTC and the gap between current reality and the aspirational ideals of the NSF-LTC is huge, at least for people with MS. No time scale was set for the NICE guidance, but eight years is a long time and the NHS is not close to achieving even the key recommendations.

Lastly the response rate from NHS organisations was lower: only four of ten SHAs responded, the Welsh Regional Office did not respond, and only 51 of 151 commissioners responded. Whilst we cannot be certain, we believe that the major structural changes occurring in the NHS when the audit was conducted is the major reason. Most organisations were over-stressed simply managing day-to-day matters and it was usually difficult to identify any person who knew about and took responsibility for services for people with long-term neurological conditions or even neurological services.

Evaluation of recommendations made in 2008

Recommendation in 2008	Observation in 2011
Every NHS organisation should have one specific person or role responsible for services for people with long-term neurological conditions including multiple sclerosis.	Unfortunately our data cannot be specific because we did not ask who did not have a person with any responsibility for multiple sclerosis or neurology or long-term conditions.
Every NHS organisation should involve people with multiple sclerosis in setting standards, in service development and in commissioning.	30% of commissioners had formal mechanisms to involve people with multiple sclerosis in planned service developments compared to 25% in 2008. 36% of acute trusts involved people with multiple sclerosis in service development in 2011 compared with 39% in 2008.
Every NHS organisation should have one specific person or role responsible for monitoring and reducing the rate of skin pressure ulceration.	Data were not collected on this, but we note a continuing fall in the reported prevalence in our patient survey.
Commissioning organisations should commission specialist neurological rehabilitation services to enable every person with multiple sclerosis to have ready and rapid access to these services.	20% of commissioners do not commission specialist neurological rehabilitation at a neurological level and only 24% commission in line with the NSF-LTC of better; in 2008 the comparable figures were 27% and 23%. The patient survey and general practice data suggest that only 36% of patients could access specialist services (no changes) and only 26% of general practices could refer to specialist services.
Acute trusts/provider units should ensure that any person with multiple sclerosis in their care for whatever reason has timely access to an expert neurology service and an expert neurological rehabilitation service.	58% of acute trusts felt that they could meet all the specialist neurological needs of multiple sclerosis patients in their care, and 51% of general practices felt that this was true locally to them. However only 18% of patients actually admitted reported this to be the case. This question was not asked in 2008.
Acute trusts/provider units should ensure that health professionals engage people with multiple sclerosis fully in all clinical decisions.	59% of people with multiple sclerosis reported full satisfaction with involvement in clinical decisions, compared with 53% in 2008.
Acute trusts/provider units should give people with multiple sclerosis information about relevant local non-statutory services as well as national services.	In 2008 36% of newly diagnosed patients reported being given locally relevant information, and in 2011 42 % reported this, an improvement.
The Department of Health should review the organisational framework of the NHS so that one organisation becomes responsible for ensuring that the population of people with multiple sclerosis in a defined area has access to services that can meet all of their clinical needs in a timely way, across the whole range of problems they face, managed in a coordinated way, and with staff who have appropriate expertise.	A major reorganisation of the NHS has started, but: <ul style="list-style-type: none"> • it is not at all clear that the new organisations will lead to any better integration of services; • the strategic health authorities who had some responsibility have been abolished and no organisation will have obvious responsibility for maintaining integrated commissioning to meet all service needs of people with multiple sclerosis.

The challenges facing the NHS in achieving the goals set in 2003 and 2005 are great, and probably seem insurmountable to many people. It is also likely that the general perception is that much money is needed to achieve the standards outlined and that the NHS cannot afford it despite a large absolute increase in funding.

However, the real challenge is not how to **add** new services to existing services; the real challenge is how to alter the whole approach of the healthcare system so that it can respond appropriately to the needs of most of the patients using it – patients with long-term disabling conditions. The change needs to affect every aspect of the system from how tariffs are organised, through commissioning and performance management and through the organisation of services on to the clinical interactions between patients and clinicians.

The increasing focus on identifying and paying for specific individual ‘treatments’ as if they were isolated commodities to be traded is only going to worsen the quality of care for most patients who will need multiple treatments sometimes together, sometimes in a particular sequence, and always spread out over time. Many of the interventions will themselves take weeks or months, and may need repeating. A healthcare market that has separate providers focusing on separate specific treatments or small parts of the overall package of care needed will make it almost impossible to achieve improvement in the current situation.

A related challenge is in reorganising and reallocating resources so that they are used more appropriately and efficiently. For example, there is reasonable evidence that specialist neurological rehabilitation services are effective at reducing disability and dependence (which will reduce care costs) and yet there are no more specialist rehabilitation services available now that there were five years ago. Indeed some are being reduced or cut. If about one third of the country can run specialist services from within their budget, then presumably other areas which have a similar budget should be able to do so.

This challenge may extend into more political areas, specifically the relationship between Health and Social Services. In general the major costs of rehabilitation are met by the NHS but it is Social Services who reap the benefit in terms of reduced care costs. Furthermore, efficient use of NHS resources, especially inpatient rehabilitation resources, requires close cooperation with Social Services in order to achieve a timely safe discharge out of hospital. In this context it was disappointing to observe a slight deterioration in the quality of information exchange between Health and Social Services.

A second unrelated area of challenge concerns the multiplicity of services needed by people with MS, services that currently span several or many healthcare departments or organisations and also includes Social Services, Housing etc.

The NSF-LTC recognised this problem as being a central difficulty for most people with long-term disability and made integration of care through case management coupled with facilitation of self-management the first quality requirement. The results of this audit show that this is simply not occurring.

This audit suggests that many people with MS are in touch with MS specialist nurses who might be considered as potential or actual case managers. Some words of caution are needed. Firstly, it is probable that the presence of MS nurses in an area will have increased both participation by patients and participation by organisations. Thus the sample is biased in relation to data about MS nurses.

Secondly, in some cases MS nurses work primarily in the context of disease management clinics in which the people seen will generally not be severely disabled. In other areas their role is circumscribed, for example not being allowed to visit people at home.

Case managers anyway have limitations as a solution. They may go on holiday or be unavailable when needed. Even the most highly trained case manager cannot be fully expert in all areas of management.

The number of MS specialist nurses available is too small to meet the huge needs of the large number of people in the community with long-term disability.

One solution is to employ a large number of case managers for all people with long-term neurological disability, including people with MS, but unless there is also an increase in specialist neurological rehabilitation this will not achieve much in the areas where there is no specialist rehabilitation. An alternative is to increase the availability of specialist neurological rehabilitation services so that they are always able to respond to the needs of patients, not necessarily by directly providing all services themselves but by identifying the service needed and ensuring that the person with MS is seen by that service while also ensuring that the service has all the information needed about MS and about the person so that the problem is resolved. In other words the case-management integration of services would occur through the specialist neurological rehabilitation service.

The specialist neurological rehabilitation service would have to work in very close collaboration with specialist neurological services, which would obviously take lead responsibility for all aspects of diagnosis and treatment of the disease itself.

Qualitative data from people with MS

The comments illustrated the very large range of experiences of people with MS. One notable general feature was inconsistency: many individuals had some good and some bad experiences and no one type of service or profession gained universal praise or criticism.

The data are certainly consistent with the quantitative data where they cover similar ground. For example, failures in communication between and failures in the integration of different services were often mentioned. Also mentioned were difficulties in accessing therapy services and problems in getting help quickly when needed.

The comments on the attitudes and behaviours of some staff are, at first sight, worrying but it is difficult to place these in a context. The importance of maintaining a professionally appropriate attitude and style of communication is stressed in all NICE guidelines and most other documents and in all professional training.

More generally it has proved possible to undertake an analysis of the comments made. The methodology was by no means perfect, but the comments made were individually short and of unknown provenance. We feel that this was a worthwhile addition, but that further improvement could be undertaken next time.

Methodology – challenges?

One major challenge in undertaking an audit of all services that are involved with people with a particular long-term condition such as MS is that the healthcare is delivered within a huge range of services. People with MS only receive a small proportion of all care over their life-time within a specialist MS or neurology service. Or, put another way, only a small proportion of people with MS who are seen within secondary care over one year will actually be primarily seen within a specialist neurology or MS service.

This has two major methodological consequences if one is trying to audit the totality of services provided to people with MS. Firstly, there is no single or even small number of centres or services that can provide the data. Almost all community and hospital services may be involved. Secondly, most of these services do not specifically concern themselves with the patient's underlying diagnosis of MS, which is usually outside their area of interest and expertise. Thus they will often not even consider that they are giving a service to people with MS, and may not answer the questions.

Yet, from the perspective of a person with MS the major concern is with all of their problems, not simply the urinary tract infection or other problem being focused on by the acute medical or surgical service. Indeed it is usually the secondary exacerbation of the many problems arising from their MS that concerns them, but these are either not recognised or not attended to by the clinical service involved.

Following on from this, many of the important services used by people with MS such as equipment services, urology services and potentially specialist pain services are commissioned and provided for more generally without regard to the underlying diagnosis. While this is quite appropriate clinically, it also makes it difficult to determine whether individuals with a particular condition – in this case MS – are receiving an appropriate service in terms of quality and quantity. For example equipment services are universally commissioned, yet data from patients show a poor level of provision. This finding is probably valid, as it was also found in 2000 and 2002 by the Audit Commission.^{3,4}

Another consequence is that no one person takes long-term responsibility for ensuring good services are available. All three audits have found that there is usually a person with named responsibility at least for services related to the national service framework for long-term conditions and sometimes for services to people with MS. However, in practice we find that the individual concerned is often new in post or about to leave, or the post is vacant. This has an obvious consequence in terms of data collection – it is much more difficult – but it also implies that no-one has any long-term commitment to developing and maintaining services.

Finally, the constant re-organisation of the NHS not only makes data collection and service improvement difficult, it also makes comparison over time difficult. For example, the first audit had a relatively large number of regional health authorities responsible for performance management; in the second audit ten SHAs were responsible for performance management, and although there were still ten SHAs in 2011, they were being disbanded and only four provided data. Similarly the size of PCTs is constantly changing, and secondary care trusts are amalgamating and encompassing several hospitals. Community services have been separated from PCTs over the last two years.

In addition to these fixed challenges, there was also a breakdown for about ten days of the web-based data-collection tool, just at the peak time of data entry. This may have prevented some people with MS and some organisations from providing data. We did extend the period of data collection by several weeks, but an initial failure may have discouraged some people so much that they simply did not try again.

Despite all these problems, we believe that our findings are reasonably secure because they are consistent across several different perspectives – commissioners, providers, general practitioners, people with MS and performance management (although the number of SHAs was too small on this occasion to draw firm conclusions). This is a powerful validating mechanism.

Methodology – changes

The audit methodology is largely unchanged from the two previous rounds, in that we have used similar questions and we have used a similar data-collection tool, and we have used a similar approach to identifying and contacting organisations and people with MS. However, there were some important changes.

The first difference was the inclusion of questions relating to seven of the eleven quality requirements of the NSF-LTC. This addition has been successful. It did not obviously make the process of data collection more difficult, and the results have both cross-validated the data from the questions concerning the NICE recommendations, and have added some new information.

The second difference was the inclusion of general practices. Their absence was an obvious weakness of the first two audits, especially because general practice has a leading role in the management of people

with long-term conditions. We had intended to recruit up to 600 practices randomly selected, but we only obtained data from 49. However, our experience suggests that it is certainly useful, in that it provides more cross-validating data.

The third difference arose from our experience in the second audit. In the second audit several organisations made contact with us because they provided community services; some were still within PCTs, and others were part of hospital trusts or were independent NHS organisations. Thus on this occasion we tried to identify and contact organisations responsible for providing services to people in the community.

There are several difficulties in trying to collect data about services delivered in the community. Firstly, often community services are a part of a larger organisation also providing hospital services or other services (e.g. Mental Health). Thus one cannot know whether the organisational data from a trust encompasses some community services.

Secondly, there is no register of community services. Indeed, there is no good definition of and there is no agreement about what the phrase 'community services' actually encompasses: actual delivery of a service in a home; delivery in a community hospital, some of which are quite large; outpatient or day hospital services; entitled 'community services'; and so on.¹³ Third, there is an obvious overlap between general practice and the services delivered within general practices and community services.

Finally, we have included a qualitative analysis of comments made by people with MS in the audit report in this round. Although there are obvious weaknesses in the method (limited data from any one patient, multiple people analysing the data), we believe that the results are nonetheless very informative.

Conclusion

This audit has demonstrated again the power of collecting data from a wide variety of sources, because although each may suffer from bias and other problems, the consistency across all data sources greatly strengthens the conclusions one can draw. Thus this is a very cost-efficient way to audit services nationally.

Overall there have been some slight improvements, but the extent is small and it is still difficult to know whether the changes are simply random variation or whether they constitute a real trend. Even if they are indicative of actual improvement, the rate is extremely slow and much further improvement is needed for people with MS to receive a satisfactory service and even more to achieve a high quality service.

The changes in method, particularly the addition of questions relating to the NSF-LTC, have improved the quality and informativeness of the audit. Further improvements can still occur.

Another audit in 2014 using the same system and most of the same questions with some small changes and additions should allow us to determine whether actual improvement is occurring.

In the meantime we have drawn up a list of specific observations that we think are important, showing the conclusion drawn and making a recommendation on what now needs to occur. These are shown in the first table below; detailed recommendations follow in the second table.

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.
	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.

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 Neuropathic pain: The pharmacological management of neuropathic pain in adults in non-specialist settings (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.

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.
- 2 Department of Health. *National Service Framework for Long-term Conditions*. London: DH, 2005.
- 3 Audit Commission. *Fully equipped: the provision of equipment to older or disabled people by the NHS and social services in England and Wales*, 2000. <http://www.audit-commission.gov.uk/nationalstudies/health/socialcare/Pages/fullyequipped.aspx> [Accessed 18 August 2011]
- 4 Audit Commission. *Fully equipped 2002: assisting independence*, 2002. <http://www.audit-commission.gov.uk/nationalstudies/health/socialcare/Pages/fullyequipped2002.aspx> [Accessed 18 August 2011]
- 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.
- 6 MS Trust. http://www.mstrust.org.uk/atoz/prevalence_incidence.jsp [Accessed 05 September 2011]
- 7 World Health Organization. *International classification of functioning, disability and health*, 2001. http://books.google.co.uk/books?id=pwb9ywSVKxwC&dq=WHO+ICF&printsec=frontcover&source=bl&ots=JxF1Azlius&sig=OrgwBPJsefi4AcD7Z45gsERMV28&hl=en&ei=BibeStC9CYW04QaZ1eAK&sa=X&oi=book_result&ct=result&resnum=2&ved=0CA4Q6AEwAQ-v=onepage&q=&f=false [Accessed 18 August 2011]
- 8 Wade, D. *NHS services for people with multiple sclerosis: a national survey*. London: Royal College of Physicians and Multiple Sclerosis Trust, 2006.
- 9 Royal College of Physicians and Multiple Sclerosis Trust. *National audit of services for people with multiple sclerosis 2008*. London: RCP and MS Trust, 2008.
- 10 The Information Centre. <http://www.qof.ic.nhs.uk/index.asp> [Accessed 10 November 2010]
- 11 Health in Wales. <http://www.wales.nhs.uk/ourservices/directory> [Access 10 November 2010]
- 12 Y. Nilsagård, Cecilia Lundholm, E. Denis and L-G. Gunnarsson. *Predicting accidental falls in people with multiple sclerosis — a longitudinal study*. *Clinical Rehabilitation*, 2009;23:259-269
- 13 Wade DT. *Community rehabilitation or rehabilitation in the community?* *Disability and Rehabilitation* 2003;25:875-881

Appendix 2: NICE CG8 key recommendations and sentinel marker

Key recommendation one: specialised services

Specialised neurological and neurological rehabilitation services should be available to every person with MS when they need them usually when they develop any new symptom, sign, limitation on their activities or other problem, or when their circumstances change.

For this audit the following definitions were used.

Specialised neurological service

A service within one organisation, contracted for as a unitary whole (for MS at least) and including the following:

- Consultant Neurologists with a special interest in MS (i.e. committed to seeing people with MS as a significant part of their work).
- Consultant neuro-radiologists with direct access to an MRI scanner.
- Access within the service to all specialist neurological investigations such as neuro-physiology and neuropathology.
- At least one nurse (or other healthcare professional) specialising in MS.
- Inpatient beds with neurologically trained nurses able to admit patients acutely, after a relapse.
- Access to rehabilitation staff (physiotherapy, occupational therapy, speech and language therapy, clinical psychology, social work) who have neurological training either within the service, or on a contractual basis but available throughout all working hours.
- Outpatient neurological services.

Specialised neurological rehabilitation service

This definition is based on the guideline document. It is a service within one organisation, contracted for as a unitary whole (for MS at least), and including the following:

- One Consultant in Neurological Rehabilitation, or a Consultant in Rehabilitation Medicine who has a special interest in MS and with at least 50% of their contracted time being committed to seeing people with neurological disease.
- At least one nurse (or other healthcare professional) specialising in MS.
- Inpatient beds with neurologically trained nurses able to admit patients acutely, after a relapse or for assessment.
- A full neurological rehabilitation team, including physiotherapy, occupational therapy, speech and language therapy, clinical psychology, and social work. All staff should work exclusively with neurologically disabled patients, and there should be training specific to the needs of people with MS on a regular basis.
- Outpatient neurological rehabilitation services.
- Direct and easy access to specialised other services especially ophthalmological (low vision services) and urological services.
- A specific specialised interest in the management of:
 - spasticity, including the use of botulinum toxin
 - complex seating and postural and movement and handling needs
 - swallowing difficulties.

Available when needed

The patient should be able to be in direct contact with and under the management of the service without undue delay or difficulty (see also the sixth recommendation on self-referral). Specific time frames cannot be given, but the patient should never need to be under the care of any other less specialised service while waiting (i.e. once the referral is made, patients should be transferred directly from the

referring location without an intermediate placement). The clinical need will determine what is an acceptable delay.

Key recommendation two: rapid diagnosis

An individual who is suspected of having MS should be referred to a specialist neurology service and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time).

In making this recommendation the NICE guideline developers specifically did not define an appropriate time, but suggested that a six week delay was likely to be the maximum acceptable in most circumstances. The definition of a specialist neurology service has already been given above.

Suspected of having MS

This will be determined by the referring doctor, general practitioner or hospital doctor, usually by specific mention within the referring letter (or email or other communication).

Rapidly within an audited time

As mentioned above, no specific time was set. However the recommendation requires the time between receipt of referral and the person being seen to be recorded, and to be reported to other people.

After all investigations ... completed

This refers to the set of investigations ordered at the first consultation.

Key recommendation three: seamless services

Every health commissioning organisation should ensure that all organisations in a local health area agree and publish protocols for sharing and transferring responsibility for and information about people with MS, so as to make the service seamless from the individual's perspective.

Health commissioning organisation

This refers to the PCT or consortium of PCTs that commission services.

All organisations

The focus will be on the links between:

- Within health
 - Primary (GP services) and secondary care (hospital services)
 - Medical (doctor) services and para-medical (nursing and rehabilitation) services
 - Different specialist services with secondary care (e.g. neurology to neurological rehabilitation if separate).
- Health (all) and Social Services, especially for ongoing support and care.

Local health area

This will be geographically determined, usually being related to the traditional areas covered by the District General Hospital.

Published protocol

This is a document that is available on request and/or is easily available on an Internet or Intranet web page, with documents giving the web address. There must be dissemination of the document's existence if not of the document itself.

Key recommendation four: a responsive service

All services and service personnel within healthcare sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be actively involved in all decisions and actions.

The intention of this recommendation is to ensure that services tailor their response to the needs and expectations of the patient, rather than expecting the patient to fit the service(s). It does not include ease of access (accessibility).

Varying and unique needs

This refers to two features of people with multiple sclerosis (that in fact apply to all patients): each one has his or her own set of circumstances (pattern of impairments, family setting, previous history etc); and circumstances may change over time, if only as the disease progresses.

Varying and unique expectations

This refers to the patient's wishes, hopes and anticipated outcome which, as above, will not only be unique to that individual but may change over time.

Active involvement

This has several components, all important. The first is being given appropriate information about the situation. Next the person needs to be informed about the options available and their respective advantages and disadvantages. Third, the person should be encouraged to make choices where choices are available. Last, the person should be involved in any treatment actively, for example monitoring the effects of the intervention.

Key recommendation five: sensitive but thorough problem assessment

Health professionals in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control.

This recommendation is designed to ensure that all important (distressing and/or treatable) problems are identified when a person with multiple sclerosis consults any service. It was also intended to ensure that this is achieved without causing undue distress to the person concerned.

Health professionals

This refers to any person working within the NHS in a professional capacity.

Regular contact

This refers to any person whose job is within a service and who sees people with MS more than once/week, unless that person specifically is unlikely to see a person with MS.

Systematic way

There should be a formal protocol or structured method for collecting information concerning common undetected impairments.

Key recommendation six: self-referral after discharge

Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no

longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate.

This recommendation concerns people who have no fixed further appointments with a specialist, a working definition of 'discharge'. It also only concerns specialist services.

Seen by

The person has had at least one clinical contact. In practice this should be easily established from hospital Patient Administration Systems (PAS).

Make contact

The person with MS should be able to make an appointment to be assessed by a member of the specialist service, although the contact requested may be no more than a telephone contact in which case this would also be adequate.

Sentinel marker: pressure ulcers (standard seven)

The commissioning health organisation should require all healthcare services including community services:

- *to report every pressure ulcer occurring in a person with MS,*
- *to undertake and report an investigation into what could have been done to avoid its occurrence,*
- *to agree actions that should reduce the risk of the same situation leading to a pressure ulcer.*

This recommendation was added because pressure ulceration was considered the most easily recorded, unambiguous, simple marker of an obviously bad clinical outcome for the patient. Although not every pressure ulcer can be avoided, each one is worthy of investigation. Moreover the management of skin pressure ulceration is expensive to the Health Service [Grey et al, 2006].

Appendix 3: National Service Framework for Long-term Conditions and multiple sclerosis

There are eleven quality requirements, but not all are especially relevant to people with multiple sclerosis. Furthermore we did not wish to overload the respondents with too many additional questions. We therefore selected seven quality requirements as being of importance to people with multiple sclerosis, and derived questions relating to them. Each of the seven chosen requirements is given below with a brief outline of why it was chosen.

Quality requirement one

People with longterm neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

This was chosen because integration of services (referred to as *seamless services* in NICE CG8) is of great importance to people with MS as their needs often span many organisations. Furthermore developing supporting self-management skills is considered an important part of healthcare for all people with long-term conditions.

Quality requirement five

People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

This was chosen because having access to rehabilitation services for all the problems faced is also emphasised in NICE CG8 (referred to as being *flexible*) and it is also of great importance to people with multiple sclerosis.

Quality requirement six

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

This is of particular importance to people with multiple sclerosis because most are of working age when the condition starts. This topic is not covered at all in the seven NICE CG8 standards.

Quality requirement seven

People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

This is also of great concern to people with multiple sclerosis and this topic is also not specifically covered in NICE CG8. Furthermore at least two national reports have emphasised that the NHS should put more resources into the timely provision of all necessary equipment [refs] but the general perception is that this has not yet occurred.

Quality requirement nine

People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

This requirement is less obviously relevant because at least some comprehensive rehabilitation services consider that palliation is integral to good rehabilitation. However this is not universally the case, and certainly many people with multiple sclerosis experience uncontrolled pain (see results). Thus it is important, and not covered by NICE CG8.

Quality requirement ten

Carers of people with long term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

Although the detailed NICE CG8 does make recommendations concerning supporting families, the six key recommendations do not. But multiple sclerosis has a major impact upon families who provide care and support, and this is of central importance to many people with multiple sclerosis who often report that their families receive insufficient support.

Quality requirement eleven

People with long term neurological conditions are to have their specific neurological needs met while receiving care for other reasons in any health or social care setting.

People with multiple sclerosis have many admissions, in fact usually the majority of all their admissions, under the care of other specialities, even if the problem is ultimately caused by the multiple sclerosis (e.g. urinary tract infection, skin pressure ulceration) and a common concern is that the medical and nursing teams are unable to manage the multiple sclerosis and other problems relating to it. Thus this was considered of great importance.

Appendix 4: Participating organisations

Participating acute hospital trusts

Airedale NHS Foundation Trust
Barking Havering & Redbridge Univ Hosps NHS Trust
Barnet & Chase Farm Hospitals NHS Trust
Barts and The London NHS Trust
Basildon and Thurrock University Hospital NHSFT
Bedford Hospital NHS Trust
Bradford Teaching Hospitals NHS Foundation Trust
Brighton and Sussex University Hospitals NHS Trust
Buckinghamshire Healthcare NHS Trust
Burton Hospitals NHS Foundation Trust
Calderdale & Huddersfield NHS Foundation Trust
Cambridge University Hosps NHS Foundation Trust
Chesterfield Royal Hospital NHS Foundation Trust
City Hospitals Sunderland NHS Foundation Trust
Colchester Hospital University NHSFT
Dartford & Gravesham NHS Trust
Derby Hospitals NHS Foundation Trust
Ealing Hospital NHS Trust
East and North Hertfordshire NHS Trust
East Kent Hospitals University NHSFT
East Lancashire Hospitals NHS Trust
East London NHS Foundation Trust
East Sussex Hospitals NHS Trust
Gateshead Health NHS Foundation Trust
Gloucestershire Hospitals NHS Foundation Trust
Great Western Hospitals NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust
Harrogate and District NHS Foundation Trust
Heatherwood and Wexham Park Hospitals NHSFT
Hillingdon Hospital NHS Trust
Homerton University Hospital NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
Imperial College Healthcare NHS Trust
James Paget University Hosps NHS Foundation Trust
Kettering General Hospital NHS Foundation Trust
King's College Hospital NHS Foundation Trust
Kingston Hospital NHS Trust
Lancashire Teaching Hospitals NHS Foundation Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Mid Staffordshire NHS Foundation Trust
Milton Keynes Hospital NHS Foundation Trust
Norfolk and Norwich University Hospitals NHSFT
North Bristol NHS Trust
North Cumbria University Hospitals NHS Trust
North East Lincolnshire Care Trust Plus
North Middlesex University Hospital NHS Trust
Northampton General Hospital NHS Trust
Northumberland, Tyne and Wear NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
Nottingham University Hospitals NHS Trust
Nuffield Orthopaedic Centre NHS Trust
Peterborough & Stamford Hosps NHS Foundation Trust
Plymouth Hospitals NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Royal Berkshire NHS Foundation Trust
Royal Devon & Exeter NHS Foundation Trust
Royal Free Hampstead NHS Trust
Royal United Hospital Bath NHS Trust
Salford Royal NHS Foundation Trust
Salisbury NHS Foundation Trust
Sandwell & West Birmingham Hospitals NHS Trust
Scarborough and NE Yorks Healthcare NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
South Devon Healthcare NHS Foundation Trust
South London Healthcare NHS Trust
South Tees Hospitals NHS Foundation Trust
South Tyneside NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
Southport & Ormskirk Hospital NHS Trust
Stockport NHS Foundation Trust
Surrey & Sussex Healthcare NHS Trust
Sussex Community NHS Trust
Tameside Hospital NHS Foundation Trust
Taunton & Somerset NHS Foundation Trust
The Dudley Group of Hospitals NHS Foundation Trust
The Leeds Teaching Hospitals NHS Trust
The Mid Yorkshire Hospitals NHS Trust
The Newcastle upon Tyne Hospitals NHSFT
The North West London Hospitals NHS Trust
The Pennine Acute Hospitals NHS Trust
The Queen Elizabeth Hospital King's Lynn NHS Trust
The Queen Victoria Hospital NHS Foundation Trust
The Rotherham NHS Foundation Trust
The Shrewsbury and Telford Hospital NHS Trust
The Walton Centre NHS Foundation Trust
United Lincolnshire Hospitals NHS Trust
University College London Hospitals NHSFT
University Hosp Birmingham NHS Foundation Trust
University Hospital of North Staffs NHS Trust
University Hospital of South Manchester NHSFT
University Hospitals Bristol NHSFT
University Hospitals Coventry & Warwickshire NHST

University Hospitals of Leicester NHS Trust
University Hospitals of Morecambe Bay NHS Trust
Walsall Hospitals NHS Trust
West Hertfordshire Hospitals NHS Trust
West Middlesex University Hospital NHS Trust

West Suffolk Hospital NHS Trust
Weston Area Health NHS Trust
Whipps Cross University Hospital NHS Trust
Yeovil District Hospital NHS Foundation Trust

Participating community trusts and PCT provider arms

Bassetlaw Community Health
Birmingham Community Healthcare NHS Trust
Bridgewater Community Healthcare NHS Trust
Bristol Community Health
Central London Community Healthcare
Derbyshire Community Healthcare Services
Ealing & Harrow Community Services
Hampshire Community Healthcare
Hertfordshire Community NHS Trust
Hounslow and Richmond Community Healthcare NHS Trust
Isle of Wight NHS Primary Care Trust
Liverpool Community Health
NHS Bolton - Provider Services
NHS Camden - Provider Services
NHS Eastern and Coastal Kent - Community Services
NHS Herefordshire - Provider Services

NHS Islington - Provider Services
NHS Leeds - Community Healthcare
NHS Norfolk - Norfolk Community Health & Care
NHS North Lancashire - Provider Services
NHS Northamptonshire - Provider Services
NHS Rotherham - Community Health Services
NHS South East Essex - Community Healthcare
NHS Surrey - Community Health Services (East Locality)
NHS Surrey - Community Health Services (NW Locality)
NHS Surrey - Community Health Services (SW Locality)
NHS West Essex (SP)
NHS Wiltshire Community Health Services
NHS Worcestershire - Provider Services
Plymouth Teaching PCT (provider)
Solent NHS Trust
Trafford Provider Services

Participating primary care trusts

Heart of Birmingham Teaching Primary Care Trust
Liverpool Primary Care Trust
NHS Ashton, Leigh and Wigan
NHS Birmingham East and North
NHS Bolton
NHS Bournemouth and Poole
NHS Bradford and Airedale
NHS Brighton & Hove
NHS Camden
NHS County Durham
NHS Cumbria
NHS Darlington
NHS Devon
NHS Dudley
NHS Gloucestershire
NHS Great Yarmouth and Waveney
NHS Hampshire
NHS Harrow
NHS Hertfordshire
NHS Knowsley
NHS Lincolnshire
NHS Luton
NHS Medway
NHS Mid Essex
NHS Middlesbrough

NHS Norfolk
NHS North of Tyne - Newcastle Primary Care Trust
NHS North of Tyne - North Tyneside PCT
NHS North of Tyne - Northumberland Care Trust
NHS North Somerset
NHS North Yorkshire and York
NHS Nottinghamshire County
NHS Oldham
NHS Rotherham
NHS Salford
NHS Sefton
NHS Sheffield
NHS Somerset
NHS South East Essex
NHS Swindon
NHS Telford and Wrekin
NHS Tower Hamlets
NHS Trafford
NHS Warwickshire
NHS West Kent
NHS Westminster
NHS Wiltshire
Sandwell Primary Care Trust
Solihull NHS Care Trust

Participating local health boards

Abertawe Bro Morgannwg University Health Board (Commissioning)
Abertawe Bro Morgannwg University Health Board (SP)
Aneurin Bevan Health Board
Betsi Cadwaladr University Health Board (SP)

Participating strategic health authorities

NHS East of England
NHS South Central
NHS South West
NHS West Midlands

Participating general practices

Beaumont Street Surgery	The Ridgeway Surgery
Belgrave Medical Centre	The Tudor Surgery
Birchwood Medical Centre	The Vallance Centre
Broomhill Health Centre	The West Wight Practice
Caen Medical Centre	The White House Surgery
Caldbeck Surgery	Toft Road Surgery
Carmel Medical Practice	Towerhouse surgery,
Chadderton Town Health Centre	Warwick House Medical Centre
Donald Wilde Medical Centre	Wellington Road Family Practice
Dorchester Road Surgery	Whitwick Health Centre
Dr D Irwin & Partner	Wickham Park Surgery
Elizabeth Courtauld Surgery	Wolstatnon Medical Centre
Gables Surgery	Woodland Avenue Practice
Gorton St Practice	Yorkeleigh Surgery
Gosford Hill Medical Centre	
Haider Medical Centre	
Hampstead Group Practice	
Harptree Surgery	
Higher Broughton Health Centre	
Hilly Fields Medical Centre	
Kiveton Park Medical Practice	
Marple Bridge Surgery	
Montpelier Health Centre	
New Wokingham Road Surgery	
NF Cavenagh & Partners, The Hollies	
Portslade Health Centre	
Raleigh Surgery	
St Chads Medical Practice	
Stanground Surgery	
Sundon Medical Centre	
Sunniside Surgery	
Swallowfield Medical Practice	
The Burnham Surgery	
The Microfaculty	
The Orchard Practice	

