

Draft Clinical Standards ~ November 2008

# Neurological Health Services

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# **1 Introduction to neurological health services in Scotland**

## **Background**

Disorders of the nervous system are common. It is estimated that ten million people in the UK live with some form of neurological condition which has an impact on their lives. The most common physically disabling condition affecting young people, multiple sclerosis (MS), has a particularly high prevalence in Scotland compared with the rest of the UK<sup>1</sup>.

Neurological conditions account for one in five emergency hospital admissions, one in eight general practice consultations and a high proportion of disability, particularly severe and progressive disability, in the population<sup>2</sup>.

The scarcity of services for people presenting with neurological symptoms was presented to the Scottish Government Health Directorates (SGHD) and in response NHS Quality Improvement Scotland (NHS QIS) was given the task of undertaking a review of services.

## **Pre-scoping process**

NHS QIS set up a steering group in 2005 to review and scope the provision of neurological health services in the context of the strategic direction set out by the SGHD in Partnership for Care: Scotland's health white paper 2003<sup>3</sup>. The group reported in April 2006, and identified the need to undertake a stocktaking exercise to establish the nature and quantity of existing service provision. It also recommended the development of generic clinical standards for the provision of services for those affected by neurological conditions, to be based on the principles in the Department of Health's National Service Framework (NSF) for long-term conditions<sup>4</sup>.

## **Review of neurological health services**

The management consultancy Scott-Moncrieff was commissioned to carry out the stocktaking exercise and published their report in 2007. They found that services available to those with neurological conditions in Scotland vary significantly between NHS boards.

Specific findings of the report included:

- services for people with neurological conditions varied across Scotland
- NHS boards were unable to describe their neurological health services accurately
- NHS boards appeared to consider neurological health services a low priority
- NHS boards were experiencing recruitment difficulties for their neurological health services
- there were no waiting times targets for follow-up appointments
- there was a lack of communication among services provided for people with neurological conditions
- availability of inpatient beds was limited, particularly in services such as rehabilitation, palliative and respite care

- specialist nurses were considered a valuable resource, but their provision varied greatly across the boards, and
- the recent pilot of telemedicine neurological services in the north of Scotland was regarded as successful, by patients, consultants and nurses<sup>5</sup>.

### **Development of the draft clinical standards for neurological health services**

NHS QIS set up a standards project group, which met for the first time on 31 January 2008, to develop clinical standards for neurological health services. The project group was drawn from across Scotland and its membership aimed to reflect the multidisciplinary nature of the services required to manage neurological conditions.

Dr Richard Metcalfe was recruited as a clinical advisor to lead the work of the group. Dr Metcalfe is a consultant neurologist for NHS Greater Glasgow and Clyde, and is chair of the Scottish Neurosciences Council. Dr James Miller, Chief Executive of the Royal College of Physicians and Surgeons of Glasgow, was appointed as chair of the whole project. The project group membership is set out in Appendix 3.

### **Patient and public involvement**

The involvement of a range of stakeholders including voluntary sector organisations, patients, patient representatives, carers and the public has been of fundamental importance from the outset.

NHS QIS convened an advocacy group consisting of representatives of the Neurological Alliance of Scotland and other patient groups to ensure the standards have a patient focus. The membership of this group is set out in Appendix 3. This group met in advance of any detailed developmental work to ensure that its opinion was factored into the planning and management of the work.

Members of the advocacy group sat on the neurological health services standards project groups with an equal voice in the decision-making process. Patients and patient representatives were invited to sit on the project groups or to contribute to the development of the standards by any means that best suited them.

The role of patients and the public will be equally important during the national consultation of the draft standards.

### **Scope of the standards for neurological health services**

The project group made the decision to produce generic standards applicable to all neurological health services with the exclusion of paediatric neurological health services and services for people with acquired brain injury and stroke. Paediatric neurological health services were excluded as the services are provided separately from those provided for adults. Acquired brain injury and stroke services were excluded on the basis that they have already been the subject of specific standards setting and auditing arrangements and that they generally do not involve neurologists as major care providers<sup>6-10</sup>.

In addition to the generic standards, the project group developed condition-specific standards for five conditions which represent a high proportion of all neurological chronic conditions managed both in primary and secondary care.

These conditions are:

- epilepsy
- headache
- motor neurone disease
- multiple sclerosis, and
- Parkinson's disease.

The overall aim was to produce standards which deal with the whole patient journey and would result in an improvement in care for all those suffering from neurological conditions. In selecting these conditions for some specific standards, the project group wanted to emphasise the value of sub-specialty clinics and multidisciplinary working in chronic disease management. The project group recognised the potential for other patient groups to feel excluded but felt this could be addressed by ensuring the generic standards could be applied to services provided for all patients with neurological conditions.

It is intended that the standards will support rather than duplicate existing quality initiatives, for example national waiting times targets<sup>11</sup>.

### **Who do these standards apply to?**

The standards are applicable to all NHS territorial boards as well as the State Hospitals Board for Scotland and the National Waiting Times Centre. The standards apply to any care setting within an NHS board including primary, secondary and tertiary care.

The following special health boards will not be directly assessed against the standards but the development of the standards may have implications for them:

- NHS 24
- NHS Education for Scotland
- NHS Health Scotland
- NHS National Services Scotland (in particular Information Services Division)
- NHS Quality Improvement Scotland, and
- Scottish Ambulance Service.

The SGHD has an overarching responsibility to ensure that the work of NHS boards, particularly in developing national quality improvement measures, is co-ordinated.

### **National co-ordination of data collection and information provision**

From its inception, the neurological health services standards project group was concerned that, in the interests of patient equity, the sharing of good practice and avoidance of duplication of effort and resources, a national approach to data collection and provision of information should be adopted. It has emerged that, whilst a number of different NHS agencies have a contribution to make, no single

organisation has responsibility for co-ordination of these activities across NHSScotland.

The group feels strongly that this is a gap which must be filled in order to allow the embedded continuous quality improvement process which it sees as an essential component of neurological services in the future. Standard 1.1 makes reference to this need but because of the lack of existing structure, is addressed to NHSScotland as a whole. During the consultation period the neurological services standards project group, supported by NHS QIS, will be exploring with relevant stakeholders how this should be achieved.

### **Quality dimensions**

From the outset the project group was asked to consider the development of standards with reference to the six dimensions of healthcare quality listed in a 2001 Institute of Medicine report titled, Crossing the Quality Chasm<sup>12</sup>.

The six dimensions of quality are:-

- **Safe:** avoiding injuries to patients from the care that is intended to help them
- **Effective:** providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit
- **Patient-centred:** providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions
- **Timely:** reducing waits and sometimes harmful delays for both those who receive and those who give care
- **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy, and
- **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Each criterion within the standards was found to apply to at least one of the above quality dimensions.

### **Next steps**

The draft standards will go through a process of consultation with key stakeholders such as NHS staff, members of the public and patient organisations.

During the consultation period NHS QIS will continue to work with members of the project group and NHSScotland to develop plans for using the standards for the performance assessment of NHS boards. We intend to publish the final standards during summer 2009. We will also publish an implementation plan alongside the standards, which will detail how the standards will be implemented and how NHS QIS and other organisations within NHSScotland will provide support. This development reflects the new strategic direction of NHS QIS.

## 2 How to participate in the consultation process

NHS QIS will use several different methods of consultation during the development of the draft standards:

- wide circulation of the draft standards document to relevant professional groups, health service staff, voluntary organisations and individuals
- open meetings
- public consultation exercises involving distribution of comments forms and/or electronic questionnaires
- focus group discussions, and
- pilot review visits.

If you would like to know how you can participate in the consultation process, please contact:

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### Submitting your comments

Responses to the draft clinical standards for neurological health services should be submitted (by post, phone, fax or email) to the above contact details by **Friday 27 February 2009**.

### Consultation feedback

At the end of the consultation period all comments will be collated and the project group will respond to them. The responses to all comments will be available on request from Abigail Cork, Project Officer.

### **3 Vision for neurological health services in Scotland**

Our vision is that every patient in Scotland referred with a disorder of the nervous system experiences a quality of care which gives confidence to patient, referrer and provider. This will be achieved by ensuring that the individual:

- is assessed by the right person at the right time
- has timely access to investigations which promote care
- is encouraged to participate in decision-making on a partnership basis when desired, and
- has easy access to information and services which enhance the long-term management of their condition.

## **4 Draft clinical standards for neurological health services**

### **Generic standards for all neurological health services**

- Standard 1 General neurological health services provision
  - Standard 2 Access to all neurological health services
  - Standard 3 Patient encounters in all neurological health services
  - Standard 4 Management processes in all neurological health services
- 

### **Epilepsy services standards**

- Standard 5 Delivery of specialist epilepsy services
  - Standard 6 Diagnosis of epilepsy
  - Standard 7 Condition management of epilepsy
- 

### **Headache services standards**

- Standard 8 Delivery of specialist headache services
  - Standard 9 Diagnosis of headache
  - Standard 10 Condition management of headache
- 

### **Motor neurone disease services standards**

- Standard 11 Delivery of specialist motor neurone disease services
  - Standard 12 Diagnosis of motor neurone disease
  - Standard 13 Condition management of motor neurone disease
- 

### **Multiple sclerosis services standards**

- Standard 14 Delivery of specialist multiple sclerosis services
  - Standard 15 Diagnosis of multiple sclerosis
  - Standard 16 Condition management of multiple sclerosis
- 

### **Parkinson's disease services standards**

- Standard 17 Delivery of specialist Parkinson's disease services
  - Standard 18 Diagnosis of Parkinson's disease
  - Standard 19 Condition management of Parkinson's disease
-

## Standard 1: General neurological health services provision

### Standard statement 1

An effective and comprehensive neurological health service is available and offered across all NHS boards.

#### Rationale

The ability to describe and monitor existing services is an essential prerequisite to improvement. Data collection as part of the clinical process is a requirement for continuous quality improvement of services. Consistent methods of data collection across NHS boards will allow the assessment of neurological health services to ensure they are provided to a comparable level across NHSScotland. SGHD has the responsibility to ensure this consistency.

The provision of written and oral information and further contact points enhances understanding and patient care.

**References: 5, 13, 14, 15**

#### Essential criteria

1.1	NHSScotland ensures that there is a mechanism for the national co-ordination of information and data provision for neurological health services in Scotland.
1.2	The NHS board co-operates with other NHS boards and NHSScotland to develop and implement a common electronic database suitable for the collection of clinical and management data as part of the clinical process. The target implementation date for a system is October 2012.
1.3	The NHS board provides nationally consistent information to patients about their condition.
1.4	The NHS board works collaboratively with members of the Neurological Alliance of Scotland and specific patient groups to ensure that patients are made aware of the resources available through voluntary sector partners.
1.5	The NHS board defines and publishes its existing designated services for patients with neurological conditions.
1.6	The NHS board has a minimum 3-year plan for the provision of neurological health services to its population, and this plan is subject to annual review.

## Standard 2: Access to all neurological health services

### Standard statement 2

Patients with suspected neurological disorders are assessed by clinicians who specialise in neurological conditions. Patients are assessed within timescales dictated by their clinical needs.

#### Rationale

Evidence suggests that neurological conditions are most effectively dealt with by specialist clinicians.

Timely access to neurological health services is important in order to achieve good outcomes for patients with some neurological conditions. SGHD has established overall waiting times targets, but some patients will need to be seen within shorter timescales. Providing clear and efficient referral systems will enable NHS boards to achieve targets.

Access to neurological health services for patients in remote or rural areas is improved by access to telemedicine.

**References: 4, 5, 11, 16, 17, 18, 19, 20, 21**

#### Essential criteria

2.1	The NHS board demonstrates that 90% of outpatient demand for all neurological health services can be met within established resources without resorting to waiting times initiatives, reliance on temporary staffing or other short-term measures.
2.2	First referral patients are referred and triaged electronically. They are allocated to the appropriate waiting list within 5 working days of receipt of the referral at the centre in 95% of cases.
2.3a	The neurology service has a communication process for discussion of urgent outpatient cases with a neurologist.
2.3b	Where the neurologist identifies a case as urgent the patient is seen within 10 working days of triage in 90% of referrals.
2.4	Initial contact following a request for a neurological consultation for inpatients in non-neurological settings occurs within 24 hours in 90% of referrals.
2.5	Neurology units provide access to inpatient facilities for minimum 80% of cases within 48 hours of acceptance of referral.
2.6	Individuals affected by chronic neurological disease are provided with a contact point within the relevant neurology service to allow for re-entry into the service.
2.7	District general hospitals and regional neurology centres have on-site 24-hour access to telemedicine facilities.

## Standard 3: Patient encounters in all neurological health services

### Standard statement 3

Neurological health services provide a high quality of care, satisfying patients, referrers and providers.

#### Rationale

Patient satisfaction is fundamentally dependent on the quality of the consultation. Other factors such as a good physical environment, timeliness and provision of information are important to enhance the interaction between patient and clinician.

Patients and referring clinicians benefit from rapid, accurate and legible communications from the specialist services after outpatient visits and inpatient stays.

**References: 3, 4, 14, 22, 23**

#### Essential criteria

3.1	The professional development and maintenance of standards of all staff working within neurological health services is monitored by the NHS board.
3.2a	The NHS board implements a system to collect patient feedback on its neurological health services. The first data collection cycle is completed by 2010 and repeated annually thereafter.
3.2b	The NHS board implements a system to collect clinician feedback on its neurological health services. The first data collection cycle is completed by 2010 and repeated annually thereafter.
3.3	The NHS board delivers a minimum half-day directed training in communication for all staff who have direct contact with patients with neurological conditions. All staff receive the training every 3 years.
3.4	Patient waiting times in clinic are monitored and patients receive an explanation for the delay if they have to wait for more than 30 minutes beyond their appointment time.
3.5	Patients are provided with practical information in advance of their first appointment specific to the appointment and department.
3.6a	The outpatient service is conducted in a safe and comfortable environment for patients and is surveyed annually to ensure the quality is maintained.
3.6b	Facilities are available on neurological wards for private discussions between staff, patients, family and carers.
3.7a	New patient encounters are scheduled to allow a minimum of 30 minutes consultation time with a neurologist and 30 – 40 minutes for trainees.

3.7b	Return patient encounters are scheduled to allow a minimum of 15 minutes consultation time with a neurologist and 15 – 20 minutes for trainees.
3.7c	Clinicians have a facility to schedule additional time where a prolonged consultation is anticipated.
3.8	90% of outpatient letters are dispatched within 5 working days of the consultation.
3.9a	All inpatients are discharged with a printed immediate discharge summary.
3.9b	Discharge information is sent electronically to the GP in 95% of cases.
3.9c	90% of final discharge summaries are dispatched within 5 working days of discharge.

## Standard 4: Management processes in all neurological health services

### Standard statement 4

Neurological health services have an effective patient management process after the first encounter.

#### Rationale

Patients with neurological conditions benefit from the ready availability of a variety of different specialist investigation and management resources.

A third of all patients attending neurology outpatient departments have neurological symptoms unexplained by disease but can benefit from specialist management. In addition patients with neurological conditions are much more likely to develop psychiatric disorders than the general population. Failure to recognise and treat such co-morbid disorders is common and may seriously undermine the patient's neurological management and worsen their prognosis.

Community health partnerships (CHPs) have a role in integrating primary care and specialist services with social care. This role will support services to provide consistent care throughout a patient's journey and discharge from neurological health services.

**References:** 5, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44

#### Essential criteria

4.1	At the conclusion of the first consultation, all patients are provided with a typed written plan which details working diagnosis, immediate treatment recommendations, further investigation and management arrangements.
4.2a	70% of neuro-imaging requests by neurologists are reported by a neuroradiologist.
4.2b	70% of neurophysiology requests by neurologists are reported by a neurophysiologist.
4.3	Referring units accept 80% of patients back from the neurological unit at the conclusion of the care episode within 2 working days of transfer request.
4.4a	The neurology service has access to an integrated team providing a diagnostic and treatment service for patients with neurological symptoms unexplained by disease, and patients with defined neurological disease that have co-morbid psychiatric disorders.
4.4b	80% of patients referred to this diagnostic and treatment service from inpatient consultations will have initial contact within 24 hours, or within 4 weeks if referred from outpatient consultations.

4.5	Initial contact following a request for a neurological consultation for inpatients in non-neurological settings occurs within 24 hours in 90% of referrals.
4.6	Palliative care is provided for patients with neurological conditions and their family and carers, when clinically dictated, and in accordance with the wishes of the patient.
4.7	Each regional neurology centre has identified contacts with the individual responsible for neurological conditions in the local CHPs to facilitate management in the community.

## Standard 5: Delivery of specialist epilepsy services

### Standard statement 5

Good quality epilepsy care is delivered and managed by a network of specialists in the condition.

#### Rationale

Patients with epilepsy receive good quality care when treatment and therapy is provided by well-educated and well-trained health professionals.

Managed clinical networks (MCNs) should be implemented to drive the continuous improvement of care in line with SGHD policy. The delivery of services through managed clinical networks ensures care is delivered and managed in a co-ordinated way by experienced specialist staff.

**References: 45, 46**

#### Essential criteria

5.1	The NHS board ensures that staff who work within epilepsy services have specialist skills and training.
5.2	Services for epilepsy are part of a managed clinical network.
5.3	Practice nurses who carry out primary care annual reviews for patients with epilepsy have attended an epilepsy training course in the past 5 years, or can demonstrate equivalent experience from continuing professional development (CPD).

## Standard 6: Diagnosis of epilepsy

### Standard statement 6

The diagnosis of epilepsy is confirmed in a dedicated first seizure clinic.

#### Rationale

The diagnosis of epilepsy is more accurate when made by a doctor who specialises in epilepsy, resulting in better patient outcomes. Post diagnosis care and support for patients is best provided by epilepsy specialist nurses.

**References: 47, 48**

#### Essential criteria

6.1	The diagnosis of epilepsy is confirmed by a doctor who specialises in epilepsy.
6.2	Patients with a new diagnosis of epilepsy have an appointment with an epilepsy specialist nurse within 6 weeks of the initial assessment.
6.3	Patients with epilepsy seen at a first seizure clinic are given an epilepsy specialist nurse's contact details at time of the diagnosis.
6.4	Patients who drive who are referred for possible new onset epilepsy are provided with driving advice by the referring doctor.
6.5	Patients referred for possible new onset epilepsy are requested to bring an eyewitness to first seizure appointment. This request is noted in the referral letter.

## Standard 7: Condition management of epilepsy

### Standard statement 7

Patients with epilepsy will continue to receive the correct medication and dosage while staying in hospital.

#### Rationale

The care of patients with epilepsy is improved by ensuring that the correct medication continues to be received at the right dosage whilst in hospital for any reason.

All health professionals who have contact with patients with epilepsy should be able to manage seizures and have clear lines of support for further assistance.

Surgery is an option for patients who have drug-resistant epilepsy and all patients who could benefit from this should have access to assessment.

**References: 47, 48**

#### Essential criteria

7.1	Patients with epilepsy in NHS hospital care because of co-morbidity receive uninterrupted and correct anticonvulsants.
7.2	All neurology departments in the NHS board have guidelines for the review of patients with epilepsy who have drug-resistant seizures.
7.3	All medical, nursing and allied health professional (AHP) staff who care for patients with epilepsy are made aware of the procedure to be followed in the event of a seizure and of the first aid management required.
7.4	Patients with drug-resistant epilepsy are referred for specialised assessment for suitability for surgical treatment.

## Standard 8: Delivery of specialist headache services

### Standard statement 8

An effective and comprehensive specialist headache service is available across all NHSScotland boards.

#### Rationale

Headache is a complex condition and can be difficult to diagnose and manage effectively. SGHD is increasingly encouraging specialist services to deliver care to their patients by following a multidisciplinary approach which ensures that patients can receive co-ordinated care from healthcare professionals with expertise in the diagnosis, management and follow-up of patients with headache. Doctors in the specialist headache service must be able to demonstrate the following core competencies:

- the ability to conduct a full medical examination and headache history and appropriate neurological examination
- knowledge of appropriate guidelines such as SIGN Guideline 107: Diagnosis and management of headache in adults, and the British Association for the Study of Headache Guidelines for all doctors in the diagnosis and management of migraine and tension-type headache
- an understanding of the psychosocial aspects of headache
- an understanding of the natural history of headache
- a sound knowledge of the pharmacological treatments for headache, their uses, side effects, drug interactions and contraindications
- an understanding of co-morbid factors influencing effective headache management, for example, psychiatric illnesses
- an understanding of the use of, and appropriate referral to appropriate specialist investigations, and understanding the interpretation of results of such investigations
- an understanding of the role of patient support organisations, and
- the ability to understand the impact of headache on family, friends and work colleagues of the patient.

To maintain the level of expertise, headache must remain a significant part of the doctor's clinical workload (equivalent to at least two sessions a month). Evidence for the above competencies includes the completion of nationally recognised qualifications or training including at least 30 sessions within a headache service.

Patients with headache are generally seen initially by doctors in primary or secondary care without a special interest in headache. It is important that a headache education programme delivered by members of the multidisciplinary team is available to all clinical staff to ensure that patients receive a high standard of care in any care setting. An educational programme should cover the following as a minimum:

- the diagnosis of migraine
- medication overuse headache
- sinister causes of headache, and
- services available locally for the diagnosis and treatment of headache.

**References: 5, 49, 50, 51, 52**

<b>Essential criteria</b>	
8.1	The NHS board provides access to a co-ordinated non-acute headache service led by a doctor who specialises in headache, as part of the general neurology service.
8.2a	The NHS board provides an educational programme on acute and non-acute headache for primary and secondary care colleagues within the NHS board.
8.2b	The educational programme provided by the NHS board is promoted to health professionals in the NHS board area.
8.2c	The educational programme on headache is compulsory for all specialist trainee doctors in the NHS board undergoing early stage training in acute medicine.
8.3	The headache service sets minimum information requirements for referral into the service.
<b>Desirable criterion</b>	
8.4	The headache service provided includes a consultant neurologist, a GP with a special interest in headache and a clinical nurse specialist.

## Standard 9: Diagnosis of headache

### Standard statement 9

Patients with headache have timely and ready access to any necessary investigation resources.

#### Rationale

Most headache is primary – a headache that is not associated with an underlying physical cause. Some patients will need to be investigated either for reassurance or because a suspected underlying cause is possible due to particular symptoms and signs (named 'red flags'), for example in suspected subarachnoid haemorrhage (SAH), suspected meningitis or suspected brain tumour.

The analysis of a headache diary used by a patient to record their headache symptoms in the weeks before the appointment can improve diagnosis.

**References: 53, 54, 55, 56, 57, 58, 59, 60, 61, 62**

#### Essential criteria

9.1	All patients referred to the headache service are sent a headache diary with their appointment information.
9.2	GPs have direct access to computerised tomography (CT) scanning for headache when they decide it is clinically indicated.
9.3	Neurological investigations for patients referred to the headache service are carried out in line with the recommendations for investigation types and timescales in SIGN Guideline 107: Diagnosis and management of headache in adults.
9.4	Neurological investigations for acute headache are carried out in line with recommendations in SIGN Guideline 107: Diagnosis and management of headache in adults.

## Standard 10: Condition management of headache

### Standard statement 10

Patients with headache have ongoing access to specialist headache services appropriate to their needs.

#### Rationale

Headache is a common condition which can be significantly disabling. There are many effective treatments and NHS boards should ensure that patients have access to appropriate therapies.

**Reference: 53**

#### Essential criteria

10.1	The NHS board's drug formulary includes all headache medications recommended in SIGN Guideline 107: Diagnosis and management of headache in adults.
10.2	The headache service has sufficient capacity to follow up patients with chronic headache.

#### Desirable criterion

10.3	The headache service has access to a psychologist and a physiotherapist with experience in pain management.
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## Standard 11: Delivery of specialist motor neurone disease services

### Standard statement 11

An effective and comprehensive motor neurone disease service is available and offered across all NHSScotland boards.

#### Rationale

Patients with motor neurone disease receive better quality care when diagnosis, treatment and therapy are delivered within a specialist multidisciplinary team in their local NHS board.

**References: 63, 64**

#### Essential criteria

11.1	Patients with suspected motor neurone disease are referred to a defined motor neurone disease service.
11.2	The multidisciplinary team consists of, as a minimum: a doctor who specialises in motor neurone disease, a motor neurone disease regional care specialist, a physiotherapist, an occupational therapist (OT), a speech and language therapist, a dietitian, and a palliative care physician.

## Standard 12: Diagnosis of motor neurone disease

### Standard statement 12

Patients with suspected motor neurone disease have their diagnosis confirmed by a doctor who specialises in motor neurone disease, with access to appropriate investigation resources.

#### Rationale

Timely and easy access to any necessary investigation resources is essential to promote an efficient and effective diagnostic process for patients with suspected motor neurone disease.

**References: 5, 63, 64**

#### Essential criteria

12.1	On request from a doctor who specialises in motor neurone disease, patients with suspected motor neurone disease have access to relevant investigation resources including imaging and physiology.
12.2	The diagnosis of motor neurone disease is confirmed by a doctor who specialises in motor neurone disease.
12.3a	Once diagnosis is confirmed, the motor neurone disease regional care specialist makes contact with the patient within 2 working days of this confirmation.
12.3b	Within 10 working days of confirmed diagnosis, patients with motor neurone disease are assigned a key worker to manage the provision of services in both the NHS and social care settings to ensure necessary support is available.
12.3c	Once the diagnosis is confirmed, patients with motor neurone disease and their carers are offered contact details for specialist support services provided by voluntary sector organisations.

## Standard 13: Condition management of motor neurone disease

### Standard statement 13

Patients with motor neurone disease and their carers are offered a wide range of support at all stages of their condition.

#### Rationale

Motor neurone disease is a degenerative condition which can often be rapidly progressive. Patients with motor neurone disease have complex needs which can affect all aspects of their lives.

Maintaining the patient's ability to communicate is essential and every effort should be made to ensure patients' independence during the course of the disease.

Communication within the motor neurone disease services, throughout all stages of the condition, is central to delivering a better quality of life for the patient with motor neurone disease and their carers.

**References: 63, 64**

#### Essential criteria

13.1a	A nutritional assessment is available for patients with motor neurone disease at all stages of their condition.
13.1b	A respiratory assessment is available for patients with motor neurone disease at all stages of their condition.
13.2	A needs assessment is offered to those caring for people with motor neurone disease at all stages of the patient's condition. The assessment is updated as the disease progresses.
13.3	Onward referrals across the motor neurone disease services are dealt with flexibility and speed.

## Standard 14: Delivery of specialist multiple sclerosis services

### Standard statement 14

An effective and comprehensive specialist multiple sclerosis (MS) service is available across all NHSScotland boards.

#### Rationale

MS is a complex condition and can be difficult to diagnose and manage effectively. SGHD is increasingly encouraging specialist services to deliver care to their patients following a multidisciplinary approach which ensures that patients can receive co-ordinated care from healthcare professionals who specialise in the diagnosis, management and follow-up of patients with MS.

**References: 5, 65, 66, 67, 68**

#### Essential criteria

14.1a	The NHS board provides patients with MS with access to a specialist MS multidisciplinary team.
14.1b	The MS multidisciplinary team consists of, as a minimum: a consultant who specialises in the diagnosis and management of MS, an MS clinical nurse specialist, physiotherapist, occupational therapist, speech and language therapist, dietitian, and rehabilitation services.
14.2a	A structured patient and family education programme is offered to newly diagnosed patients at diagnosis.
14.2b	A structured patient and family education programme is offered to all patients with MS.
14.3	A structured education programme is offered to all health professionals who have contact with patients with MS.

## Standard 15: Diagnosis of multiple sclerosis

### Standard statement 15

The NHS board provides a co-ordinated MS diagnosis service with access to a multidisciplinary team experienced in the diagnosis of MS.

#### Rationale

Timely and ready access to any necessary investigation resources is essential to promote a more efficient and effective diagnostic process for patients with suspected MS.

**References: 5, 65, 66, 67, 68**

#### Essential criteria

15.1	Patients presenting with symptoms suggestive of central nervous system demyelination are investigated and the results explained to them within 12 weeks of the initial presentation.
15.2	Contact with an MS clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 2 weeks of the diagnosis.
15.3	A follow-up is offered to patients who have been diagnosed with an MS clinically isolated syndrome.

#### Desirable criterion

15.4	The NHS board has access to a diagnostic centre for patients with suspected MS.
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## Standard 16: Condition management of multiple sclerosis

### Standard statement 16

Patients with MS have ongoing access to MS specialist services appropriate to their needs.

#### Rationale

MS services should be delivered by specialist staff who are better able to identify symptoms that may indicate a relapse or a symptom unrelated to an individual's MS. MS patients may also have complex needs that require local access to a wide range of services delivered in accessible locations.

Patients with MS benefit from access to services for the management of:

- tremor
- spasticity
- fatigue
- continence
- cognitive issues
- chronic pain
- diet
- speech and language
- psychological issues, and
- sexual dysfunction.

**References: 65, 66, 67, 68**

#### Essential criteria

16.1a	Patients with MS have access to a review by an MS specialist service at least every 12 months.
16.1b	Patients with MS are given contact details for the MS service and have the opportunity to self-refer.
16.2a	Patients with MS with suspected relapse have access to a relapse assessment clinic supported by an MS multidisciplinary team within 1 week of contact.
16.2b	Following the initial relapse assessment, a review is carried out by a member of the MS multidisciplinary team.
16.3a	All patients with MS who meet the existing guidelines are offered specialised disease modifying drug therapies for MS.
16.3b	All patients with MS have access to symptom management therapies.
16.3c	All patients with MS have access to equipment for assisting with daily living where that equipment can be provided by NHSScotland, and directed to social services for other equipment provision.

16.4	People affected by MS have ongoing access to self-management options.
16.5	Patients with advanced or complex needs have access to assessment in their place of residence by a member of the MS multidisciplinary team where they are unable to access services at hospitals or clinics.

## Standard 17: Delivery of specialist Parkinson's disease services

### Standard statement 17

An effective and comprehensive Parkinson's disease service is available and offered across all NHSScotland boards.

#### Rationale

Patients with Parkinson's disease and related conditions receive better quality care when diagnosis and treatment are delivered within a multidisciplinary team in their local NHS board.

An effective Parkinson's disease service also offers their specialist services to patients with conditions related to Parkinson's disease, such as progressive supranuclear palsy (PSP) and multiple system atrophy (MSA).

**References: 5, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80**

#### Essential criteria

17.1	Patients with suspected Parkinson's disease and related conditions are referred to a defined Parkinson's service delivered through a multidisciplinary team.
17.2	The Parkinson's disease multidisciplinary team consists of, as a minimum: a doctor who specialises in Parkinson's disease, a Parkinson's disease nurse specialist, a physiotherapist, an occupational therapist, a speech and language therapist, a dietitian and a pharmacist.

## Standard 18: Diagnosis of Parkinson's disease

### Standard statement 18

Patients with suspected Parkinson's disease have their diagnosis confirmed by a doctor who specialises in Parkinson's disease.

#### Rationale

The diagnosis of Parkinson's disease is more reliably made by specialists who have a significant portion of their workload dedicated to patients with Parkinson's disease and related conditions.

Patients with Parkinson's disease need access to support from all the professions within the multidisciplinary team throughout the course of their condition.

**References: 5, 69, 70, 80, 81, 82**

#### Essential criteria

18.1	The diagnosis of Parkinson's disease is confirmed by a doctor who specialises in Parkinson's disease.
18.2a	At diagnosis, patients with Parkinson's disease are provided with access to a Parkinson's disease nurse specialist.
18.2b	At diagnosis, patients with Parkinson's disease are provided with local access to allied health professionals.
18.3	The diagnosis of Parkinson's disease is reviewed and reconsidered if atypical clinical features develop.

## Standard 19: Condition management of Parkinson's disease

### Standard statement 19

Patients with Parkinson's disease have ongoing access to specialist Parkinson's disease services and are encouraged to be involved in decision-making when any treatment or therapy is being administered.

#### Rationale

Patients with Parkinson's disease need to have support from their Parkinson's disease MDT at every stage of their condition.

Effective management of medicines is essential to the treatment of Parkinson's disease. Failure to take the correct dosage of medication at the time needed can have significant consequences for the patient, which may take time and resources to resolve. Patients with Parkinson's disease have an important role to play in this task and should be encouraged to manage their own medication where they are willing and able to do so. This remains true wherever the patient is receiving care – in their own home, in hospital, or in a care home.

**References: 69, 70, 81, 82, 83, 84**

#### Essential criteria

19.1	The timing and dosage of medication for Parkinson's disease is specified and adhered to when the patient is in hospital.
19.2	Inpatients with Parkinson's disease are given the opportunity to manage their anti-Parkinson's disease medication intake, unless they are unable to do so.
19.3	Reconciliation of the record of medicines and dosages is undertaken at each patient visit to ensure that the patient, GP, consultant and Parkinson's disease nurse specialist determine accurately what anti-Parkinson's disease drugs the patient is taking.
19.4	Patients with Parkinson's disease have their condition and medication reviewed regularly in a timescale dictated by their clinical need. This is typically every 6 months (but has a usual range of 3 to 12 months) and as a minimum scheduled to take place every 12 months.
19.5	The Parkinson's disease service assesses patients with Parkinson's disease and related conditions for referral to specialised neurosurgical services.
19.6	Patients with Parkinson's disease and their carers are offered guidance and support throughout the course of the patient's condition.

## **5 Appendices**

**Appendix 1 About NHS Quality Improvement Scotland**

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**Appendix 2 Development of NHS Quality Improvement Scotland standards**

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**Appendix 3 Membership of the draft clinical standards for neurological health services project groups**

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**Appendix 4 Evidence base**

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**Appendix 5 Glossary**

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## Appendix 1: About NHS Quality Improvement Scotland

NHS QIS' vision is of an NHS that achieves excellence in the care of every patient every time. We lead on the use of knowledge to promote improvement in the quality of healthcare for the people of Scotland and perform three key functions:

- providing advice and guidance on effective clinical practice, including setting standards
- driving and supporting implementation of improvements in quality, and
- assessing the performance of the NHS, reporting and publishing the findings.

Within this remit we also have central responsibility for patient safety and clinical governance across NHSScotland.

NHS QIS has four corporate objectives:

- **improving quality** – to lead advances in the quality of care in NHSScotland based on a continually refreshed framework for quality improvement.
- **making an impact** – to make a demonstrable impact on the quality and safety of patient care and treatment.
- **sharing the knowledge** – to contribute to the advancement of knowledge and understanding on quality improvement.
- **working effectively** – to ensure NHS QIS delivers its functions effectively and efficiently.

Further information about NHS QIS is available at [www.nhshealthquality.org](http://www.nhshealthquality.org) or directly by using the contact information given on page 7 of these draft standards.

## Appendix 2: Development of NHS Quality Improvement Scotland standards

### Basic principles

A major part of the remit of NHS QIS is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, NHS QIS sets standards for clinical services, assesses performance throughout NHS Scotland against these standards, and publishes the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service.

In fulfilling its responsibility to develop and run a system of quality assurance, NHS QIS takes account of the principles set out in Fair for All and Partnership for Care, to ensure that 'our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives'. Therefore NHS QIS endeavours to ensure that consideration of equality and diversity issues feature prominently in the design, development and delivery of all its functions and policies.

NHS QIS standards are developed in accordance with the commitments of the National Health Service Reform (Scotland) Act (2004) which state that 'individual patients receive the service they need in the way most appropriate to their personal circumstances and all policy and service developments are shown not to disadvantage any of the people they serve'.

### Format of NHS QIS standards and definition of terminology

NHS QIS standards are designed to be clear and measurable, based on appropriate evidence, and written to take into account other recognised standards and clinical guidelines. All NHS QIS standards follow the same format.

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the **standard statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is expanded in the section headed **criteria**, which states exactly what must be achieved for the standard to be reached. Some criteria are **essential**, in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable** in that they are being met in some parts of the service, and demonstrate levels of quality, which other providers of a similar service should strive to achieve. The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

### Clinical governance and risk management standards

Every individual using healthcare services should expect these to be safe and effective. There are existing NHS QIS standards for clinical governance and risk management to ensure NHS boards can provide assurance that clinical governance and risk management arrangements are in place, and that they are supporting the delivery of safe, effective, patient-focused care and services. The clinical governance

and risk management standards underpin all care and services delivered by NHSScotland and provide the context within which NHS QIS service and condition-specific standards apply. They should be read in conjunction with these neurological health services standards. The clinical governance and risk management standards are available on request from NHS QIS or can be downloaded from the website ([www.nhshealthquality.org](http://www.nhshealthquality.org)).

### **Assessment of performance against the standards**

We are currently looking at developing our methods of performance assessment for the neurological health services standards. We intend to assess the standards in an innovative way that is both non-burdensome and meaningful for the NHS boards. We will do further work on this during the consultation period but would welcome any comments or views. Please send your comments using the contact details provided on page 7 of this document.

### Appendix 3: Membership of the draft clinical standards for neurological health services project groups

#### Generic neurological health services project group

<b>Name</b>	<b>Title</b>	<b>NHS board area/organisation</b>
Dr James Miller (Chair for whole project)	Chief Executive	Royal College of Physicians and Surgeons of Glasgow
Dr Richard Metcalfe	Clinical Advisor	NHS Quality Improvement Scotland
Ms Alex Bowerman	Health Delivery Directorate	Scottish Government Health Directorates
Dr Adam Burnel	Consultant in Liaison Psychiatry	NHS Greater Glasgow and Clyde
Dr Anne Coker	General Practitioner	NHS Tayside
Dr Rod Duncan	Consultant Neurologist	NHS Greater Glasgow and Clyde
Mr John Eden	Service Development Manager	Scottish Huntington's Association
Dr Alan Forster	Consultant Clinical Neurophysiologist	NHS Grampian
Dr Donald Grosset	Consultant Neurologist	NHS Greater Glasgow and Clyde
Professor Donald Hadley	Neuroradiologist	NHS Greater Glasgow and Clyde
Ms Margaret Mooney	Neurology Team Leader	NHS Greater Glasgow and Clyde
Ms Alison Rae	Occupational Therapy Team Leader	NHS Greater Glasgow and Clyde
Dr Robert Swingler	Consultant Neurologist	NHS Tayside
Mrs Susan Walker	General Manager	NHS Greater Glasgow and Clyde
Dr David Watson	General Practitioner	NHS Grampian
Dr Belinda Weller	Consultant Neurologist	NHS Lothian
Mr Andrew Wynd	Chief Executive	Scottish Spina Bifida Association

#### Epilepsy services project group

<b>Name</b>	<b>Title</b>	<b>NHS board area/organisation</b>
Dr Rod Duncan (Chair)	Consultant Neurologist	NHS Greater Glasgow and Clyde
Dr Anne Coker	General Practitioner	NHS Tayside
Ms Susan Douglas-Scott	Chief Executive	Epilepsy Scotland
Dr Susan Duncan	Consultant in Neurology	NHS Lothian
Dr Linda Gerrie	Consultant in Neurology	NHS Grampian
Ms Angela Norman	Epilepsy Specialist Nurse	NHS Tayside

### Headache services project group

Name	Title	NHS board area/ organisation
Dr David Watson (Chair)	General Practitioner	NHS Grampian
Dr Lorraine Briggs	General Practitioner	NHS Lothian
Dr Callum Duncan	Specialist Registrar in Neurology	NHS Lothian
Dr Michael McKenzie	General Practitioner with a Special Interest in Headache	NHS Greater Glasgow and Clyde
Dr Alok Tyagi	Consultant Neurologist	NHS Greater Glasgow and Clyde
Ms Heather Wallace	Chairman	Pain Concern

### Motor neurone disease services project group

Name	Title	NHS board area/ organisation
Dr Robert Swingler (Chair)	Consultant Neurologist	NHS Tayside
Ms Laura Cunningham	MND Regional Care Specialist	NHS Greater Glasgow and Clyde
Ms Fiona Macaulay	Speech and Language Therapist	NHS Tayside
Dr Lindsay Martin	Consultant in Palliative Care	NHS Dumfries & Galloway
Ms Judith Newton	MND Regional Care Specialist	NHS Lothian
Mr Stephen O'Brien	Patient representative	
Dr Richard Petty	Consultant Neurologist	NHS Greater Glasgow and Clyde
Mr Craig Stockton	Chief Executive	Scottish Motor Neurone Disease Association

### Multiple sclerosis services project group

Name	Title	NHS board area/ organisation
Dr Belinda Weller (Chair)	Consultant Neurologist	NHS Lothian
Mr Mark Hazelwood	Director	MS Society Scotland
Ms Julie Hooper	Neurological Clinical Specialist Physiotherapist	NHS Lothian
Ms Ruth Hymers	Senior Dietitian	NHS Lothian
Mr Matthew Justin	MS Nurse Specialist	NHS Lothian
Ms Alison Knox	Patient representative	Lothian
Ms Nicola McLeod	MS Nurse Specialist	NHS Lothian
Dr Paul Mattison	Consultant Neurologist	NHS Ayrshire

## Neuropsychiatry and neuropsychology services project group

Name	Title	NHS board area/organisation
Dr Adam Burnel (Chair)	Consultant in Liaison Psychiatry	NHS Greater Glasgow and Clyde
Dr Alan Carson	Consultant Neuropsychiatrist	NHS Lothian
Dr Richard Coleman	Consultant Neurologist	NHS Grampian
Dr Susan Copstick	Neuropsychologist	NHS Greater Glasgow and Clyde
Dr Jon Stone	Consultant Neurologist	NHS Lothian

## Parkinson's disease services project group

Name	Title	NHS board area/organisation
Dr Donald Grosset (Chair)	Consultant Neurologist	NHS Greater Glasgow and Clyde
Dr Katherine Grosset	General Practitioner with a special interest in Parkinson's disease	NHS Greater Glasgow and Clyde
Ms Tanith Muller	Parliamentary and Campaigns Officer Scotland	Parkinson's Disease Society
Dr George Rhind	Consultant Physician	NHS Dumfries & Galloway
Ms Elaine Thomson	Parkinson's Nurse Specialist	NHS Lanarkshire

## Advocacy Group

Name	Title	NHS board area/organisation
Dr Richard Metcalfe (Chair)	Clinical Advisor	NHS Quality Improvement Scotland
Mr Ewan Dale	Trustee	ME Association
Ms Susan Douglas-Scott	Chief Executive	Epilepsy Scotland
Mr John Eden	Service Development Manager	Scottish Huntington's Association
Ms Laura Ferguson	Scottish Regional Organiser	Myasthenia Gravis Association
Mr Mark Hazelwood	Director	MS Society Scotland
Mr Rorie Laidlay	Secretary	Epilepsy Support Group Shetland
Mr Peter Meager	Scotland Manager	The Dystonia Society
Ms Tanith Muller	Parliamentary and Campaigns Officer Scotland	Parkinson's Disease Society
Ms Christine Murphy	MDC Care Advisor	Muscular Dystrophy Campaign
Mr Alisdair Nimmo	Chief Executive Officer	Myasthenia Gravis Association
Mr Ryan Norton	Communications Manager	MS Society Scotland

Ms Madeleine Quinn	Development Officer Scotland	Progressive Supranuclear Palsy Association
Ms Yvonne Robb	MDC Care Advisor	Muscular Dystrophy Campaign
Mr Andrew Sim	Scotland Manager	Parkinson's Disease Society
Mr Craig Stockton	Chief Executive	Scottish Motor Neurone Disease Society
Mr Rodger Walker	Chair, Dumfries Branch	Parkinson's Disease Society Scottish Council
Ms Sheena Wannan	Co-ordinator	Danda South of Scotland
Mr Andrew Wynd	Chief Executive	Scottish Spina Bifida Association

Support from NHS QIS is provided by the Standards Development Unit: Miss Abigail Cork (Project Officer), Ms Hilary Davison (Acting Director of Guidance and Standards), Ms Clare Echlin (Acting Head of Standards Development Unit), Mr Scott Horton (Project Officer), and Mr Richard McManus (Programme Manager), and by the Performance Assessment Unit: Mr Sean Doherty (Team Manager Performance Assessment Team) and Ms Fiona Russell (Programme Manager).

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## Appendix 5: Glossary

<b>acute headache</b>	<p>Onset of a new headache syndrome usually within the last few weeks, days, hours or even minutes, but can be months.</p> <p>Acute headache may be:</p> <ul style="list-style-type: none"> <li>• sudden onset (for example subarachnoid haemorrhage)</li> <li>• associated with fever and with or without focal features (for example meningitis/encephalitis), or</li> <li>• daily and progressive from onset with or without focal features (for example giant cell arteritis, raised intracranial pressure, tumour, idiopathic intracranial hypertension, cerebral venous sinus thrombosis).</li> </ul> <p>Patients with acute headache require immediate or urgent assessment.</p>
<b>acute medicine</b>	The immediate and early specialist management of patients who present in hospital emergencies.
<b>allied health professional (AHP)</b>	A healthcare professional directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, and dietitians.
<b>atypical clinical features</b>	Unusual or abnormal symptoms. The development of such symptoms may indicate the progression of a condition or may be a sign that the initial diagnosis of a condition may be incorrect.
<b>central nervous system demyelination</b>	A loss of myelin in the white matter of the central nervous system (brain, spinal cord). Demyelination is the root cause of the symptoms of multiple sclerosis.
<b>chronic neurological disease</b>	A disorder of the nervous system which is characterised by a recurrence or a slow development over time that tends to last over a prolonged period.
<b>clinical nurse specialist</b>	See nurse specialist.
<b>community health partnerships (CHPs)</b>	The Scottish Government has introduced community health partnerships across Scotland. A CHP is a network of local health professionals and local organisations working in a coordinated manner to manage a wide range of local health services that are delivered in health centres, clinics, schools and homes.
<b>co-morbidity</b>	Two or more conditions that occur simultaneously within the same person.
<b>co-morbid psychiatric disorders</b>	Psychiatric disorders occurring in the presence of neurological disorder.
<b>computerised tomography (CT) scanning</b>	A specialised X-ray examination that is often used to visualise the brain and spinal structures. A common test for neurological conditions.
<b>consultant who specialises in the diagnosis and management of neurological conditions</b>	A doctor who has specialised knowledge and competence in a particular area of medical practice, such as in epilepsy, multiple sclerosis, Parkinson's disease or motor neurone disease. The consultant may also sub-specialise in a specific condition or group of conditions such as epilepsy, dystonia or Huntington's disease. Neurological conditions or their chosen sub-specialty must be a significant part of their clinical workload.

<b>continuing professional development (CPD)</b>	An ongoing commitment to learning in various forms, which maintains and enhances professional standards of work, and develops the ability to recognise good practice.
<b>desirable criteria</b>	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
<b>essential criteria</b>	A criterion that should be met wherever a service is provided.
<b>healthcare professional</b>	Professionals trained in a particular area of healthcare delivery and directly involved in the delivery of clinical care to patients, ie physicians, nurses and occupational therapists.
<b>integrated team</b>	This term is used for a team providing a diagnostic and treatment service for patients with neurological symptoms unexplained by disease and patients with defined neurological disease that have co-morbid psychiatric disorders. The team consists of, as a minimum: a liaison psychiatrist with dedicated sessions in neurology and a neuropsychologist with dedicated sessions in the assessment and treatment of these conditions. It is desirable that the team also includes a neurologist with a special interest, access to physiotherapy services, speech therapy and occupational therapy with experience of these disorders and supervised therapists to deliver psychological interventions (who may have a psychology, medical or nursing background).
<b>key worker</b>	A professional who is identified as being responsible for the patient's assessment and care planning during the course of the illness.
<b>managed clinical networks (MCNs)</b>	Linked groups of health professionals and organisations working in a co-ordinated manner, unconstrained by existing professional and NHS board boundaries, to ensure equitable provision of high-quality, clinically-effective services throughout Scotland.
<b>motor neurone disease (MND)</b>	A progressive neurodegenerative disease that attacks the upper and lower motor neurones. Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing.
<b>motor neurone disease regional care specialist</b>	A motor neurone disease regional care specialist carries out the same role as a clinical nurse specialist within MND specialist services. However the role may be carried out by either a nurse or an allied health professional.
<b>MS clinically isolated syndrome</b>	A first neurological event that is suggestive of demyelination. Individuals with this syndrome are at high risk of developing clinically definite MS.
<b>multidisciplinary team (MDT)</b>	A team composed of members from different healthcare professions with specialised skills and expertise who work together to address the whole range of issues affecting the patient during the course of their condition.
<b>multiple sclerosis (MS)</b>	A disease of the central nervous system that is an unpredictable condition that can be relatively benign, disabling, or devastating, leaving the patient unable to speak, walk, or write.
<b>neuro-imaging</b>	The use of X-ray studies and magnetic resonance imaging (MRI) to detect abnormalities or trace pathways of nerve activity in the central nervous system.

<b>Neurological Alliance of Scotland</b>	A forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland.
<b>neurological conditions</b>	A disturbance in structure or function of the central nervous system resulting from developmental abnormality, disease, injury or toxin.
<b>neurological health services</b>	The provision of any health services for patients with neurological conditions.
<b>neurological symptoms unexplained by disease</b>	This term refers to patients presenting with attacks resembling epilepsy, blackouts, weakness, sensory symptoms, movement disorders, dizziness and cognitive symptoms that are not explained by the presence of neurological disease. These are also referred to as conversion symptoms, dissociative symptoms and functional symptoms.
<b>neurologist</b>	A doctor who specialises in conditions of the brain, spinal cord, peripheral nerves and muscles.
<b>neurology service</b>	An individual service dedicated to providing specialist neurological services to patients.
<b>neurophysiologist</b>	A doctor who specialises in the testing of the function of the nervous system (electroencephalograms [EEGs] and tests on nerves and muscles), to determine if a patient is suffering from a neurological condition.
<b>neurophysiology</b>	The branch of medicine that deals with the functions and activities of the central nervous system in the diagnosis and treatment of neurological conditions.
<b>neuroradiologist</b>	A physician who specialises in the field of neuroradiology and imaging to determine if a patient is suffering from a neurological condition.
<b>neuroradiology</b>	The branch of medicine that deals with the use of radioactive substances in the diagnosis and treatment of neurological conditions.
<b>neurosurgical services</b>	Services providing surgery of the nervous system, including the nerves, the brain, and the spinal cord.
<b>NHS board's drug formulary</b>	A list of prescription drugs, including generic and brand name drugs, which are funded through the NHS.
<b>non-acute headache</b>	Non-acute headache can be disabling but is not serious. Most non-acute headache is primary (eg migraine, tension type headache or cluster headache) but can be secondary (eg medication overuse headache, cervicogenic headache).
<b>nurse specialist</b>	A healthcare professional who has specialised knowledge and competence in a particular area of neurology, such as in epilepsy, multiple sclerosis, Parkinson's disease or motor neurone disease. Also known as a clinical nurse specialist in some settings.
<b>occupational therapist (OT)</b>	A healthcare professional who specialises in using productive or creative activity to treat or rehabilitate patients.
<b>palliative care</b>	The active total care of patients and their families by a multidisciplinary team when the patient's disease is no longer responsive to curative treatment.

<b>Parkinson's disease (PD)</b>	Parkinson's disease is a slowly progressing, degenerative disease that is usually associated with the following symptoms all of which result from the loss of dopamine-producing brain cells: tremor or trembling of the arms, jaw, legs, and face; stiffness or rigidity of the limbs and trunk; slowness of movement; postural instability, or impaired balance and co-ordination.
<b>Parkinson's disease and related conditions</b>	Conditions which are more rapidly progressive and less responsive to treatment than idiopathic PD and represent a more widespread degenerative process. The two main types are multiple system atrophy (MSA) and progressive supranuclear palsy (PSP).
<b>patient encounter</b>	The experience of a patient when in contact with any service provided by the NHS.
<b>physiotherapist</b>	A healthcare professional specialising in the treatment of disorders with exercises and other physical treatments.
<b>practice nurse</b>	A registered NHS nurse working in a GP practice to provide a wide range of nursing services, including screening, advice and treatment to patients.
<b>primary care</b>	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
<b>rationale</b>	The rationale of a standard provides the reasons why a standard is considered to be important.
<b>referral</b>	The process by which a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
<b>regional neurology centre</b>	Centre that provides nursing and physician assessment to patients with neurological issues such as Parkinson's disease, multiple sclerosis, headaches and seizure disorders, on a regional basis. In Scotland there are four regional neurological centres serving the population.
<b>rehabilitation services</b>	Services provided to help patients to achieve the highest level of function, independence and quality of life possible, particularly after an illness or injury.
<b>relapse</b>	The return of signs and symptoms of a disease after a period of absence.
<b>secondary care</b>	Hospital-based care services which are provided on an inpatient or outpatient basis.
<b>SGHD</b>	Scottish Government Health Directorates
<b>spasticity</b>	A condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and may interfere with movement, speech and manner of walking.
<b>specialist palliative care</b>	The active total care of patients with progressive, far-advanced conditions and limited prognosis, and their families, by a multidisciplinary team.
<b>standard statement</b>	An overall statement of desired performance.

<b>subarachnoid haemorrhage (SAH)</b>	A serious, potentially life-threatening condition where blood leaks out of blood vessels over the surface of the brain. A subarachnoid haemorrhage requires urgent emergency treatment.
<b>telemedicine</b>	Real-time ward-based medicine carried out using audio-visual equipment available in a treatment or consulting area. The facilities enable healthcare professionals to examine patients with the guidance of a remotely located physician.
<b>triage</b>	The sorting out and classification of patients or casualties to determine priority of need and proper place of treatment.
<b>voluntary sector organisation</b>	Organisations that carry out social activities which are not for profit or funded by the government.
<b>waiting time initiatives</b>	Extra activities carried out by service providers to reduce the length of their waiting lists.

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