

CLINICAL
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Summary

**National Audit of Services for
People with Multiple Sclerosis 2008**

NATIONAL REPORT

June 2008

Commissioning organisations:

The Royal College of Physicians, London and the Multiple Sclerosis Trust, Letchworth

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GLOSSARY

MS	Multiple sclerosis
NSF LTC	National Service Framework for Long-Term Conditions
PCT	Primary Care Trust
RO	Regional Office
SHA	Strategic Health Authority
Trust	Acute care Trusts (hospitals)
LHB	Local Health Boards
DoH	Department of Health

PREFACE

People with multiple sclerosis face many challenges – often a prolonged period of symptoms but no diagnosis, an uncertain prognosis which can encompass anything from a relatively normal life to severe disability for years, loss of social roles such as work and parenting, loss of independence, and many unpleasant symptoms. The NHS should help people face and minimise these challenges; unfortunately it is not always successful at this.


The National Institute for Health and Clinical Excellence (NICE) recognised the need for improved NHS services and produced national guidance on the management of multiple sclerosis in 2003. The six key recommendations and one sentinel marker of service quality could also be used as seven standards that the NHS should achieve. An initial audit by the Royal College of Physicians and the MS Trust in 2005/6 showed that standards were rarely met in full and there was a high level of dissatisfaction amongst people with multiple sclerosis. The two organisations joined forces again in 2007/08 to repeat the exercise on a national scale (England and Wales).

Here we present the results of the first full national audit that measures the quality of NHS services for people with multiple sclerosis against the seven standards derived from the NICE national clinical guideline.

The results and subsequent recommendations are relevant to all NHS organisations – hospitals and other service providers, commissioners, and those who are responsible for monitoring the quality and adequacy of services to the whole population. The results should help to improve their performance in delivering high quality services to people with multiple sclerosis. Moreover they should also be relevant to the implementation of the National Service Framework for Long-Term Neurological Conditions across the UK.

People with multiple sclerosis, and people with other longterm neurological conditions should also find the report helpful. It provides data to support local initiatives for service development.

We believe it is imperative that the NICE national clinical guideline is fully implemented, to improve the health of people with multiple sclerosis and to ensure that they have equal access to healthcare. We hope that this audit will assist all those who commission or provide care for people with multiple sclerosis, identifying where improvements in services and/or commissioning are required. This will require significant national investment in neurological rehabilitation services, and a great increase in the attention paid to the monitoring and prevention of skin pressure ulcers.



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EXECUTIVE SUMMARY

“Some 10 million people in the UK are living with a neurological condition which has a significant impact on their lives, and they make up 19% of hospital admissions.” (Neurological Alliance, 2003). This document reports upon an audit of NHS services for people with multiple sclerosis (MS), and identifies four areas in which the NHS can take action to improve the standard of care. People with MS have a wide variety of clinical problems and a varied and unpredictable disease course, which makes an audit of these services a useful marker of service quality for many other neurological conditions.

Moreover, with an estimated mean direct medical cost of £6,810 per person per year, MS is an expensive condition, with much of that expense being avoidable with good management¹. A grade 4 pressure ulcer, for example, which is always avoidable, costs the NHS an estimated £10,551, with total costs in the UK estimated as being £1.4–£2.1 billion - or around 4% of the total NHS expenditure².

Background

In November 2003 NICE made six key recommendations concerning the management of people with MS, and identified one sentinel marker for service quality. In 2005/6 an initial audit identified major failures in NHS services. In 2007/8 a full national (England and Wales) audit was undertaken collaboratively by the Royal College of Physicians (RCP) and the MS Trust. A multi-professional working party oversaw the audit which used the key recommendations and sentinel marker identified in the NICE guideline as seven standards by which to measure the quality of services offered.

Methodology

Data were collected from four sources: 1300 people with MS (as service users); 127/157 NHS Trusts (as service providers); 140/172 service commissioning organisations, and 7/13 organisations responsible for performance management. The available data suggest that the sample was representative of its population.

Results

Key Results

- ⇒ Access to neurological rehabilitation is unacceptably low, with very limited commissioning and only slightly less limited actual provision
- ⇒ Access to specialist neurological services is generally good
- ⇒ Time between initial referral and final diagnosis remains long
- ⇒ Patient involvement both in the planning of individual personal care and in service provision and development is very poor
- ⇒ Assessments are perceived by people with MS generally to be carried out in a sensitive and thorough manner
- ⇒ Integration of care between health and social services is felt to be poor

¹ G Kobelt, J Berg, P Lindgren, N Russell, R Nixon *Costs and quality of life of multiple sclerosis in the United Kingdom 2006* in *European Journal of Health Economics* S96-S104

² National Institute for Health and Clinical Evidence *Pressure ulcer management - cost analysis of the new recommendations in the prevention and treatment of pressure ulcers quick reference guide* Implementing NICE Clinical Guideline no. 29 London:NICE;September 2005; Bennett G, Dealey C, Posnett J *The cost of pressure ulcers in the UK* *Age & Ageing* 2004;33(3):230-235; Allman RM, Goode PS, Burst N, Bartolucci AA, Thomas DR. Pressure ulcers, hospital complications, and disease severity: impact on hospital costs and length of stay *Adv Wound Care*. 1999;12(1):22-30

The major deficit in care provision is the access to specialist neurological rehabilitation. This is particularly important for people with a chronic disabling condition which is characterised by periods of relapse and by a wide range of neurological losses (e.g. weakness, loss of sensation, bladder function, fatigue).

Some service improvements have been made since the NICE guideline was published. However the level of commissioning and monitoring of services for people with MS is low; improvement probably resulted from the commitment of local clinical champions.

The audit identified the lack of any 'ownership' for ensuring that the NHS as a whole provides adequate services across the whole range of services necessary to meet the needs of people with MS. Though informal networks and local clinical arrangements clearly exist, and work well in places, there is no identified person, role or organisation with responsibility for ensuring adequacy of services. The audit also highlights ambiguity both about the nature of and the responsibility for 'specialist services', and about long-term conditions; the emphasis should be on long-term **neurological** conditions.

The main recommendations that follow from this audit are:	
All NHS Organisations	<ul style="list-style-type: none"> ⇒ should have one specific person or role responsible for services for people with long-term neurological conditions including multiple sclerosis (MS) ⇒ should involve people with MS in setting standards, in service development and in commissioning ⇒ should have one specific person or role responsible for monitoring and reducing the rate of skin pressure ulceration
Commissioning Organisations	<ul style="list-style-type: none"> ⇒ should commission specialist neurological rehabilitation services to enable every person with MS to have ready and rapid access to these services
Acute Trusts/ Provider Units	<ul style="list-style-type: none"> ⇒ should ensure that any person with MS in their care for whatever reason has timely access to an expert neurology service and an expert neurological rehabilitation service ⇒ should ensure that health professionals engage people with multiple sclerosis fully in all clinical decisions ⇒ should give people with multiple sclerosis information about relevant local non-statutory services as well as national services
Department of Health	<ul style="list-style-type: none"> ⇒ should review the organisational framework of the NHS so that one organisation becomes responsible for ensuring that the population of people with MS 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

INTRODUCTION

Neurological disease is an important cause of significant disability in people aged under 65 years, but data on the management by health services of people with long-term neurological conditions are largely absent. The resource implications of neurological disability are not accurately known, but are considerable both directly (i.e. money paid to provide care) and indirectly (i.e. loss of productive activity).

There are no data to indicate whether the health resources used by people with neurological disability are either effective or efficiently distributed. Indeed it is not clear whether the total resource available is even sufficient for the needs.

In this situation it is important to gather data. Current NHS information systems are incapable of collecting data in relation to disability (as opposed to disease) and are incapable of collecting data across groups of disease (such as neurological disease).

One way to investigate the management of people with long-term neurological conditions by the Health Service is to focus on a specific disease or disorder that may indicate the overall standard of care.

Multiple sclerosis is a useful marker condition for investigating the management of other disabling neurological disorders. It is relatively common (1 in 700 of the population), and it manifests in a wide variety of ways covering most of the situations faced by people with other neurological diseases.

Furthermore several national documents have made recommendations about services for people with multiple sclerosis, most notably the National Clinical Guideline on the Management of Multiple Sclerosis in Primary and Secondary Care published by the National Institute for Health and Clinical Excellence (NICE) in November 2003 and the National Service Framework for Long-Term Conditions (NSF LTC) [2005].

Between October 2005 and March 2006 the Royal College of Physicians and the MS Trust undertook an initial audit of the provision of services for people with multiple sclerosis, judging the service against seven standards derived from the six key recommendations and one sentinel marker proposed within the NICE guideline:

- The provision of specialised services
- Rapid initial diagnosis
- Provision of seamless services across all boundaries
- Involvement in clinical decisions
- Sensitive but thorough assessment
- Self-referral
- Registration and investigation of each new skin pressure ulcer

The 2005/6 audit investigated services within six of the 28 Strategic Health Authority areas then existing in England (North West London; Greater Manchester; Dorset/Somerset; Kent; Birmingham and County Durham). Wales, Scotland and Northern Ireland were not included.

The conclusions of the 2005/6 audit were notified to all strategic health authorities, primary care trusts and acute hospital trusts (not simply those that took part), and were published³ in July 2006. They were summarised as follows:

“The **main finding** of this audit is that the standards set by the seven key recommendations made in the NICE National Guideline for the Management of Multiple Sclerosis are not being met in that:

- Service providers are not using them to guide service delivery;
- Service commissioners are not using them either to commission services or to monitor service delivery;
- Service performance managers are not using them to monitor that the health care needs of their population are being met;
- A few organisations adhere partially to one or two, but most do not adhere to any. Furthermore, most organisations are not specifically planning to implement any of the recommendations.”

This full national audit of England and Wales undertaken in 2008 retained the focus on multiple sclerosis both as an important single disease causing long-term disability, and as a marker condition indicative of the more general standard of services for people with long-term neurological disorders.

The overall aim was to improve services for people affected by multiple sclerosis. The original objectives were:

- 1 To quantify the differences between recommendations made in the NICE National Clinical Guidelines and actual service provision and to identify variations across England and Wales, through comparing data obtained from:
 - i) people responsible for governance of health service provision (SHAs and ROs)
 - ii) health care commissioners (PCTs/LHBs)
 - iii) service providers (Acute Trusts)
 - iv) people with MS needing and using services
- 2 To measure progress in the implementation of the National Clinical Guideline for Multiple Sclerosis
- 3 To compare performance against relevant parts of the National Service Framework for Long Term Conditions where possible
- 4 To develop further strategies to facilitate improvement of service delivery to people with multiple sclerosis in England & Wales
- 5 To increase awareness in the organisational level of the NHS of the NICE National Clinical Guideline for MS

³ Wade, Derick *NHS services for people with multiple sclerosis: a national survey. An audit of commissioning, provision, and experience of services used by people with multiple sclerosis in 2005–6, against recommendations from Nice Clinical Guideline 8* 2006: Royal College of Physicians and the Multiple Sclerosis Trust

Method

The audit was carried out by the the Clinical Evaluation and Effectiveness Unit of the Royal College of Physicians (London) in collaboration with the MS Trust. It covered England and Wales, and collected data concerning service provision from four different points of view to ensure that a comprehensive set of information was generated.

General outline

The audit used a 360° approach, collecting data from all four parties involved in the services:

- People with multiple sclerosis - service users
- Acute NHS hospital Trusts - service providers
- Primary Care Trusts (PCTs) and Local Health Boards (LHBs) - service commissioners
- Strategic Health Authorities (SHAs) and Regional Offices (ROs) - service performance managers

The audit collected data from service providers, service commissioners and organisations responsible for monitoring service provision that referred to the situation in January and February 2008 and their plans for the next 12 months. For people with multiple sclerosis the data related to experiences over the preceding 12 months (i.e. 2007).

The organisational data were collected from senior people within the various organisations. No direct or prospective data were collected; the data concerned service organisation and delivery rather than actual clinical practice with individual patients.

The population and services studied

Data were collected concerning NHS services delivered to the whole population of England and Wales. Scotland and Northern Ireland were not included as their health service arrangements are different, and because the NICE recommendations only applied to England and Wales. The audit did not include Social Services because NICE recommendations are specific to health organisations.

In all cases the data concerned delivery of NHS health services to people with multiple sclerosis. **Specifically the audit was not restricted to services designated as multiple sclerosis services.** People with multiple sclerosis frequently (and appropriately) use a wide variety of services and the NICE recommendations applied to all services; they did not specifically refer to designated multiple sclerosis services.

Collecting data from relevant organisations

Data on the monitoring of service commissioning (performance management) were collected from SHAs in England and ROs in Wales.

Data on service commissioning were collected from PCTs in England, and LHBs in Wales. In Wales the Health Commission Wales commissions designated specialist services and it stated that it considered multiple sclerosis services to fall within its remit. Consequently Health Commission Wales was also approached for data on service commissioning (but they did not provide any information).

Data of service provision were collected from Acute Trusts (i.e. hospitals) because it was assumed that the great majority of health service provision to people with multiple sclerosis for problems associated with their multiple sclerosis would be delivered by acute sector trusts and hospitals. Non-neurological specialist trusts, mental health trusts, ambulance trusts and learning disability trusts were not approached.

Within an organisation it was not easy to know who would both know the answers and have the time to respond. Therefore we approached a variety of people within each organisation (different organisations used different titles):

- Chief Executive
- Medical Director
- Lead for long-term conditions
- Managers for clinical governance, effectiveness or audit
- Public health directors
- Head of commissioning

In addition neurologists, MS specialist nurses and others were asked if they could identify and, if possible, contact named individuals working in their local organisations who might be able to help.

Standards

Seven standards were derived from the six key recommendations and one sentinel marker given in the National Clinical Guideline for Multiple Sclerosis⁴.

Organisations: data collection

Questionnaires were developed to collect audit data related to the standards. The questions collected data that measured the extent to which an organisation used the recommendations (see appendix 1) when considering services that were or should be used by people with MS.

In addition, for each organisation, some initial contextual information was gathered. This concerned who took responsibility for the questionnaire and the perceived involvement of the organisation within overall services for people with MS.

The questions developed and the answer options 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 extreme indicating specific use of the NICE guideline recommendation and the other indicating that nothing was done. In between we specifically included an option on using the National Service Framework for Long-Term Conditions (NSF LTC) because many organisations had used this to guide their work in 2005.

The following options were available, and we asked respondents to choose the most specific that was true for them:

- specifically for people with MS
- in line with the National Service Framework for Long Term Conditions
- for neurology as a whole
- at a broader level (i.e. within General Medical Services)*
- no
- not known

⁴ National Collaborating Centre for Chronic Conditions. *Multiple Sclerosis: National clinical guideline for diagnosis and management in primary and secondary care* (NICE Clinical Guideline 8) London: Royal College of Physicians, 2003 (www.rcplondon.ac.uk/pubs/books/MS/index.asp)

* The qualifier for the broader level option – "i.e. within General Medical services" – was offered to acute trusts only.

The questionnaires and other aspects of the audit (e.g. web-based data entry system) were piloted by various people (see acknowledgements), modified in the light of feedback and then used.

The questionnaire was placed on the website of the Royal College of Physicians. The person or people within an organisation were given the URL link to the system and a unique username and password, and could enter data at any time during the data collection period. For each question, the respondent could add additional explanatory information (or make any other comments). Organisations completed data entry between 4th February 2008 and 31st March 2008.

The final organisational audit questionnaires used are available on the audit website: <http://msaudit.rcplondon.ac.uk/>.

People with MS: sample selection and data collection

People with MS from England and Wales were recruited in several ways, aiming for a sample that included people from the whole geographic area, people diagnosed within the last 12 months, and a full range of disabilities.

Recruitment occurred in several ways. The audit was displayed prominently on the website of the MS Trust, and all supporters were notified via newsletter. MS Society branches and MS Therapy Centres were also notified, and notices were posted on all websites, fora and discussion groups known to be used by people with MS. Invitation cards were also 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 preferred option was to complete a form electronically on the internet. The RCP website hosted the questionnaire. Anyone could register online. Alternatively people could contact the MS Trust and ask for a paper form which was then entered by volunteers at the MS Trust.

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

- Have multiple sclerosis. The person with multiple sclerosis 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 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 fell into three major groups:

- 1) The first group focused on the seven recommendations from the NICE guideline. The questions asked about the person's experience as set against each recommendation.
- 2) The second group were contextual, giving information about the person 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 small group asked about satisfaction with NHS services.

In addition each person was 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: <http://msaudit.rcplondon.ac.uk/>

Data handling

All data were collected, directly or indirectly, using a custom-built web-based questionnaire straight into an initial data-base and they were then imported into SPSS version 15 and analysed. The primary analysis was descriptive.

As in the 2005/06 audit, there were a small number of organisations who registered and participated, but who stated that their role was undertaken by a neighbouring organisation on their behalf. In total 13 provider Trusts stated that 3 additional other Trusts provided their services for them. This was largely accounted for by one Neurological Centre, the Walton Centre in Liverpool. Twelve Trusts (three in Wales) stated that their services were provided by the Walton Centre.

For the two single Trusts stating that two other Trusts provided their service, we populated the forms of the secondary Trusts with data provided by the primary Trust (i.e. the data were replicated). This allowed us to acknowledge that services were provided.

However one particular Trust, the Walton Neurological Centre also accounted for twelve other Trusts. It seemed unreasonable to duplicate one set of data so many times and so we have presented data from the Walton Centre separately, with their consent. It should be noted that two of the 12 Trusts additionally completed questionnaires while stating that services were delivered by the Walton Centre. These data were **not** used.

Presentation of results

Data from people with multiple sclerosis are presented first so that the reader can set the organisational results in the context of reported experience.

Organisational data has been presented question by question, contrasting data from those responsible for monitoring, service commissioning and service provision. Each part is preceded by the key points identified. In the key points **the percentages given are specific to England**. In the tables relating to each question we have also contrasted the replies from England with the replies from Wales.

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.

RESULTS - SURVEY OF PEOPLE WITH MULTIPLE SCLEROSIS

Key messages:

- The data analysed came from 1300 people with MS (1220 in England, 80 in Wales)
- Data represents 2.5% of the whole population of people with MS

The web tool was accessed by 1631 persons. Of these 7 were excluded as they were not persons with MS and 260 people only gave registration information [31 of these had made occasional comments or given very sporadic answers to questions].

Of the remaining 1364 persons there were 38 who said they had not been in contact with the NHS about a problem related to their MS over the last 12 months. The other 1326 persons said they had been in contact with the NHS during this time but 19 of these gave no further information. Six responses were from people living in Scotland and one person's area of residence was unknown.

Therefore the detailed results that follow are for 1300 persons with multiple sclerosis, 1220 living in England and 80 in Wales.

Background about respondents

Key messages:

- The geographical spread of the sample of people with MS was reasonable
- The median age was 51 years at the time of survey. The median age at diagnosis was 39 years, suggesting a sample diagnosed at a slightly older age of onset than usual.
- The median duration of disease was 9 years, less than might be expected
- Two thirds (73%) were women, as would be expected
- One hundred and twenty three people (9%) had been diagnosed within the last 12 months, a higher proportion than expected (4%) reflecting the emphasis on obtaining information about the process of diagnosis
- Most people felt that MS had a major (48%) or moderate (37%) effect on their life with only 1% saying there was no effect; this level of impact would be expected given the requirement that the person should have used the NHS within the last year

Age of responders

The age of responders was known for 1290 (1213 England, 77 Wales).

England

The median age was 51 years, interquartile range 43 to 59 years, 80th centile range 36 to 65 years, range 18 to 88.

Wales

The median age was 53 years, interquartile range 43 to 62 years, range 28 to 81.

Age at diagnosis

The age at diagnosis with MS was known for 1284 (1208 England, 76 Wales).

England

The median age at diagnosis was 39 years, interquartile range 31 to 46 years, 80th centile range 26 to 53 years.

Wales

The median age at diagnosis was 41 years, interquartile range 21 to 49 years.

Duration with MS since diagnosis

Duration with MS since diagnosis was known for 1293 (1214 England, 79 Wales).

England

The median time since diagnosis was 9 years, interquartile range 4 to 17 years, 80th centile range 2 to 26 years.

Wales

The median time since diagnosis was 9 years, interquartile range 5 to 14 years.

Females comprised 73% (891) and males 27% (326) of the English responders (unknown for 3). The breakdown for Wales was 76% (61) and 24% (19) respectively.

General experience of services for problems related to MS

Key messages:

- 78% of people with multiple sclerosis thought that specialist neurological services were available but only 41% thought that they had access to specialist neurological rehabilitation services
- Most people (82%) had access to specialist MS nurses and 58% to specialist MS physiotherapists
- When asked about satisfaction with NHS services, 10% were not at all satisfied and 23% were very satisfied; when asked about dissatisfaction, 7% were very dissatisfied and 40% were not at all dissatisfied
- Rates of satisfaction and dissatisfaction were similar in England and Wales
- When asked how the NHS had helped with their self-defined greatest problem, 10% thought that the NHS had done well but 16% were very unsatisfied, agreeing that the NHS "had not really tried"

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."

Key messages:

- About three quarters of people with MS (73% England; 76% Wales) thought that they could be seen by a specialist neurologist if needed
- Only one third of people with MS (36% in England, 31% in Wales) thought that they could be seen by a specialist neurological rehabilitation service if needed
- Perceptions were similar in England and Wales

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)."

Key messages:

- Over half (60%) of all newly diagnosed patients were seen by a neurologist within 6 weeks, and nearly half had all tests completed within six weeks of first seeing a neurologist
- The median (IQR) time between initial referral and final diagnosis was 20 (7-39) weeks; this implies that half of all people took more than 20 weeks in total to achieve final diagnosis (against a NICE standard of 12 weeks)
- Just over half of people were given written information about the disease and were given information about **national** support organisations after diagnosis, and 60%-67% were given contact details about a specialist neurologist or specialist nurse
- Only 16% were given information on specialist therapists or an opportunity to attend an educational course and only 38% were given information about **local** support groups

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."

Key messages:

- 66% of people with MS reported that the sharing of information between health organisations made the transfer of care easy
- 59% of people felt that information sharing from Health to Social Services made transfer of care difficult

Key recommendation four: involvement in clinical decisions

"All services and service personnel within the health care 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."

Key messages:

- Half (54%) of people felt that they had been involved in clinical decision making as much as they wanted

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."

Key messages:

- 75% of people with MS thought that their initial assessment had been thorough, and the same proportion thought it had been carried out sensitively.

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.”

Key messages:

- 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

Sentinel marker: skin pressure ulcers

“The commissioning health organisation should require all health care 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.”

Key messages:

- 69 people (6%) developed a skin pressure ulcer over the year preceding this survey; only 37 were investigated by the NHS (as far as the person knew)

Optional information

Key messages:

- Fatigue was troublesome to 92% of respondents, and affected daily activities for 1-2 hours each day in 69%
- Walking difficulties were experienced by 86%; 75% used aids or support while walking
- Transferring from bed to chair was possible independently in 84%
- 24% used wheelchairs indoors
- 72% of people had some bladder problems, with 56% experiencing incontinence and 13% using a catheter
- 67% of people had problems with pain and 72% of these had daily pain and 59% took daily analgesia (successfully in 58%)
- The five top problems rated as the worst from the person’s point of view were limited mobility (321), fatigue (193), pain (99), bladder problems (49) and poor balance (45); 56% felt these were well or moderately helped by the NHS

RESULTS - SURVEY OF ORGANISATIONS

Key messages:

- In England 82% of Trusts, 84% of PCTs, and 60% of SHAs participated
- The proportions were lower in Wales

Participants in organisational audit with analysable data:

	SHA/RO	PCT / LHB	Trust
ENGLAND			
Approached	(n=10)	(n=150)	(n=148)*
Analysed	(n=6; 60%)	(n=126; 84%)	(n=122; 82%)*
WALES			
Approached	(n=3)	(n=22)	(n=9)*
Analysed	(n=1; 33%)	(n=14; 64%)	(n=5; 55%)*

* excludes 10 from England and 3 from Wales that are served by the Walton NHS Trust (including the Walton Centre for Neurology and Neurosurgery). The data returned from the Walton are described separately.

A significant minority of providers did not provide information. The reasons for not doing so are not known.

Four Strategic Health Authorities declined to participate; some stated that the subject matter of the audit was not within their remit; they did not acknowledge any role in monitoring the implementation of NICE guidance.

It is also apparent that a smaller proportion of organisations from Wales participated.

Managerial responsibility for services for people with MS

Key messages:

- Less than half of all organisations (17% - 44%) had someone specifically responsible for services for people with MS
- Nearly half (48%) of all provider Trusts did not have someone responsible for either MS services or the NSF

This question was asked to ascertain the level of interest the organisation had in MS specifically and in long-term neurological conditions in general. This would also 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.

Specialised clinical time contracted specifically for people with multiple sclerosis

Key messages:

- Contracted professional time devoted to people with MS within organisations is low
- Providers contract more specific time than other organisations

This question was asked to gain an insight into the priority organisations gave to services specifically for people with MS.

Process of performance monitoring/ commissioning services

Key messages:

- Services are rarely commissioned using any data that might determine need for services by people with MS (6%) or even by people with long-term neurological conditions (15%)
- Only a minority of commissioners plan to use formal needs assessments when commissioning next year (MS, 6%; LTC, 25%)
- Patients are rarely involved in commissioning decisions or planning services
- A significant proportion (30%-50%) of service commissioners also provide services directly to people with MS

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.

Although organisations that commission services should, in principle, be separate from those who provide services, **some commissioning organisations also ran relevant provider services.**

54% (68/126) of English PCTs and 29% (4/14) of Welsh LHBs had a unit or units providing services for people with multiple sclerosis, presumably in addition to other services provided by hospitals and acute Trusts. Four PCT provider units opted to complete the audit and their data are included, but there is no additional information on the remaining 68 PCT provider services.

Acute Trust services

Key messages:

- Only a minority (41%) of Trusts provided all necessary services from within their own organisation
- There are no specialist inpatient beds available to people with MS needing neurology or neurological rehabilitation in over half of all acute Trusts
- 20% of Trusts do not provide any in- or out-patient neurological rehabilitation services
- Specialist medical and nursing time for people with MS is contractually specified in 61% and 64% of Trusts respectively, with 45% specifying physiotherapy time
- The median actual amount of specialist time specifically contracted for people with MS is 8 hours per week (doctors); this equates to two planned activities

Service provision at the level of hospitals was very complex, with some Trusts providing all services from within their own resources and others using other providers, especially for specialist neurological rehabilitation.

Trusts had very few beds available for people with MS needing access to neurological or neurological rehabilitation services, the median being zero. For neurological rehabilitation the number of out-patient clinics was also very low (median = 0), but neurology out-patient clinics were more available.

Within hospitals there was a wide range of professions who have a part of their job specifically devoted to MS: occupational therapists, clinical (neuro)psychologists, orthoptists, dieticians, social workers, pain specialists, mental health nurses, continence nurses and counsellors. However the majority of contractually specified clinical commitment applies to doctors, nurses and physiotherapists.

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."

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

For specialist neurological services

Key messages:

- 48% of service providers do provide a specialist service for people with MS, 37% provide a service for neurological problems.
- Commissioning usually focuses on neurology (60%) not MS (14%)
- Organisations rarely monitor whether the quantity of service provision is adequate, and 60% of performance monitoring organisations do not even monitor the adequacy of neurology services in general
- 22% of Trusts in England have no plans to improve neurological services in the next year
- Commissioners rarely (9%) monitor the performance of neurology service providers in relation to people with multiple sclerosis

These questions were asked to establish whether the NICE guideline was being executed. 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'.

For specialist neurological rehabilitation services

Key messages:

- Only 31% of providers have neurological rehabilitation services that follow NICE or NSF-LTC standards
- A minority (23%) of commissioners commission specialist neurological rehabilitation services at the national standards (NICE/NSF)
- A small minority of Trusts (13%) and commissioners (4%) check that rehabilitation services are adequate for people with multiple sclerosis, and 80% of performance managers do not monitor adequacy of commissioning of neurological rehabilitation even at the level of neurology as a whole.
- Less than 20% of all organisations have any plans to improve rehabilitation service for people with multiple sclerosis in 2008-9 but 52% of commissioners and 36% of Trusts have some plans either to improve general neurological rehabilitation services or to be in line with the NSF
- 17% of commissioners monitor service provision against the NSF; monitoring of services at the level of people with MS is rare

The majority of the health care needed by people with multiple sclerosis 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; the needs cannot be met effectively by non-specialist rehabilitation services or by neurology services. These questions aimed to investigate the provision of this resource.

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)."

Key messages:

- Only 20% of Trusts and 8% of commissioners specifically consider the speed of finalizing a diagnosis of multiple sclerosis
- Planning for improvement is mainly at the level of neurology in general, in 49% of providers and 18% of commissioners
- In Wales one Trust is planning improvement but commissioners have no plans even for specialist neurological services
- Over 60% of service providers give guidance to GPs on referrals to neurology in general, but a minority (18%) give specific guidance on referrals of people with (suspected) multiple sclerosis

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 multiple sclerosis and the final confirmation of the diagnosis. NICE suggested that 12 weeks should be the maximum delay.

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."

Key messages:

- Protocols for transferring responsibility from service providers to other organisations were present in no more than 47% (between hospitals) at least to the level of neurology as a whole, and no more than 20% specifically for people with multiple sclerosis
- Commissioners had less interest in hospital transfers, and focused more on transfers between secondary and primary care (35% to at least the level of neurology); 67% of performance monitoring organisations were only concerned at a broader level
- 43% of Trusts and 52% of commissioners in England had plans to improve transfers between primary and secondary care to at least the level of neurology, with 38% of Trusts and 43% of commissioners making plans to the same level in relation to Social Services
- The majority of existing protocols and planned changes were general, and not specific to multiple sclerosis

Key recommendation four: a responsive service

"All services and service personnel within the health care 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."

Key messages:

- A minority of providers (36%) provided and a small minority of commissioners (9%) considered the whole range of services available for people with multiple sclerosis
- 50% of the performance monitoring organisations in England did not check on the range of service commissioning at all, at any level
- 34% of Trusts but only 5% of commissioners in England monitored the adequacy of services provided or commissioned
- 39% of providers had plans to reduce identified deficiencies in service provision for people with multiple sclerosis
- Only 8% of commissioners planned to commission to reduce identified deficits, and no strategic health authority had plans to monitor the adequacy of service commissioning for people with multiple sclerosis
- 83% of service providers required staff to involve patients in clinical decisions but 29% of commissioners and 33% of performance monitoring organisations did not ensure that this occurred, or did not know whether it did
- A minority of providers (31%) and a small minority (12%) of commissioners involved people with multiple sclerosis in the process of service development
- Only 50% of SHAs involved people with neurological disease in service planning

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.

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."

Key messages:

- No performance monitoring organisations monitored whether structured assessment protocols were commissioned at any level
- 23%-25% of commissioners and 25%-35% of service providers commissioned or used structured assessment protocols specifically for people with multiple sclerosis for personal activities of daily living, cognition and mood
- Few commissioners (11%) actually monitored whether service providers used structured protocols
- 19% of providers and 8% of commissioners had plans to increase the use of structured assessments for people with multiple sclerosis

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."

Key messages:

- 84% of Trusts and 60% of PCTs allowed self-referral back to specialist services at any level, although the proportions were lower specifically in relation to people with multiple sclerosis (63% and 31% respectively).
- Only 5% of providers (1/20) and 4% of commissioners (2/50) not currently allowing self-referral had plans to allow it next year.
- Performance monitoring bodies did not monitor commissioning for this at any level
- Only 12% of commissioners monitored the performance of service providers against this criterion

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.

42% of service providers and 13% of commissioners had plans to increase self-referral in the next year, only one of the 20 providers not allowing it now plans to change that situation and only two of 50 commissioners not allowing it now plan to change that situation.

Sentinel marker: pressure ulcers

"The commissioning health organisation should require all health care 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."

Key messages:

- The occurrence of skin pressure ulcers was rarely monitored at the level of people with MS (8%) and nearly half (48%) of all providers did not monitor the occurrence of skin pressure ulcers at all
- 34% of commissioners made no attempt to monitor the occurrence of skin pressure ulcers, and 84% of SHAs took no interest in skin pressure ulcers
- The level of monitoring of the **change in incidence rates** of skin pressure ulcers was equally low, with 30% of Trusts not responding to changes in incidence rates
- 55% of commissioners and 42% of providers had plans to improve detection and monitoring of skin pressure ulcers at any level; MS specific plans were rare

This sentinel marker was intended to pick up systematic failures in care, and was chosen 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.

DISCUSSION

The majority of service providers generally report that they use national documents such as the National Institute for Health and Clinical Excellence (NICE) clinical guideline and National Service Framework for Long Term (neurological) Conditions (NSF for LTC) to set service standards and policies. Commissioners are aware of such guidance, but they seem less likely to use disease specific guidance when commissioning services. The role of ensuring that adequate services are provided to the population as a whole is not held by anyone. The problems inherent in categorising services as specialist or non-specialist and as for people with MS or not complicates matters. The continuing failure to monitor skin pressure ulceration is extremely worrying, especially as 6% of the population surveyed had a **new** skin pressure ulcer in a twelve month period. However it is pleasing to note that people with MS seemed reasonably satisfied with the NHS services they received.

Methodology – what is "specialist"?

The first, large problem is one that extends across the NHS and is not restricted to this particular audit – what defines a 'specialist service', and how are such services commissioned and provided? Two approaches are possible.

One approach bases specialism on frequency; a disorder, condition, or procedure that is rare will (by this definition) require a specialist service. This is generally the approach used by the Department of Health in relation to specialist commissioning. However difficulties arise when conditions are part of a spectrum. For example specialist services for acquired brain injury are difficult to define because people may have a head injury of any severity, and there is no obvious or practical way to draw a line in the resulting continuum. How are the 'rare' patients to be separated from the remainder?

The alternative approach, which underlies the NICE guideline on MS, is to define specialism by the expertise and competence of the service; if a service has a particular expert skill and knowledge, then it is specialist in that area. Thus a specialist neurological rehabilitation service (for example) is one that undertakes rehabilitation of people with neurological diseases but not other disorders (such as orthopaedic disorders).

In this audit it seems likely that most providers considered specialist in relation to expertise, whereas Strategic Health Authorities considered it in relation to specialist services as defined by the Department of Health.

This issue needs urgent resolution, not simply from the point of view of this audit. A person with MS admitted to a District Hospital with a relapse or a worsening associated with a urinary tract infection, or some other condition arising from their MS wants and needs to be seen by a team that has expertise in MS and its management. Specialist services, as defined by the Department of Health, will rarely if ever be available to people with MS because the condition is too common. Yet non-specialist services (as defined by expertise) have great difficulty in providing appropriate clinical care.

In this audit, it is impossible to know how any particular service or person interpreted questions on specialist services.

Methodology – roles of organisations

Some organisations have several roles, and some roles are not 'owned' by anyone.

An effective service to a population requires someone to undertake 'performance management'; ensuring that the service provided by the NHS is of good quality and is sufficient to meet need. This role seemed to belong to Strategic Health Authorities (SHAs) and Regional Offices. Unfortunately four of ten SHAs did not respond but for those who did respond, the answers suggest that they do not consider that they have any specific role in

performance management of primary care trusts, or in ensuring that their population receives an appropriate quality and range of service. Primary Care Trusts (as service commissioners) did not seem to use any needs assessment when commissioning, and so did not take on this responsibility either.

Therefore it is not at all clear who within the NHS is responsible for ensuring that people with MS do have access to and receive high quality services, meaning services that cover the whole range of their (health) needs that have appropriate expertise and are available in sufficient quantity.

PCTs not only commission services but also provide primary health care services (general practices). In addition over half of PCTs also provided specialist secondary care services for people with MS. This was unexpected, and complicates interpretation of our results. Some secondary care providers may have been missed. Further, we did not collect data from the specialist services run by primary care trusts and so we do not have any data on their quality. It may also be difficult in future to make a direct comparison if we include this additional group of service providers (i.e. those run by PCTs).

Methodology – service organisation

Our third problem arises from the varied and disparate nature of service delivery, with organisations providing a proportion of health care services to a proportion of patients with varied formal or informal links with other organisations. For example a District Hospital might have a visiting neurology service provided by a Regional Centre, and patients might be admitted to the Regional Centre for investigation but to the District Hospital for most treatments. A third organisation, such as a community-based rehabilitation service run by a Primary Care Trust might provide specialist rehabilitation in a hospital or simply in the community.

This made it difficult for some hospitals to respond accurately and fairly.

It is perhaps best illustrated by the situation around the Walton Centre in Liverpool. The Walton Centre has both a specialist neurology and a specialist neurological rehabilitation service, and has formal arrangements with eleven surrounding hospitals to provide these services to neurology patients (including those with MS).

However it is improbable that every person with MS needing immediate support from a specialist service (e.g. if they have a relapse, or fall and injure themselves sufficient to require hospitalisation on account of their pre-existing disability) will be admitted to the Walton Centre, or seen by the Walton Centre teams within the first day or so. Consequently there is only data concerning the specialist neurological and neurological rehabilitation services provided by the Walton Centre directly and on an out-reach and advisory basis and there is no data on the services people with MS received when seen by other services within their local hospital.

Therefore data provided to this audit are difficult to interpret because they may apply to all services provided within the boundaries of an organisation albeit by people from other organisations, or simply to services provided by staff in the organisation within their own buildings, or to services provided in other settings.

The challenge is how to audit a diffuse network that has no formal existence (i.e. no management structure).

In summary, there are some **weaknesses** that arise from the way that services are labelled, and from the fact that in practice services work together in informal networks. Audit questions delivered to organisations fail to capture the complexity of actual service delivery, and both the local situation and local interpretation of the questions will have affected the answers given.

Strengths

These weaknesses are countered by several strengths. The major strength of this audit is the collection of data from all parties. In general the data are remarkably consistent which suggests the results are valid.

The audit was national, and the response rate was reasonable (with the exception of the Strategic Health Authorities). This will enable comparison in future, and makes the results resistant to the effects of ongoing organisational changes.

Third, the audit mechanism seems to have been well received, and allowed the collection of much qualitative data (i.e. the free text entries) which will add great detail to the results. Full analysis of the qualitative data will take time and will be published separately.

The sample of people with MS covered the spectrum of problems faced by people with MS who use NHS services. Thus, although it may not be statistically entirely representative it is sufficiently representative to allow conclusions to be drawn.

However the sample size both of people with MS and of organisations was not large enough to allow valid comparisons between different areas of England, and even the comparison between England and Wales is not likely to be methodologically valid given the low response rate from organisations in Wales. Moreover the large differences between the methods used in the initial 2005/6 audit and this audit do not allow any valid comparison over time.

Overall responsibility for service organisation and provision

Two features emerged concerning Strategic Health Authorities and Regional Offices. Their rate of participation was relatively low (six out of ten SHAs). Moreover the data from those who did participate suggest that SHAs do not feel any responsibility for monitoring the commissioning of or provision of clinical services for their population.

In practice it seems that SHAs are primarily concerned with the financial health and performance of the PCTs and Trusts within their area. They may have a role in commissioning designated specialist services, but clearly services for people with MS were not perceived as specialist. The data suggested that SHAs did not particularly commission neurology services either.

At the same time it seems that neither PCTs nor SHAs use any formal assessment of population need when considering services.

It must be acknowledged that independent epidemiological information germane to the provision of services for people with MS (and almost all other long-term neurological conditions) is almost completely absent. In addition existing NHS information systems are unfortunately unable to capture data relating to simple important questions such as the need for specialist pain relief services, or urological and continence services, or even the rate at which new wheelchairs are needed by people with MS.

There does not appear to be any mechanism whereby the totality of service commissioning and provision is monitored for its quality or quantity. Thus it is unclear how the NHS can be assured that it is meeting the needs of a population (such as people with MS) if:

- No-one is monitoring the services provided at a population level
- No-one is using an independent estimate of need to plan or purchase services

Therefore, in order to assure that people with MS might receive an appropriate level and range of services, **we recommend** that:

- Epidemiological research into the natural history of MS focused on impairments and activity limitations and service should be made a high priority
- The NHS reconsiders the design and capability of its information systems so that use of resources according to problems presented (and not exclusively disease diagnosis) can be recorded accurately
- The NHS encourages the development of funded, formal networks focused on long-term conditions so that there is a mechanism to collect and collate information about services in terms of their quality and quantity

Data sources and data quality

The response rate of over 80% from both PCTs and Trusts is high, especially given the demands made of them by other supervisory bodies. The characteristics of non-responders are not known. However the sample was large and seems to be representative. The information from PCTs and Trusts should be generally applicable.

Only 6/10 Strategic Health Authorities responded which makes this sample prone to bias and uncertainty. Generalisation from the information gathered is much less secure. Nonetheless it is unlikely that the remaining SHAs were better than those who did respond; the failure to respond suggests an even lower level of concern about monitoring the provision of services.

The data from organisations in Wales are especially difficult to interpret given the smaller number of organisations, the lower response rate, and the existence of a fourth level (Health Commission Wales, who did not provide data despite indicating that they were responsible for specialist commissioning).

The sample of people with MS was of a reasonable size (1300) and encompassed people with a wide variety of difficulties and having problems of different degrees of severity. In the absence of good epidemiological data on **prevalent** cases of MS, the sample should be considered reasonably representative of people with MS **who use NHS services**.

It was not always possible to determine whether a provider Trust would be expected to see people with MS. For example Mental Health Trusts were explicitly excluded on the grounds that they would rarely be responsible for managing any aspect of the health of people with MS. However some Mental Health Trusts made contact because they did offer specific psychological support and services to people with MS. Other Trusts were contacted who stated that they did not see anyone with MS; sometimes they actually meant that they did not have a neurology service, and they acknowledged offering physiotherapy etc.

It was also difficult to know who to contact when seeking information. There is no single role or post that is found in every organisation that would be expected to take responsibility for knowing about services. Although neurologists were the single biggest source of information from Trusts (69/126), there was a huge range of named posts in PCTs, with no title occurring more than four times (Commissioning Manager and MS Specialist Nurse).

Trusts also found it difficult to think in terms of providing services to people with MS. They usually seemed to operate within a model of 'specialist' named services. Thus they may have overlooked urological incontinence clinics and neuropathic pain clinics used by many people with multiple sclerosis, and this difficulty has also probably affected the data provided.

The data quality was high, in that the scope for transcription errors was removed by using a web-based submission process (some patient forms were transcribed, but over 80% were directly entered).

Thus there is ambiguity about how people interpreted, and responded to particular questions. It was and remains difficult to construct simple questions to tease out answers about very complex services. On the other hand, the use of four separate data sources allowed some cross-validation, and the information seems entirely consistent.

Key recommendation one: specialised services

It was notable that specialist neurological services were available to most people and in most areas. This is to be expected. Indeed it was surprising that there were areas where specialist neurology services were not commissioned (according to the responses) because every person with MS who is eligible should have access to a specialist neurology service to obtain disease modifying drugs (e.g. interferon beta).

In contrast neurological rehabilitation services were only available to about 40% of the MS population. This discrepancy between access to neurology and access to neurological rehabilitation was apparent in all answers (people with MS, Trusts, PCTs).

Thus we can draw **a strong and valid conclusion that neurological rehabilitation services are absent for the majority of the UK MS population.**

This is disturbing for two reasons:

1. For most people with multiple sclerosis it is the symptoms and disabilities that constitute the greatest lifetime problems. Yet this aspect of their healthcare is not provided for at all in many areas.
2. Second, there is good and increasing evidence that specialist neurological rehabilitation services and the treatments and therapies involved benefit people with MS. Thus they are being deprived of access to effective health care.

Key recommendation two: rapid diagnosis

The process of diagnosis seems to be reasonably rapid for about half of all people, but the time taken is not within the 12 weeks suggested by the guideline. Indeed many people had delays greater than 20 weeks. The recently introduced 18 week wait initiative may help speed up this process.

It was also reassuring that a majority of recently diagnosed people were given some information about national support organisations, and were given contact details about specialist nurses or doctors. Of more concern was the relatively infrequent provision of locally relevant information and support.

In conclusion there is scope for improving the process of diagnosis by increasing the provision of locally relevant information and support, but otherwise the process is already at least reasonable and likely to improve as waiting times are reduced in the whole NHS.

Key recommendation three: seamless service

The people with MS generally felt that transfer between health organisations was reasonable, but they were much less happy with transfers to Social Services. The reasons underlying this are not known.

Relevant written protocols were only present in about half of all Trusts, but many had plans to improve matters over the next year. In contrast commissioners had less interest in specifying or monitoring the existence and use of protocols aimed to improve transfer of clinical responsibility.

It is recommended that NHS organisations formally develop protocols for the transfer of care from and to their organisation with all other organisations both within and outside Health. This need is recognised in the NSF for LTC.

Key recommendation four: a responsive service

This recommendation is in essence requiring services to be patient-centred (as does the NSF for LTC). To be patient-centred there must be:

- an adequate amount of provision of each service to meet all need
- an adequate range of services to meet the many different needs of patients
- involvement of the person with MS in all clinical decisions to the extent that each person wishes

The difficulty in this audit was to know who was responsible for ensuring that there were adequate services across the range.

The results make it obvious that only a minority of Trusts provided a full range of services from within a single organisation.

At the same time, and more importantly, commissioners rarely specifically commissioned the whole range of specialist services needed.

Consequently in the great majority of places in England and Wales it is unlikely that a person with MS will be able to access, easily at least, all the specialist services they might need. In some places trusts consider that they do have the full range within their own organisation (even though commissioners have not explicitly commissioned them in that way), and so the actual situation may not be as poor as the data suggest.

More optimistically many service providers were making plans to improve matters, though few commissioners were.

The commitment of service providers to patient involvement was high, but there was less explicit commitment at the level of service commissioning. People with MS, however, only felt adequately involved in about half (54%) of all clinical decisions, which contrasts with the 83% of hospitals who stated that it was their policy to do this for neurological patients (but only 39% explicitly stated this intention in relation to people with MS).

The explicit involvement of people with MS in service planning and other management activities was also reasonable in service providers but low in commissioning organisations.

Key recommendation five: sensitive but thorough assessment

The only way to establish that assessments were thorough and sensitive was through asking about written policies or protocols, and only about 30% of service providers did this specifically for people with MS; commissioning organisations were unlikely to specify this detail in any contract.

Interestingly two thirds of people with MS thought that their assessment had been thorough and sensitive, suggesting that the existence of written documents is certainly not essential to ensure good clinical practice.

One may **conclude** that clinical practice is probably at a reasonable standard despite the lack of written protocols.

Key recommendation six: self referral

In the context of current NHS developments it was surprising that two-thirds of hospitals allowed self-referral by people with MS and many were planning an increase. Moreover commissioners were also supportive in about 30% of instances. People with MS equally felt able to self-refer back to neurology.

The situation was not the same when referring back to neurological rehabilitation (presumably because there was no such service available).

On the other hand, very few of the organisations not currently supporting self-referral had any plans to do so.

It is recommended that the organisation responsible for performance managing PCTs and service commissioning should encourage commissioners to commission providers to allow self referral, especially to neurological rehabilitation services once they have been commissioned.

Sentinel marker: skin pressure ulcers

The rate of skin pressure ulceration in our sample of people with MS was high – 6%. However this may follow from the low priority given to skin pressure ulcers by all NHS organisations. Only half of service providers monitored skin pressure ulceration in any way whatsoever, and one-third of PCTs did not monitor skin pressure ulceration at all.

NICE has stressed the importance of preventing and treating pressure ulcers in its Clinical Guideline 29. The estimated cost of treating skin pressure ulcers amounts to an estimated 4% of the NHS budget.

The NICE clinical guideline also stresses the importance of commitment within organisations and by management:

- There should be an integrated approach to the management of pressure ulcers with a clear strategy and policy supported by management.
- Care should be delivered in a context of continuous quality improvement where improvements to care following Guideline implementation are the subject of regular feedback and audit.

The low priority given to skin pressure ulceration by all organisations, and the high rate of skin pressure ulcers acquired over the preceding year by patients surveyed is of great concern.

This was the **sentinel marker** of service quality for people with multiple sclerosis put forward by NICE. On the basis of our results **one must conclude** that NHS services for people with multiple sclerosis are of a **poor quality**. The responsibility for this seems to be spread across all levels of NHS organisations – in England the SHAs, PCTs and the Trusts and in Wales the ROs, the LHBs, and the Trusts.

Main conclusions and recommendations

This audit has covered the whole of England and Wales, and has covered all NHS organisations that might be involved in the provision of healthcare to people with multiple sclerosis within the NHS. One important organisation was not involved – the Department of Health.

Various conclusions can be drawn from this audit:

1. The planning, development and management of services that can respond to the varied, complex and changing problems experienced by people with multiple sclerosis is seriously impeded by the lack of an organisation that has explicit responsibility and the necessary expertise to ensure that services with appropriate expertise are available to all people with MS when they need them. The lack of any organisation having overall responsibility also hinders the collection and collation of data that will allow a comprehensive audit of service quality and the evidence needed to improve services.

The audit suggests that in practice services do form informal networks that cover many aspects of care, but that these are not supported by a management structure, or

collection of information about the network's activities, or formal protocols concerned with transfers of care between organisations.

2. The NHS is not giving any priority to specialist rehabilitation services. Commissioners and providers have focused on specialist neurological services and have yet to concern themselves with rehabilitation. However the major problems faced by patients are mostly concerned with rehabilitation and very few patients identified neurological problems as being their major concern.
3. The term 'specialist service' is itself an additional source of confusion and difficulty. The reality is that a person with MS who has a problem that is associated with (caused by) their MS should be seen in a service that has expertise in MS, or has immediate access to such expertise. The majority of contacts with the NHS will be as a result of secondary problems, not problems that concern the diagnosis and treatment of the underlying disease process (multiple sclerosis). Nonetheless the person's multiple sclerosis is the major factor that has to be considered in management and the service needs expert knowledge of MS and expert skills in the management of people with MS.

The audit was made more difficult by the varying interpretations placed upon the terms 'services for people with MS' and 'specialist services'. Somehow service organisations must recognise that people with MS often have particular needs when they present with a clinical problem secondary to the MS.

4. Clinically the biggest concern is with skin pressure ulcers. A rate of 6% of people with MS having skin pressure ulceration is unacceptable. However the real concern is the general lack of interest by all organisations in the problem of skin pressure ulcers. They are not monitored or investigated, and there are few plans to improve matters.
5. Two other areas of clinical practice raise some concern, and they relate to treating the person with MS as an individual. Only half of all people with MS felt fully involved in clinical decisions about their care and it seems that newly diagnosed patients are not given information about **local** support available from voluntary organisations.

The main recommendations that follow from this audit are:	
<p>All NHS Organisations [unless they have no involvement at all with people with MS or services for them]</p>	<ul style="list-style-type: none"> ⇒ should have one specific person or role responsible for services for people with long-term neurological conditions including multiple sclerosis (MS) ⇒ should involve people with MS in setting standards, in service development and in commissioning ⇒ should have one specific person or role responsible for monitoring and reducing the rate of skin pressure ulceration
<p>Commissioning Organisations</p>	<ul style="list-style-type: none"> ⇒ should commission specialist neurological rehabilitation services to enable every person with MS to have ready and rapid access to these services
<p>Acute Trusts/ Provider Units</p>	<ul style="list-style-type: none"> ⇒ should ensure that any person with MS in their care for whatever reason has timely access to an expert neurology service and an expert neurological rehabilitation service ⇒ should ensure that health professionals engage people with multiple sclerosis fully in all clinical decisions ⇒ should give people with multiple sclerosis information about relevant local non-statutory services as well as national services
<p>Department of Health</p>	<ul style="list-style-type: none"> ⇒ should review the organisational framework of the NHS so that one organisation becomes responsible for ensuring that the population of people with MS 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