NHS Quality Improvement Scotland

Clinical Standards ~ *October 2009*

Neurological Health Services

NHS Quality Improvement Scotland is committed to equality and diversity. We have assessed this area of work for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. An equality and diversity impact assessment report has been published along with these standards and is available online or in hardcopy upon request.

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1 Introduction to neurological health services in Scotland

Disorders of the nervous system are common. It is estimated that 10 million people in the UK live with some form of neurological condition that has an impact on their lives[1]. They frequently cause misery and disability rather than being life threatening. They are, however, associated with significant morbidity and the single most common disorder, headache, has major economic consequences in terms of lost working days[2].

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[1].

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[3].

For a variety of historical reasons, neurological services in the UK have lagged behind comparable European economies[4-7]. The contrast between the frequency of disorder and availability of trained staff and investigation resource to properly assess and manage these disorders has been evident to patients and professionals for many years. Steps are now being taken to address this issue, but the problems of shortage of trained staff and training opportunities remain.

NHS Quality Improvement Scotland (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 Scottish Government in Partnership for Care: Scotland's health white paper 2003[8]. The group reported in April 2006, and identified the need to undertake a stocktaking exercise to establish the nature and quantity of existing neurological service provision. The management consultancy firm Scott-Moncrieff was commissioned by NHS QIS to carry out the review of neurological health services across Scotland 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 to deliver neurological health services
- there were no waiting times targets for follow-up appointments
- there was a lack of communication among service providers 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 NHS boards, and
- the recent pilot of telemedicine neurological services in the north of Scotland was regarded as successful by patients, consultants and nurses[9].

The NHS QIS steering group set up in 2005 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.[10]

2 Development of the standards for neurological health services

A project group was convened in 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. A number of subgroups were also convened to consider the requirements for condition-specific services. The project group membership is set out in Appendix 3.

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 project.

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 publication, Crossing the Quality Chasm[18].

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.

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 currently do not involve neurologists as major care providers[11-15]. The project group did, however, recognise the increasing role of neurologists in acute stroke care.

In addition to the generic standards, the project group developed condition-specific standards for five conditions that 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 that will address the patient journey from the point of referral into the service and will result in an improvement in care for all those suffering from neurological conditions. In selecting these conditions for specific standards, the project group wanted to emphasise the value of 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[16].

Patient and public involvement

The involvement of a range of stakeholders including voluntary sector organisations, patients, patient representatives, carers and the public was 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 was equally important during the national consultation of the draft standards. In early 2009, a series of patient focus group meetings took place throughout Scotland to ensure maximum engagement of patients, their families and carers.

Consultation

Following publication of the Draft Clinical Standards for Neurological Health Services in November 2008[17], a formal consultation was undertaken. During this period, professional groups, health service staff, voluntary organisations and the public were given the opportunity to influence the further development of the standards.

In addition, two NHS boards (NHS Dumfries & Galloway and NHS Lothian) were peer reviewed against the standards in a pilot exercise in April 2009. The peer review visits allowed the project group to receive feedback on the draft standards and the effectiveness of the review process.

Finalising the standards

NHS QIS received a large and generally encouraging response to the draft standards. All feedback collected throughout the consultation period was discussed by the project group to produce final standards. The response of the project group to individual comments is available on request.

Who do these standards apply to?

The standards are applicable to all NHS territorial boards as well as 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
- Scottish Ambulance Service, and
- State Hospitals Board for Scotland.

Assessment of performance against the standards

In consultation with NHS boards, NHS QIS intends to assess services against these standards in an innovative way, identifying methods that reduce the administrative burden on the service, but remain meaningful.

From its inception, the neurological health services clinical standards project group was concerned that a national approach to data collection and provision of information should be adopted. 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.

To address this gap, the Neurological Services Data and Audit Group was formed, supported by NHS QIS, to explore with relevant stakeholders how this should be achieved. The work of the group will be taken forward to ensure these standards are embedded into a continuous quality improvement process and reflect the NHS QIS integrated cycle of improvement strategy which is outlined in Appendix 1.

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 that 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 that promote care
- is encouraged to participate in decision-making on a partnership basis when desired, and
- has easy access to information and services that enhance the long-term management of their condition.

3 Clinical standards for neurological health services

Generic standards for all neurological health services

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

Epilepsy services standards

Standard 5	Access to specialist epilepsy services
Standard 6	Diagnosis of epilepsy
Standard 7	Ongoing management of epilepsy

Headache services standards

Standard 8	Access to specialist headache service
Standard 9	Diagnosis of headache
Standard 10	Ongoing management of headache

Motor neurone disease services standards

Standard 11	Access to specialist motor neurone disease services
Standard 12	Diagnosis of motor neurone disease
Standard 13	Ongoing management of motor neurone disease

Multiple sclerosis services standards

Standard 14	Access to specialist multiple sclerosis services
Standard 15	Diagnosis of multiple sclerosis
Standard 16	Ongoing management of multiple sclerosis

Parkinson’s disease services standards

Standard 17	Access to specialist Parkinson’s disease services
Standard 18	Diagnosis of Parkinson’s disease
Standard 19	Ongoing 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

Individuals should have access to all aspects of neurological care regardless of where they live.

Patient care is enhanced by the provision of up-to-date and accurate written and verbal information.

Consistent and ongoing data collection allows NHS boards to monitor and review their services on an ongoing basis, for the purpose of service improvement. Success will not occur without clinician and management engagement, the active participation of NHS board IT departments and a long-term approach to system development.

The Neurological Services Data and Audit Group will identify and agree a common dataset for neurological services to ensure consistency across all NHS boards.

References: 9, 19, 20, 21, 22

Essential criteria

1.1 The NHS board makes accurate and current information available about its existing designated services for patients with neurological conditions.

1.2 The NHS board has a minimum 3-year plan for the provision of neurological health services to its population. This plan is published and subject to annual review.

1.3 The NHS board works collaboratively with the Neurological Alliance of Scotland, other patient support groups and charities to ensure that patients and their carers are made aware of the resources available nationally and locally through voluntary sector partners.

1.4 The NHS board provides accurate and current information to patients and their carers about their condition.

1.5 The NHS board provides resources to ensure collection and analysis of data in relation to neurological services activity and outcomes, as identified by the Neurological Services Data and Audit Group.

1.6 The data collected within the common dataset is used to improve patient care.

Standard 2: Access to neurological health services

Standard statement 2
Patients with suspected neurological conditions 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. The Scottish Government Health Directorates has established overall maximum waiting times targets, but some patients will need to be seen within shorter timescales. Providing clear and efficient referral systems will enhance NHS boards' ability to achieve targets.

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

References: 9, 10, 16, 23, 24, 25, 26, 27, 28

Essential criteria

2.1 The NHS board demonstrates that a minimum of 90% of outpatient demand for all neurological health services can be met by substantive resources without resorting to waiting times initiatives, reliance on temporary staffing or other short-term measures.

2.2 Outpatients 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 at least 95% of cases.

2.3a The NHS board ensures that the neurology service has a communication process for discussion of urgent cases with a neurologist at all times.

2.3b Where the neurologist identifies an outpatient referral as urgent, the patient is seen within 10 working days of triage in at least 90% of referrals.

2.4 Initial advice following an urgent request for a neurological opinion for inpatients in non-neurological settings occurs within 24 hours.

2.5 At least 80% of patients with a neurological condition requiring transfer are admitted under the care of a neurologist within 48 hours of acceptance.

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 neurological health services

Standard statement 3
Neurological health services provide a high quality of care that meets the needs of patients, referrers and providers.

Rationale

The ability to meet a patient's needs 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.

Rapid, accurate, legible and accessible communication between all those involved with the patient is also of paramount importance.

References: 8, 10, 20, 29, 30

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 systems to collect patient feedback to improve the neurological health services on an ongoing basis.

3.2b The NHS board implements systems to collect feedback from clinicians referring into the service to improve the neurological health services on an ongoing basis.

3.2c The NHS board implements systems to collect neurological service staff feedback on its neurological health services on an ongoing basis.

3.2d The NHS board acts on the patient, referrer, and staff feedback it collects.

3.3 The NHS board provides access to, and demonstrates participation in, communication training for all staff having direct contact with patients with neurological conditions.

3.4 Patient waiting times in clinics 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 Designated private facilities are available on wards for 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 clinician and 30–40 minutes with trainees.

3.7b Return patient encounters are scheduled to allow a minimum of 15 minutes consultation time with a clinician and 15–20 minutes with trainees.

3.7c Clinicians have a facility to schedule additional time where a prolonged consultation is anticipated.

3.8 A minimum of 90% of outpatient letters are electronically dispatched within 5 working days of the consultation.

3.9a All inpatients are discharged with a printed immediate discharge summary.

3.9b Immediate discharge information is sent to the GP electronically in at least 95% of cases.

3.9c Final discharge summaries are dispatched electronically to the GP within 5 working days of discharge in at least 95% of cases.

Standard 4: Management processes in neurological health services

Standard statement 4
Neurological health services have an effective patient management process from the point of first referral.

Rationale

Patients with neurological conditions benefit from the ready availability of a variety of different specialist investigation and management resources. In some cases, complex needs demand access to a wide range of services, including rehabilitation, self-management options and palliative care. A common rate-limiting step in the delivery of care of the acutely ill patient is the ability to access the acute neurology inpatient unit and its associated resources.

One third of all patients attending neurology outpatient departments have neurological symptoms unexplained by disease, but who may benefit from specialist management. In addition, patients with neurological conditions are much more likely to have 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.

Access to clinical neuropsychology is important for the diagnosis of disorders of cognition, the management of patients with neurologically unexplained symptoms and psychological support for patients with other neurological conditions.

Community health partnerships (CHPs), or equivalent, 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: 9, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62

Essential criteria

4.1 At every consultation, all patients are offered a copy of the GP's letter or a management plan. Any changes to medication are provided in writing immediately to the patient.

4.2a All neuro-imaging procedures are reported by a neuroradiologist, or a general radiologist who has had specialist neuroradiological training.

4.2b All neurophysiology procedures are performed and reported by a neurophysiologist, or medically trained staff with neurophysiological training.

4.3 At the conclusion of the care episode, 80% of patients are transferred back from the neurological unit to the referring unit within 2 working days of transfer request.

4.4a The neurology service has access to an integrated neuropsychology and neuropsychiatry service 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 At least 80% of patients referred to this service requiring urgent assessment will have initial contact within 24 hours if referred from inpatient consultation, or within 20 working days if referred from outpatient consultation.

4.5 The neurology service has access to specialist neuropsychological assessments and rehabilitation contributing to the diagnosis and management of neurological conditions.

4.6 The NHS board provides designated rehabilitation services specifically for people with neurological symptoms.

4.7 There are multidisciplinary systems in place, with input from a specialist clinical pharmacist, for:

- safe use of medicines
- access to formulary medicines
- use of non formulary and unlicensed medicines
- education of non medical and medical prescribers, and
- regular medicines reconciliation and review.

4.8 The neurology service has channels of communication with the individual responsible for long term conditions in the local community health partnerships, or equivalent, to co-ordinate the provision of services, equipment and medication, by the NHS and social services.

4.9 People affected by neurological conditions have ongoing access to self-management options.

4.10 Patients with advanced conditions or complex needs have access to assessment and treatment in their place of residence by a member of the neurology multidisciplinary team where they are unable to access services at hospitals or clinics.

4.11 Patients with neurological conditions have access to equipment for assisting with daily living where that equipment is normally provided by NHSScotland.

4.12a Palliative care is provided for patients with neurological conditions, their family and carers, as required throughout the course of their illness, and in accordance with the wishes of the patient.

4.12b Specialist palliative care is provided for patients with complex needs.

4.12c Patients with neurological conditions are encouraged to discuss advance care planning, when clinically appropriate.

Standard 5: Access to specialist epilepsy services

Standard statement 5
The NHS board provides a comprehensive epilepsy service with access to appropriately trained specialist staff.

Rationale

Patients with epilepsy receive better quality care when diagnosis and treatment are provided by well-educated and well-trained healthcare professionals.

References: 63, 64, 65

Essential criteria

5.1 Patients with suspected first seizure or epilepsy are referred to a specialist in epilepsy.

5.2 Healthcare professionals 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
Patients with suspected epilepsy or first seizure are referred to epilepsy specialist services.

Rationale

The diagnosis of epilepsy is more accurate when made by a medical practitioner who specialises in epilepsy, resulting in better patient outcomes.

Patients with suspected first seizure should be treated as a neurological emergency and seen by a medical practitioner who specialises in epilepsy.

Post-diagnosis care and support for patients is augmented by access to epilepsy specialist nurses.

References: 63, 64

Essential criteria

6.1 The diagnosis of epilepsy is confirmed by a medical practitioner who specialises in epilepsy.

6.2 Patients with a diagnosis of first seizure or epilepsy are offered an appointment with an epilepsy specialist nurse that takes place within 30 working days of the initial assessment.

6.3 Patients with a driving licence who are referred for possible seizure are advised by the referring doctor not to drive, until they are seen by a medical practitioner who specialises in epilepsy.

6.4 Patients referred for possible first seizure or new onset epilepsy are requested to bring an eyewitness to the appointment.

Standard 7: Ongoing management of epilepsy

Standard statement 7
Patients with epilepsy have ongoing access to epilepsy specialist services appropriate to their needs.

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 healthcare 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 with drug resistant epilepsy and all patients who could benefit from this should have access to assessment.

Misdiagnosis of epilepsy and co-morbid mental health problems are common and have serious health consequences for the patient.

References: 63, 64

Essential criteria

7.1 Patients with epilepsy in NHS hospital care receive uninterrupted and correct anticonvulsants.

7.2 All medical, nursing and allied health professional (AHP) staff caring 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.

7.3 Patients with poorly controlled seizures have access to specialist assessments for epilepsy surgery, non-epileptic seizures and neuropsychological and neuropsychiatric conditions.

Standard 8: Access to specialist headache services

Standard statement 8
Patients receive co-ordinated care from healthcare professionals with expertise in the diagnosis and management of patients with headache.

Rationale

Headache is a common and in some cases complex condition that can be difficult to diagnose and manage effectively. Management can be improved by adopting the multidisciplinary, co-ordinated, team-based approach recommended by the Scottish Government Health Directorates.

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 neurology or multidisciplinary headache service 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 and treatment of migraine
- medication overuse headache
- sinister causes of headache, and
- services available locally for the diagnosis and management of headache.

References: 9, 20, 66, 67, 68, 69

Essential criteria

8.1 The NHS board provides access to a co-ordinated non-acute headache service led by a doctor who specialises in headache, and has defined links with the general neurology service.

8.2a The NHS board provides an educational programme on acute and non-acute headache for primary care colleagues within the NHS board.

8.2b The educational programme provided by the NHS board is promoted to healthcare professionals in the NHS board area.

8.2c The educational programme on acute headache is compulsory for all trainee doctors (currently FY1 – ST2) undergoing training in acute medicine.

8.3 The headache service provides guidance on the minimum required information to be sent for all referrals to the service.

Standard 9: Diagnosis of headache

Standard statement 9
Patients with headache have 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 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.

References: 70, 71, 72, 73, 74, 75, 76, 77, 78, 79

Essential criteria

9.1 GPs have direct access to computerised tomography (CT) scanning according to the clinical indicators set out in current SIGN guidelines.

9.2 Neurological investigations for patients with non-acute headache are carried out in line with the recommendations for investigation types and timescales in current SIGN guidelines.

9.3 Neurological investigations for acute headache are carried out in line with recommendations in current SIGN guidelines.

Standard 10: Ongoing 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 that can be significantly disabling. There are many effective treatments and NHS boards should ensure that patients have access to relevant therapies.

References: 70, 80

Essential criteria

10.1 The headache service has the capacity to follow up patients with chronic headache as clinically indicated.

10.2 The headache service has defined links to a pain management service.

Standard 11: Access to specialist motor neurone disease services

Standard statement 11
An effective and comprehensive motor neurone disease service is available and offered across all NHS 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: 81, 82, 83, 84

Essential criteria

11.1a Patients with suspected motor neurone disease are referred to a neurologist.

11.1b Patients with clinically definite or clinically probable 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, the patient and carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services:

- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- pharmacy services
- mental health services.

11.3 The NHS board provides rapid access to demonstrably effective care pathways covering all aspects of the illness, including links to specialist palliative care and respiratory medicine, gastrostomy services and social services.

Standard 12: Diagnosis of motor neurone disease

Standard statement 12
Patients with suspected motor neurone disease have their diagnosis confirmed by a neurologist, with access to appropriate investigation resources and the specialist motor neurone disease multidisciplinary team.

Rationale

Timely access to necessary investigations is essential to an efficient and effective diagnostic process for patients with suspected motor neurone disease.

Following diagnosis, patients benefit from rapid access to a motor neurone disease multidisciplinary team.

References: 9, 81, 82

Essential criteria

12.1 On request from a neurologist, patients with suspected motor neurone disease have access to relevant investigation resources including imaging and neurophysiology within 20 working days.

12.2a The diagnosis of motor neurone disease is confirmed and conveyed to the patient by a neurologist.

12.2b Patient review, after neurophysiology and imaging takes place, is achieved within 15 working days.

12.3a The motor neurone disease regional care specialist makes contact with the patient within 2 working days of confirmation of the diagnosis.

12.3b Patients with motor neurone disease and their carers are offered contact details for specialist support services provided by voluntary sector organisations.

Standard 13: Ongoing 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 that can be rapidly progressive. Patients with motor neurone disease have complex needs that can affect all aspects of their lives.

Maintaining the patient's ability to communicate is essential. Every effort should be made to encourage advance care planning to ensure patient autonomy 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.

There is evidence that nutritional and respiratory support improves the quality of life for the patient with motor neurone disease and their carers.

References: 55, 81, 82, 85,

Essential criteria

13.1a A needs assessment is offered to patients with motor neurone disease at all stages of the patient's condition. The assessment is updated as the disease progresses.

13.1b 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.

13.1c At all times, an identified individual is allocated responsibility for co-ordinating the delivery of care relevant to the assessed needs.

13.2a The service assesses and meets the communication needs of patients with motor neurone disease at all stages of their condition.

13.2b The service assesses and meets the nutritional needs of patients with motor neurone disease at all stages of their condition.

13.2c The service assesses and meets the respiratory needs of patients with motor neurone disease at all stages of their condition.

Standard 14: Access to specialist multiple sclerosis services

Standard statement 14
An effective and comprehensive specialist multiple sclerosis (MS) service is available across all NHS boards.

Rationale

MS is a complex condition and can be difficult to diagnose and manage effectively. Management can be improved by adopting the multidisciplinary, co-ordinated, team-based approach recommended by the Scottish Government Health Directorates.

References: 9, 20, 86, 87, 88, 89, 90

Essential criteria

14.1a The NHS board provides patients with MS with access to a multidisciplinary team that specialises in the management of MS.

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, the patient and carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services:

- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- neurorehabilitation services
- pharmacy services
- mental health services.

14.2a An MS specific structured patient and family education programme is offered to newly diagnosed patients at diagnosis.

14.2b An MS specific structured patient and family education programme is offered to all patients with MS and can be accessed throughout the course of the condition.

14.3 A structured education programme specific to MS is offered to all healthcare professionals who have regular 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. Patients may require support from the multidisciplinary team throughout the diagnostic process.

References: 9, 87, 88, 89, 90, 91

Essential criteria

15.1 Patients referred with symptoms suggestive of central nervous system demyelination are offered investigation, and if undertaken, the results explained and therapeutic options discussed with them.

15.2 Contact with an MS clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of the diagnosis.

15.3 Patients who have been diagnosed with a clinically isolated syndrome of demyelination are provided with information on how to access MS specialist services in the future.

Standard 16: Ongoing 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 experienced professionals who are better able to identify and manage relapses and symptoms related to MS. MS patients may also have complex needs that require access to a wide range of services.

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

- chronic pain
- cognitive issues
- continence
- fatigue
- motor problems – mobility, spasticity, weakness, tremor
- nutrition
- psychological issues
- sexual dysfunction
- speech and language
- visual problems.

Other specialist services may also need to be accessed:

- environmental control services
- ongoing maintenance rehabilitation
- orthotic services
- pharmacy services
- palliative care.

References: 87, 88, 89, 90

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 5 working days of contact.

16.2b Following the initial relapse assessment, a review is carried out by a member of the MS multidisciplinary team.

16.3 Patients with MS who meet the existing local formulary guidelines are offered specialised disease modifying drug therapies.

Standard 17: Access to specialist Parkinson's disease services

Standard statement 17
An effective and comprehensive Parkinson's disease service is available and offered across all NHS 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), dementia with Lewy bodies (DLB) and multiple system atrophy (MSA).

References: 9, 92, 93, 94, 95, 96, 97, 98, 99, 100, 101, 102, 103

Essential criteria

17.1 Patients with suspected Parkinson's disease and related conditions are referred to a defined Parkinson's disease 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, the patient and carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services:

- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- pharmacy services
- mental health services.

Standard 18: Diagnosis of Parkinson's disease

Standard statement 18
Patients with suspected Parkinson's disease are referred to Parkinson's disease specialist services.

Rationale

The diagnosis of Parkinson's disease is more reliably made by doctors 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: 9, 92, 93, 103, 104, 105, 106

Essential criteria

18.1 The diagnosis of Parkinson's disease is confirmed by a doctor who specialises in Parkinson's disease.

18.2 Patients with Parkinson's disease and their carers are provided with ongoing access to a Parkinson's disease nurse specialist.

18.3 The diagnosis of Parkinson's disease is reviewed and reconsidered if atypical clinical features develop.

Standard 19: Ongoing management of Parkinson's disease

Standard statement 19
Patients with Parkinson's disease and their carers have ongoing access to specialist Parkinson's disease services and are encouraged and supported to be involved in decision-making about treatment or therapy at all stages of their condition.

Rationale

Patients with Parkinson's disease and their carers need to have support from their Parkinson's disease multidisciplinary team 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 that may take time and resources to resolve. Patients with Parkinson's disease and their carers 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: 92, 93, 104, 105, 107, 108

Essential criteria

19.1a The timing and dosage of medication for Parkinson's disease is specified and adhered to when the patient is in hospital.

19.1b 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.

19.2 Reconciliation of the record of medicines and dosages is undertaken at each patient visit to ensure that the patient, GP, consultant, pharmacist and Parkinson's disease nurse specialist determine accurately what anti-Parkinson's disease drugs the patient is taking.

19.3 Patients with Parkinson's disease are offered a regular review of their condition and medication, according to their clinical need, but at least annually.

19.4 The Parkinson's disease service assesses patients with Parkinson's disease for referral to specialised neurosurgical services.

4 Appendices

Appendix 1	**About NHS Quality Improvement Scotland**
Appendix 2	**NHS Quality Improvement Scotland standards development methodology**
Appendix 3	**Membership of the clinical standards for neurological health services project groups**
Appendix 4	**Evidence base**
Appendix 5	**Glossary**

Appendix 1: About NHS Quality Improvement Scotland

NHS Quality Improvement Scotland (NHS QIS) is a Special Health Board that provides support to NHSScotland.

NHS QIS supports NHS boards to improve the quality of patient care by:

- 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 our findings.

The Scottish Health Council, the Scottish Intercollegiate Guidelines Network (SIGN) and the Healthcare Environment Inspectorate are key components of the organisation.

NHS QIS has central responsibility to support NHS boards to deliver patient safety and clinical governance across NHSScotland.

NHS QIS also takes a leading role in co-ordinating the work of the Scottish Patient Safety Programme and provides support to the Scottish Medicines Consortium.

Further information about NHS QIS is available on our website (www.nhshealthquality.org).

Appendix 2: NHS Quality Improvement Scotland standards development methodology

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 NHSScotland 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[109] and Partnership for Care[8], 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)[110] that 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** that 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** that 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 that 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[111] 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. The clinical governance and risk management standards are available on request from NHS QIS or can be downloaded from the website (www.nhshealthquality.org).

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

Generic neurological health services project group

Name	Title	NHS board area/ organisation
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

Name	Title	NHS board area/ organisation
Dr Rod Duncan (Chair)	Consultant Neurologist	NHS Greater Glasgow and Clyde
Dr Anne Coker	General Practitioner	NHS Tayside
Ms Susan Douglas-Scott (until December 2008)	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
Ms Lesslie Young (from January 2009)	Chief Executive	Epilepsy Scotland

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	Consultant Neurologist	NHS Grampian
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 in Neurological Rehabilitation	NHS Ayrshire
Ms Sheena Wight	Lecturer in Occupational Therapy	NHS Lothian

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), Ms Karen Grant (Project Officer), Mr Scott Horton (Project Officer), Ms Michelle Lacey, (Programme Manager) 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

Term	Definition
acute headache	Onset of a new headache syndrome usually within the last few weeks, days, hours or even minutes, but can be months. Acute headache may be: ▪ sudden onset (for example subarachnoid haemorrhage) ▪ associated with fever and with or without focal features (for example meningitis/encephalitis), or ▪ 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). Patients with acute headache require immediate or urgent assessment.
acute medicine	The immediate and early specialist management of patients who present in hospital emergencies.
advance care planning	The voluntary process of discussion between an individual and their care providers, to agree and record the needs and wishes of the individual for future provision of care.
allied health professional (AHP)	A healthcare professional directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, speech and language therapists, and dietitians.
atypical clinical features	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.
central nervous system demyelination	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.
chronic neurological disease	A disorder of the nervous system that is characterised by a recurrence or a slow development over time that tends to last over a prolonged period.
clinical nurse specialist	See nurse specialist.
clinically isolated syndrome of demyelination	A first neurological event that is suggestive of demyelination. Individuals with this syndrome are at high risk of developing clinically definite MS.
communication training	In the setting of the standards, communication training refers to facilitated small group experiential learning. For medical staff a 2–3 day course run by experienced facilitators has been shown to be an effective format.
community health partnerships (CHPs) or (CHCPs)	The Scottish Government has introduced community health partnerships across Scotland. CHP and CHCPs are networks of local healthcare professionals and local organisations working in a co-ordinated manner to manage a wide range of local health services that are delivered in health centres, clinics, schools and homes.
co-morbidity	Two or more conditions that occur simultaneously within the same person.
co-morbid psychiatric disorders	Psychiatric disorders occurring in the presence of neurological disorder.
computerised tomography (CT) scanning	A specialised X-ray examination that is often used to visualise the brain and spinal structures. A common test for neurological conditions.

consultant who specialises in the diagnosis and management of neurological conditions	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.
contact	Any communication including telephone conversation, email, or letter, appropriate to the patient's needs or wishes.
continuing professional development (CPD)	An ongoing commitment to learning in various forms that maintains and enhances professional standards of work, and develops the ability to recognise good practice.
dementia with lewy bodies (DLB)	A type of dementia which occurs soon before or after the diagnosis of Parkinson's disease (in a small subset of PD patients). It is characterised by the presence of parkinsonism with impaired cognition. The patient often has fluctuations in alertness and attention, and there are early visual hallucinations.
environmental control services	A service that offers the provision of an environmental control system to maintain or improve the independence and security of people with severe physical disability, by giving them access to conventional equipment in their home via a central control.
epilepsy specialist	A medical practitioner with expertise in epilepsy as demonstrated by training and continuing education in epilepsy, peer review of practice and regular audit of diagnosis. Epilepsy must be a significant part of their clinical workload (equivalent to at least one session a week).
essential criteria	A criterion that should be met wherever a service is provided.
FY1-ST2	The first four years of post-graduate training for doctors: foundation year (FY) 1 to specialty training (ST) level 2.
general radiologist with specialist neuroradiological training	A general radiologist who has undertaken additional post-FRCR (Fellow of the Royal College of Radiologists) neuroradiology training, within a neuroscience centre, and for whom neuro-imaging reporting represents a significant proportion of their clinical workload equivalent to three or more programmed activities every week.
headache specialist	Doctors working in the specialist headache service who are not trained as neurologists 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 Guidelines 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.

headache specialist (continued)	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.
healthcare professional	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.
integrated neuropsychology and neuropsychiatry service	This term is used for a service 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 service 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).
key worker	A professional who is identified as being responsible for the patient's assessment and care planning during the course of the illness.
management plan	A written, preferably typed, plan that includes working diagnosis, immediate treatment recommendations, further investigation and management arrangements.
medically trained staff with neurophysiological training	Staff with recognised qualifications; medical staff with certificate of completion of specialist training (CCST) in clinical neurophysiology or evidence of appropriate training (minimum 2 years postgraduate training in relevant area of neurophysiology: or in existing established practice); appropriately registered healthcare scientist staff: reporting agenda for change (AFC) Grade 7 or above as per Association of Neurophysiological Scientists (ANS) criteria.
motor neurone disease (MND)	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.
motor neurone disease regional care specialist	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.
multidisciplinary team	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.
multiple sclerosis (MS)	An autoimmune condition in which the immune system attacks the central nervous system, leading to demyelination. MS is the most common disabling neurological condition affecting young adults. For some people, MS is characterised by periods of relapse and remission, while for others, it has a progressive pattern.
multiple system atrophy (MSA)	One of the rarer subtypes of parkinsonism. There is a mixture of parkinsonism, autonomic, and cerebellar features. This causes problems with movement, balance, blood pressure (resulting in postural dizziness), and bladder control.
neuro-imaging	The use of X-rays, gamma rays, ultrasound and magnetic resonance to form an image or to measure and display structure and function in the central nervous system.
neurological alliance of scotland	A forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland.

neurological conditions	A disturbance in structure or function of the central nervous system resulting from developmental abnormality, disease, injury or toxin.
neurological health services	The provision of any health services for patients with neurological conditions.
neurological symptoms unexplained by disease	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.
neurologist	A doctor who specialises in conditions of the brain, spinal cord, peripheral nerves and muscles.
neurology service	An individual service dedicated to providing specialist neurological services to patients.
neurophysiologist	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.
neuroradiologist	A physician who specialises in the field of neuroradiology and imaging to determine if a patient is suffering from a neurological condition.
neurosurgical services	Services providing surgery of the nervous system, including the nerves, the brain, and the spinal cord.
NHS board's drug formulary	A list of prescription drugs, including generic and brand name drugs that are funded by the NHS.
non-acute headache	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).
nurse specialist	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.
occupational therapist	A healthcare professional trained in the assessment and treatment of physical and psychiatric conditions using specific, purposeful activity to prevent disability and promote independent function in all aspects of daily life.
palliative care	An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
parkinson's disease	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.
parkinson's disease and related conditions	Conditions that 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).
patient encounter	The experience of a patient when in contact with any service provided by the NHS.
physiotherapist	A healthcare professional specialising in the treatment of disorders through the use of physical approaches to promote, maintain and restore physical, psychological and social wellbeing.

practice nurse	A registered NHS nurse working in a GP practice to provide a wide range of nursing services, including screening, advice and treatment to patients.
primary care	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.
progressive supracnuclear palsy (PSP)	One of the rarer subtypes of parkinsonism. There are features similar to Parkinson's disease. In addition, there are early problems with balance, changes in personality, cognitive impairment, and loss of the ability to look up and down. Speech may become slurred and swallowing may become difficult.
rationale	The rationale of a standard provides the reasons why a standard is considered to be important.
referral	The process by which a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
regional neurology centre	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.
rehabilitation services	Services provided to help patients to achieve the highest level of function, independence and quality of life possible, particularly after an illness or injury.
relapse	The return of signs and symptoms of a disease after a period of absence.
secondary care	Hospital-based care services that are provided on an inpatient or outpatient basis.
self-management	The term used when patients are encouraged to manage their own conditions with support from healthcare professionals. This may be, for example, by altering drug doses and adapting their lifestyles in response to subtle changes in symptoms.
SIGN	Scottish Intercollegiate Guidelines Network
spasticity	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.
specialist clinical pharmacist	A pharmacist who has specialised knowledge and competence in the use of medicines, including experience in the specific clinical area. The pharmacist works as a member of the multidisciplinary team to help patients get the maximum benefit from their medicines.
specialist palliative care	The active total care of patients with progressive, far-advanced conditions and limited prognosis, and their families, by a multidisciplinary team.
standard statement	An overall statement of desired performance.
subarachnoid haemorrhage (SAH)	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.
substantive resources	The existing allocated resources for the service within the given financial year. Resources that are not classed as substantive may be waiting list initiatives, reliance on temporary staff etc.
telemedicine	Real-time 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.

triage	The sorting out and classification of patients or casualties to determine priority of need and proper place of treatment.
voluntary sector organisation	Public and private sector organisations that carry out social activities that are not for profit or funded by the government.

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