National Audit of Services for People with Multiple Sclerosis
Service provider (Trusts and Community Health Organisations) proformas

Please note: This document should be used for reference only and not for data collection. Data should be submitted using the web-based data collection tool (see Quick Start Guide). We will not accept data submitted in any other format, including paper-based proformas.

Guidance
This audit concerns the provision of services for people who have multiple sclerosis. It is based on two sets of standards:

- The NICE guideline on multiple sclerosis, using the six key recommendations and one sentinel marker of service quality
- The National Service Framework for Long Term Conditions, using seven of the eleven quality requirements that are particularly relevant to people with multiple sclerosis and are not covered by the NICE standards.

This questionnaire is addressed to your organisation in its role of providing healthcare services.

The questions cover:
- The person or people completing the survey
- Features of your organisation’s management in relation to services for people with multiple sclerosis
- Questions on the seven key recommendations from NICE; the specific guideline is shown before each set of questions
- Questions on the selected seven quality requirements from the NSF-LTC; the specific quality requirement is shown before each set of questions.

We recognise that providers:
- May not provide services specifically for people with multiple sclerosis, but we expect that most providers will nonetheless admit or manage people with multiple sclerosis in some way.
- May not need to be fully aware of the NICE guidance or the National Service Framework for Long-Term Conditions (NSF LTC).
- May encompass several separate services or organisations (e.g. two hospital sites, or a hospital and a community-based service)
- May host some services provided by other provider organisations within their Trust.
- May not always find it easy to answer the questions.

Therefore when answering each question:
- Please answer concerning the service provided within your overall organisation including all its component parts
Please answer for all services delivered within your premises, even if the service is actually provided by an outside provider. Please give the greatest level of specificity (see below) you use when treating a person with multiple sclerosis.

The general answer format will be in the following hierarchy, and we would like you to choose the most specific answer in relation to your commissioning:

- 5 Services specifically for people with MS
- 4 Services in line with NSF-LTC
- 3 Services for neurology as a whole (including neurological rehabilitation)
- 2 Generic services, at a broader level than neurology
- 1 No
- 0 Not known

Finally, at the end of the questionnaire, we have left a free-text box where you may:
- Add any additional information you want
- Provide feedback on the questionnaire (both content and clarity)

Your Trust/organisation.

We would like to know something about your Trust, and how much resource is specifically devoted to services for people with multiple sclerosis.

For each person involved in completing this questionnaire please give:
- Name
- Role/Job title
- Address
- Email
- Contact number

People

0.2 Does your Trust have anyone with managerial responsibility (i.e. within their job description or title) for services in the following areas. If so please indicate the number of WTE devoted to the area.

a. Multiple sclerosis
b. Specialist neurology
c. Specialist neurological rehabilitation
d. Long-term conditions NSF

0.3 Does your Trust have anyone employed to provide specialist clinical input (defined in job plan or description) devoted to services for people with multiple sclerosis. If so please indicate the number of WTE devoted to the area.

Information
0.4 Have you used a formal needs assessment (i.e. based on a set of data) for your population when providing services?

5 4 3 2 1 0

0.5 Have you plans to use a formal needs assessment based on a data-set when providing services next year?

5 4 3 2 1 0

0.6 Do you involve people with multiple sclerosis when designing or improving services?

5 4 3 2 1 0

0.7 Have you undertaken any audits of services for people with multiple sclerosis?

5 4 3 2 1 0

0.8 Have you produced any data-based reports on services for people with multiple sclerosis?

5 4 3 2 1 0

Service specification

0.9 Do your service specifications require any return of data on patient outcome:

5 4 3 2 1 0

0.10 Do your service specifications require any return of data on patient process (e.g. waiting time):

5 4 3 2 1 0

Services

0.12 Are you specifically commissioned to provide any of the following specialist services:

a. Spasticity management

5 4 3 2 1 0

b. Specialist equipment for disabled people (as defined in National Specialist Service definition set)

5 4 3 2 1 0

c. Vocational rehabilitation

5 4 3 2 1 0

d. Urological services / continence services

5 4 3 2 1 0

e. Clinical specialist case managers (nurses/therapist)

5 4 3 2 1 0

f. Disease Modifying Treatment clinics

5 4 3 2 1 0

Service provision

0.13 How do people attending your Trust with neurological problems receive specialist neurological services:

Totally from within Trust / Provider Unit provided services, in- and out-patients

Initially from within Trust / Provider Unit services, but also transferring patients to a tertiary centre

From a visiting neurology service, with at least daily attendance

From a visiting neurology service, at least weekly attendance
0.14 How do people attending your Trust with neurological problems receive **specialist neurological rehabilitation services**:
   - Totally from within Trust / Provider Unit provided services, in- and out-patients
   - Initially from within Trust / Provider Unit services, but also transferring patients to a tertiary centre
   - From a visiting neurology service, with at least daily attendance
   - From a visiting neurology service, at least weekly attendance
   - By referral to another service or centre

0.15 In your Trust, how many designated **specialist neurological**:
   a. in-patient beds are there?
   b. out-patient clinics are there each week

0.16 In your Trust, how many designated **specialist neurological rehabilitation**:
   a. in-patient beds are there?
   b. out-patient clinics are there each week

0.17 Within your Trust:
   a. How many separate major hospital sites are there?
   b. Do you provide a separate community-based service (defined in service specification or service name)
      Yes  No  Other

**NICE GUIDLINE STANDARDS**

**Key recommendation one:**
“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.”

1.1 For **specialist neurological services**:
Do you provide specialist neurological services?  

1.2 Do you monitor the adequacy of the specialist neurological services that you provide (e.g. against needs assessment, waiting lists etc)?

1.3 Do you have documented plans to improve the provision of specialist neurological services in the next year?

1.4 Do you document and report the performance of specialist neurological services?
For specialist neurological rehabilitation services:

1.5 Do you specifically provide specialist neurological rehabilitation services?  
5 4 3 2 1 0

1.6 Do you monitor the adequacy of the specialist neurological rehabilitation services that you provide (e.g. against needs assessment, waiting lists etc)?  
5 4 3 2 1 0

1.7 Do you have specific plans to improve the provision of specialist neurological rehabilitation services in the next year?  
5 4 3 2 1 0

1.8 Do you document and report the performance of provision of specialist neurological rehabilitation services?  
5 4 3 2 1 0

Key recommendation two:
“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).”

2.1 Do you specifically provide rapid access (patient to be seen within 6 weeks) of new referrals to specialist neurology services?  
5 4 3 2 1 0

2.2 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)  
5 4 3 2 1 0

2.3 Do you provide primary care teams with guidance on rapid referral of people to neurology services?  
5 4 3 2 1 0

Key recommendation three:
“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.”

3.1 Do you have co-ordinated care pathways across organisational boundaries between:
   a. Health and Social Services?  
      5 4 3 2 1 0
   b. Different secondary care Health Organisations?  
      5 4 3 2 1 0
   c. Primary/secondary health care?  
      5 4 3 2 1 0

3.2 Do you have documented plans to request or facilitate the development of care pathways across organisational boundaries over the next year between:
   a. Health and Social Services?  
      5 4 3 2 1 0
   b. Different secondary care Health Organisations?  
      5 4 3 2 1 0
   c. Primary/secondary health care?  
      5 4 3 2 1 0

Key recommendation four:
“All services and service personnel within 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.”

4.1 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)?

4.2 Do you monitor the adequacy (range and quantity) of services needed by people with MS?

4.3 Do you have documented plans in the next year to improve the range and/or availability of services (if deficiencies have been identified)?

4.4 Do you have written policies ensuring that clinical staff involve patients in clinical decisions?

4.5 Do you have formal mechanisms to involve people with MS in planned service developments?

Key recommendation five:

“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.”

5.1 Do you have policies for clinical staff to use structured assessment protocols to cover:
   a. Personal activities of daily living (ADL)?
   b. Cognitive functioning?
   c. Mood disturbance?

5.2 Do you audit the use of structured assessments?

5.3 Do you have documented plans for the next year to increase use of structured assessments by clinical staff?

Key recommendation six:

“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.”

6.1 Do you allow a patient to self-refer back to your specialist service?

6.2 Do you audit rate of patient self-referral?

6.3 Do you have documented plans in the next year to allow self-referral back to specialist services?
Key recommendation seven (sentinel marker):
“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”

7.1 Do you audit the incidence of skin pressure ulceration in your population? 5 4 3 2 1 0
7.2 Do you actively monitor and respond to changes in incidence of skin pressure ulcers? 5 4 3 2 1 0
7.3 Do you have documented plans for the next year to monitor and reduce the incidence of skin pressure ulcers? 5 4 3 2 1 0

NSF for LTC

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.”

8.1 Are you commissioned to provide case-management services to promote integrated management between health and social services for individual patients: 5 4 3 2 1 0
8.2 Are you commissioned to provide case-management services to promote effective self-management by individual patients: 5 4 3 2 1 0

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.”

8.3 Do you provide specialist neurological rehabilitation delivered by a complete multi-disciplinary team:

a. on an in-patient basis, 5 4 3 2 1 0
b. on an out-patient basis, 5 4 3 2 1 0
c. on an out-reach, domiciliary (delivered at home) basis, 5 4 3 2 1 0
d. to people in nursing homes or residential care? 5 4 3 2 1 0
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.”

8.4 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?

5 4 3 2 1 0

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

8.5 Do you assess for, provide, and train patients or others in the use of all equipment and adaptations needed by people with multiple sclerosis?

5 4 3 2 1 0

8.6 Do you monitor the functioning, the use and the safety of all equipment and adaptations provided to people with multiple sclerosis?

5 4 3 2 1 0

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.”

8.7 Are people with multiple sclerosis able to access and use any palliative care services your organisation provides (answer ‘0’ if not provided/ select ‘not known’ if not provided):

5 4 3 2 1 0

Quality requirement ten
“Carers of people with longterm 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.”

8.8 Can your services access or refer the unpaid carers of people with multiple sclerosis to a range of specific services including:

a. 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,

5 4 3 2 1 0

b. Multiple-sclerosis specific support for carers (i.e. information, and general emotional and practical support)?

5 4 3 2 1 0

8.9 Does the Social Services organisation covering your area organize 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,
Quality requirement eleven

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

8.10 Are there services within your organisation able to recognize 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 setting.