



Neurological Services Steering Group Pre-scoping Report

April 2006

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Executive summary

Neurological conditions affect all ages, and people may experience the onset of a neurological condition at any time in their lives. There is increased prevalence of neurological conditions in older people as some conditions particularly affect older people, and others are life-long conditions. It is reported that the numbers of people with neurological conditions will grow sharply in the next two decades¹.

In light of this, a neurological services pre-scoping steering group (the group) was set up to consider both the work of NHS Quality Improvement Scotland (QIS) and that of other organisations, and to scope the current provision of services available to those affected by neurological conditions. The group agreed that to be patient focused; it should address issues concerning all services for people affected by a neurological condition.

A wide range of individuals and organisations from both within and outwith NHSScotland were involved in providing expert advice, and produced options and recommendations for the development of a programme of future work.

This work was carried out in the context of the strategic direction set by the Scottish Executive Health Department (SEHD) who identified a need for improvement in the current provision of neurological services in Scotland, further highlighted in Building a Health Service Fit for the Future² published in 2005, which outlined a number of recommendations including improvement in services for long-term (chronic) conditions.

The group convened for four meetings held between July and December 2005. For reasons of practicability, it was agreed the scope of the group be limited to:

- services for adults and paediatric-adult transition services, and
- generic issues.

The pre-scoping report has identified 12 key issues, set out in Section 5 (Methodology), which were identified by the group as requiring consideration. These were drawn from Action on Neurology: Improving Neurology Services – a practical guide³, acknowledged by the group as a foundation for identifying key issues. In addition, from comments received from group members and other parties, there is recognition of the following recurrent themes within the 12 key issues:

- patient focus
- access
- capacity and resources
- education and training, and
- information.

To best support improvement in the quality of care for those affected by neurological conditions in Scotland, these key issues and themes are to the forefront of recommendations made by the group to the NHS QIS Board. The principal recommendations are:

- The commissioning of a 'stocktaking' exercise to provide an accurate picture of services available nationally, regionally and locally to patients with neurological disorders in Scotland.
- The development of high level/generic standards for the provision of services for those affected by neurological conditions, building upon the existing Department of Health's National Service Framework (NSF) for Long-term Conditions⁴. The standards should be developed in relation to key aspects of care for people with neurological disorders in Scotland, as identified in this report.
- The development of a mechanism to assess the link between the provision of services for those affected by neurological conditions and the NSF and, in particular, its relevance and applicability to NHSScotland.

In addition to the principal recommendations above, the group agreed the following secondary recommendations. It should be noted, however, that these recommendations will not necessarily fall within the remit of NHS QIS:

- Development of a mechanism to retain and maintain current information on the provision of services for those affected by neurological conditions throughout Scotland.
- There is an increase in numbers of newly-qualified specialist neuropsychologists and an opportunity to create more posts. Services should be expanded and improved.
- Links should be formed between NHSScotland and NHS Education for Scotland (NES) for the purpose of developing training needs analysis for allied health professionals (AHPs).
- Education for healthcare professionals, patients and carers should be the subject of a separate scoping exercise.

Further information on options and recommendations made by the group are provided on pages 21-23 of this report.

Acknowledgements

Many thanks to all who have given their time, expertise and knowledge to inform the recommendations made in this report. In particular, there has been considerable support for the reflective approach taken, and many useful documents, initiatives and ideas have been shared.

NHS QIS would like to thank the following in particular for their input and support:

- the steering group members (a full membership list appears in Appendix 1)
- Mr David Currie, Consultant Neurosurgeon, NHS Grampian
- Dr Ruth Gillham, Consultant Neuropsychologist, NHS Greater Glasgow
- Mrs June Wylie, Professional Practice Development Officer, NHS QIS

1 Introduction

NHS QIS was set up as a special health board by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland. The responsibilities of NHS QIS cover all aspects of the services provided by the NHS and provide an independent check on how these services are performing. NHS QIS also supports NHS staff by issuing clear, authoritative advice on effective clinical practice and service improvements.

The aim of NHS QIS is to support the delivery of:

- higher standards of care
- improved outcomes for patients
- better experiences for patients and carers, and
- better value for money.

Objectives are achieved through four key functions that link together:

- providing advice and guidance on effective practice
- setting standards
- reviewing and monitoring performance, and
- supporting staff to improve services.

To achieve its objectives, NHS QIS provides a number of products designed to improve the quality of care and treatment delivered, at a national level. A list of these products is presented in Appendix 4.

This document is the summary of a pre-scoping exercise of services available to those affected by neurological conditions. The purpose of the exercise was to gain an overview of existing service provision in Scotland, to identify problems and areas of disparity that might require further investigation, and to make recommendations to the NHS QIS Board on how NHS QIS can best support services in improving the quality of care for those affected by neurological conditions throughout NHSScotland.

2 Background

Patient focus is critical in determining how to improve services for long-term conditions. Building a Health Service Fit for the Future² outlines the following recommendations as part of the development of a national framework for service change.

In planning the future of NHSScotland, there is a need to:

- ensure sustainable and safe local services
- view the NHS as a service delivered predominantly in local communities rather than in hospitals
- adopt preventive, anticipatory care rather than reactive management
- galvanise the whole system; with the aim of a more fully integrated NHS
- become a modern NHS using new technology
- develop new skills to support local services, and
- develop options for change **with** people, not **for** them.

NHSScotland, supported by NHS QIS, requires to make a commitment to improving the management of long-term conditions (sometimes referred to as chronic diseases), making every effort to embed the recommendations set out above in current and future work.

An estimated 10 million people in the UK live with a neurological condition that has a significant impact on their lives⁴. Approximately 350,000 (0.6% of the UK population) require help for most of their daily activities. Over one million people (2% of the UK population) are disabled by their neurological condition. These UK figures are taken from Neuro Numbers¹, and may be extrapolated downward to give an approximate estimate of corresponding Scottish numbers.

SEHD has identified a need for improvement in the current provision of services available to those affected by neurological conditions in Scotland. NHS QIS has been tasked with eliciting expert advice from within NHSScotland and associated external agencies including representatives from the voluntary sector, and has therefore established the neurological services pre-scoping steering group.

2.1 Current guidance and policy

Guidance and policy documents endorsed, suggested or recommended by the group for consideration and sourced in the UK include the following key documents:

- Action on Neurology: Improving Neurology Services – a practical guide³
- Building a Health Service Fit for the Future: A National Framework for Service Change in the NHS in Scotland²
- The National Service Framework (NSF) for Long-term Conditions⁴

2.2 Ongoing initiatives in Scotland

The identification of current work within NHS QIS and Scotland relating to neurological conditions and services was agreed as an essential consideration for the planning of any options and recommendations provided by the group. Key pieces of work identified include:

- **Routine clinical management of medically unexplained symptoms (MUS)**
Audit project - refer to Scottish Neurological Symptoms Study (below).
- **Scottish Neurological Symptoms Study**
A study report to determine:
 - the proportion of new patients attending Scottish neurology clinics with medically unexplained symptoms (MUS)
 - the age, sex, health status, level of emotional distress and the illness beliefs of patients with MUS compared with those who have medically explained symptoms, and
 - the current clinical management of patients with MUS.
- **Managed clinical networks (MCNs)**
 - Accreditation by NHS QIS of a regional MCN for epilepsy services, developed by NHS boards in Ayrshire & Arran, Greater Glasgow and Tayside. Quality assurance frameworks (QAFs) are currently being developed by the North of Scotland Epilepsy MCN and a national MCN specific to paediatric epilepsy, both of which are working towards accreditation.
 - NHS Forth Valley Multiple Sclerosis MCN has developed a QAF and is working towards accreditation, with NHS Forth Valley committed to rolling the MCN concept out to cover neurology as a whole.

2.3 Other related initiatives

- **Career and competency framework for Parkinson's disease nurse specialists**
An integrated career and competency framework undertaken jointly by the Parkinson's Disease Society, Parkinson's Disease Nurse Specialist Association and Royal College of Nursing.
- **Centre for Change and Innovation's outpatients programme**
The Outpatients Programme, launched in October 2003 by the SEHD, delivers the Centre for Change and Innovation's (CCI) commitment to improve outpatient services and to support the NHS in reducing outpatient waiting times (www.cci.scot.nhs.uk). This programme continues until March 2006, and includes:

- **Patient Pathways**

Patient pathways provide GPs with information on referral criteria for consultants, alternative referral to AHPs/specialist nurses, follow-up options, diagnostic tests and management tips. Neurology pathways include: epilepsy management, funny turns and blackouts (adults), headache assessment, headache management, relapse in multiple sclerosis, and Parkinson's disease.

- **Community Outpatient Services (COS) Project**

Community outpatient services aim to improve patient access to services closer to their home through the development of services by general practitioners with special interests (GPSIs), specialist nurses and specialist AHPs.

- **Neurology Redesign - one of five long-wait specialties**

The specialties that have traditionally had long waiting times for outpatient appointments have been targeted for a concerted redesign effort. A number of innovations are being piloted including: pooling and triage of referrals, telephone follow-up, nurse-led clinics, AHP-led clinics, telemedicine clinics and other sustainable ways of improving the outpatient experience. Three Scottish centres of neurology: Glasgow, Tayside and Grampian are taking part, releasing around 2,500 consultant outpatient appointments each year (mainly in epilepsy, headache and movement disorders clinics).

- **Patient Focused Booking**

Patient focused booking gives patients more say over the date and time of their hospital appointment and 30 major Scottish hospitals are now adopting this system.

- **Referral Management Services**

A number of NHS boards are working with CCI to develop Referral Management and Information Services (RMIS) to provide primary care with rapid feedback on triage, referrals and waiting times.

- **Sharing Good Practice**

The Sharing Good Practice programme is committed to sharing good practice and the CCI website contains a number of examples and links to other sources of good practice expertise (www.cci.scot.nhs.uk).

• **Competence Framework for Long-Term Conditions – Neurological Care**

A competence framework managed by Skills for Health (SfH), the UK Sector Skills Council (SSC) for health, develops, maintains and uses national workforce competences, which embrace National Occupational Standards (NOS) ensuring that those working in the UK health sector are equipped with the right skills.

- **National Care Standards: Short Breaks and Respite Care Services for Adults**

These standards describe what each individual person can expect from the service provider and focus on the quality of life that a person using respite care actually experiences in Scotland.

- **National Institute for Health and Clinical Excellence (NICE) guidelines**

NICE clinical guidelines recommend the appropriate treatment and care of people with specific conditions for the NHS in England and Wales, and are based on the best available evidence.

- **SIGN guidelines**

SIGN guidelines are developed to improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcome, through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence.

The recommendations will be presented to the NHS QIS Board on Thursday, 2 February 2006 and the report will be available to the public on the NHS QIS website and in a range of media as required.

Further information

For further information on this report, or to obtain a copy, please contact:

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Copies of all NHS QIS publications and further information on the organisation can also be downloaded from the website (www.nhshealthquality.org).

3 Scope of the report and exclusions

The remit of the group was agreed to be ‘the current provision of services available to those affected by neurological conditions’. This recognises that not all neurological conditions, and not all stages and aspects of some neurological conditions, are treated by neurologists.

To remain patient focused, the group agreed it should address issues concerning all services which people affected by a neurological condition might wish to access as a result of their condition. This would include services traditionally badged as ‘neurological services’ (for example, outpatient neurology) and also services such as respite or palliative care services, which are critical components of care, but not specifically badged as ‘neurological’.

For reasons of practicability, it was agreed to limit the scope of the group to:

- services for adults and paediatric-adult transition services, and
- generic issues.

Although recognised as important areas for future investigation, comments on specific neurological conditions, such as dementia, learning disability, stroke and acquired brain injury, were not included on this occasion as, for the purpose of this report, emphasis has been placed on service provision. It is, however, strongly endorsed by the group that adults affected by these conditions require a complete range of well co-ordinated services from health and social service, in line with other chronic neurological conditions.

4 Key barriers

The group's short working life (6 months) and the extensive scope of service provision for those affected by neurological conditions in NHSScotland constrained the service map produced, to one that provides a preliminary overview of current services (Appendix 3). It is unlikely this illustration is complete. The process of compiling it led the group to believe that accurate information on services available is not readily accessible.

The short working life of the group has also meant that variable quantities of evidence have been gathered to support points incorporated into the findings. Some requests for information, and the collation of same, have not been met due to circumstances outwith the control of the group.

5 Methodology

The multidisciplinary steering group included healthcare professionals and lay representatives, and was chaired by Dr Roderick Duncan, Consultant Neurologist, NHS Greater Glasgow. A full membership list is provided in Appendix 1. The following organisations/bodies were represented on the group:

- Centre for Change and Innovation
- general practice
- health and social care
- NHS: epilepsy services, clinical neurosciences, medicine, managed clinical network, occupational therapy, pharmacy and rehabilitation, and
- voluntary: Multiple Sclerosis Society Scotland, Scottish Motor Neurone Disease Association, Sue Ryder Care and the Neurological Alliance of Scotland.

The group had the following aims and objectives, to:

- provide expert advice and support to the NHS QIS project team
- scope the current provision of services available to those affected by neurological conditions in NHSScotland
- identify key policy documents, guidelines and initiatives, and
- inform the drafting of a final report, including options and recommendations.

The group convened for four meetings held between July and December 2005. One piece of work, Action on Neurology: Improving Neurology Services³ was identified by the group as a foundation for identifying key issues, which are specified under Section 6 (Key Issues and Findings).

In addition, from a broad literature search, the group identified recent UK-based publications, detailed in Section 8 (References) and Section 9 (Bibliography).

6 Key issues and findings

An initial objective was to carry out a survey of services currently available to the adult population in Scotland, aiming to:

- define current provision of neurological services
- identify disparities with respect to geography and population, and
- identify gaps in information on services available.

This service mapping exercise provided a 'snapshot' of current neurological service provision in Scotland (Appendix 3).

As indicated previously, the following key issues were identified as requiring consideration by both the report above and the group:

- person-centred services
- early recognition, prompt diagnosis and initial treatment
- emergency management
- community rehabilitation and support
- support for family and carers
- outflow from acute facilities
- treatment of chronic neurological conditions
- respite care
- palliative care
- professional knowledge for generalists
- complementary medicine, and
- cognitive impairment.

Individuals and/or subgroups were asked to comment on the key issues referred to above, and to provide recommendations for the development of a programme of work for NHS QIS in the domain of 'services available for those affected by neurological conditions'. The comments received have led to the identification of some recurring themes. These are listed below and are discussed on pages 15-20:

- patient focus
- access
- capacity and resources
- education and training, and
- information.

In addition to the key issues set out above, the group identified some issues that were deemed outside the scope of the report, or outside the remit of NHS QIS, but were acknowledged as important to people affected by neurological conditions:

- development of information technology systems to underpin service provision and to address the absence of basic epidemiological information on specific neurological conditions
- neurological activity undertaken by GPs, and
- accurate determination of numbers of patients affected by neurological conditions.

Recurring themes

As previously indicated, following the receipt of comments relating to the key issues, a number of recurring themes were identified, which are further discussed below.

Patient focus

Patient and public involvement should remain central in determining the development of service provision. Future development requires to be in accord with the following four broad themes outlined in the SEHD document Patient Focus Public Involvement⁵.

- Involvement - ensuring that public involvement is a key part of all NHS QIS business activities.
- Building capacity and communications - involving patients as partners in the planning and management of their own care; improving the ability and competency of people to take effective action to improve services, and ensuring that communication is clear, consistent and appropriate.
- Responsiveness - ensuring that a flexible range of opportunities for involvement is offered, making public participation as easy and broad as possible.
- Patient information - ensuring that people have the information that is necessary for them to be involved in decisions about their own care and to participate fully in the activities of NHS QIS.

As outlined in the NHS QIS Patient Focus and Public Involvement (PFPI) Framework⁶, the paper "...sets out the NHS QIS framework for achieving an effective partnership with the public. Their involvement is viewed as an integral and essential part of all aspects of NHS QIS activities, which will significantly contribute to the continuous improvement of health services in Scotland."

One step towards achieving patient and public involvement is the introduction of Community Health Partnerships (CHPs), the development of which is set in context in A Partnership for a better Scotland: Partnership Agreement⁷ and the Partnership for Care: Scotland's Health White Paper⁸.

At the time of publication, it is not yet possible to assess the impact of CHPs on patient and public involvement in services for patients with neurological conditions.

Within social support for patients, there is variability in access to, and consistency of referral pathways due to on-going restructuring within agencies, which can make it increasingly difficult to maintain established processes. The transition from child to

adult services is of key importance as an integral aspect of social support and service provision for those affected by neurological conditions. There is currently only one NHS board area that has a specific Young Disabled School Leavers Service, which links education and social work. Generally, it is felt the transition may be haphazard and, in many cases, there is no formal referral pathway.

There is a current requirement for balance between the work of the NHS and the voluntary sector. The Scottish Parliament, as part of the Patient Focus and Public Involvement Agenda, advocates increased joint working between NHSScotland and the voluntary sector.

Access

A number of issues were identified:

- long outpatient waiting times
- a lack of neurological inpatient beds, due to neurology handling more emergencies as general medical involvement in neurological care contracts, and
- a lack of adequate neurological consultant expansion.

The first of these is a matter of public record. Work is currently being undertaken by CCI to improve waiting times. This is outlined in the Outpatients Programme referred to in Section 2.3 (Other related initiatives on page 8). It is recognised that while work has been carried out to drive down the headline outpatient waits for a first appointment, there is a consequential impact on the new: return ratio and the availability of follow-up and review of patients with chronic neurological disease.

Current information on waiting times relating to access to investigations - imaging, neurophysiology and neuropsychiatry/liaison psychiatry - is provided below.

As at July 2005, outpatient waiting times in one NHS board, specific to imaging, are reported to be 11 weeks for computed tomography (CT) and 15 weeks for magnetic resonance imaging (MRI). Specific to emergency work, CT access is excellent, but access to MRI more difficult.

Currently, there are no waiting time figures available for neurophysiology, but it is reported that several weeks wait is standard. Access to the disciplines of neuropsychiatry and liaison psychiatry is reported as minimal and good, respectively.

The second point is more difficult to quantify. For example, acute medicine in one NHS board has approximately 30,000 admissions a year, of which 1 in 7 is neurological. However, these figures do include stroke, which is widely regarded as being more appropriately managed in stroke units than in neurology beds. Many hospitals have poor on-site neurology presence, with only complex problems referred to neurology. Many cases are still managed within medical specialties. None of these factors is currently quantifiable.

Neuropsychology services in Scotland are inconsistent with approximately six experienced full-time neuropsychologists at tertiary referral centres, and 2.2 whole

time equivalent (WTE) for the west of Scotland. Psychologists attached to community mental health services have developed an interest in neuropsychology over the past 10 years and supplement this gap by accepting referrals from GPs, psychiatric services and general hospitals. This development will be halted in the future by the requirement of a post-doctoral MSc in neuropsychology for practising neuropsychologists.

Building a Health Service Fit for the Future² reports, “Long term conditions require ongoing care, limit the patient’s quality of life, and are likely to last longer than one year. They are common in the Scottish population, more common in people living in deprived circumstances, more common in older people and, because Scotland’s population is ageing, they will become even more prevalent in the future. If we do not continue to improve our management of long term conditions at a local level, demand on acute services will continue to increase and will never be met.”

The group reported inconsistent and inappropriate protocols and care pathways for long term conditions, affecting access to routine reviews for patients.

It is important to make reference to rapidly progressing conditions at this point. The speed at which conditions, such as motor neurone disease (MND) progress is a major issue, and one that impacts on all aspects of the services that are needed and accessed by not only those suffering from such conditions, but also their families and carers.

Rapidly progressive conditions present particular challenges for both the health service and social care providers in the need for prompt referral, access, delivery and frequent monitoring. These same issues are acknowledged in the Department of Health’s National Service Framework (NSF) for Long-term Conditions⁴, and thereby further reflect as evidence the requirement for these needs to be met as factors essential to the re-design of neurological services within NHSScotland.

The Scottish Partnership on Palliative Care advises that information relating to the numbers of people affected by neurological conditions accessing end of life care is not routinely recorded, and would need to be obtained by a resourced audit.

Rehabilitation is not only delivered by specialist rehabilitation units, with much often delivered by generalist AHP personnel (eg physiotherapy, occupational therapy, speech therapy) and others. There exists inequity of access to specialist rehabilitation services. It is reported that four NHS board areas have no such service, and in eight NHS boards there is only a single consultant, of whom one is part-time. Facilities and resources available vary considerably, limiting the capacity to develop appropriate service. The requirement for a co-ordinated approach to patient management, addressing physical, psychological and social (including vocational) issues was emphasised.

Particular to rehabilitation services is the issue of spasticity management, which requires a co-ordinated approach, addressing physical and medical treatment. It is reported that only a few NHS board areas have established specific specialised clinics for management of spasticity. Access to bioengineering services is poor in some NHS board areas, with long waiting times.

In addition to the acknowledgment of an inadequacy of respite care available to those affected by neurological conditions, there is little information on needs for, and access to, respite care. Standards for respite care exist, but are not specific to patients affected by neurological conditions.

Access to neurological services, including those for the treatment of long-term (chronic) neurological conditions and specialist palliative care to allow for prompt referral, delivery and adequate follow-up, was identified as a major problem and as having high priority for action.

Capacity and resources

Capacity, as defined in Action on Neurology: Improving Neurology Services³ is “the resources available to do the work”.

Due to their limited number, specialist neurological beds are currently used mainly for diagnosis and acute management. For example, one NHS board currently has one neurology ward, highlighting the issue of limited capacity for specialist beds, and emphasising that neurology is currently a predominantly outpatient specialty.

For a proportion of neurological cases, the diagnosis is made under general medical care and no referral to neurology is made. Rehabilitation is provided in general medical, care of the elderly or (less commonly) rehabilitation beds. Patients who suffer from disabling neurological problems are usually treated in acute medical and surgical wards if they present with acute medical problems. The chronic neurological problem is not always appropriately managed in this circumstance.

Lack of capacity for the treatment of chronic neurological conditions may lead to limited and inappropriate response to changes in condition. This is also due to a lack of protocols and pathways.

To provide an accurate picture of current resources and capacity there is a requirement to carry out an audit across NHS boards in Scotland, incorporating data on inpatient neurological beds (and waiting times for neurological beds) together with data on staffing levels within neurology, levels of service (eg number and types of clinics) and outpatient waiting times.

Education and training

The group identified a number of issues that highlight the requirement for continuing professional development (CPD) and training as well as access to information among health and care professionals. These include:

- knowledge levels of and access to information for non-specialist staff, including GPs as the first point of contact for many patients presenting with a neurological condition
- the care of disabled people in non-neurological acute settings, and
- problems with communication of diagnosis

In June 2004, Skills for Health, the UK Sector Skills Council for healthcare was commissioned by the Long-Term Conditions Care Group Workforce Team to develop a competence framework for long-term conditions for neurological care that embraces NOS as statements of competence describing good practice.

Educational opportunities for AHPs are inconsistent, with a current lack of equitable access to training programmes.

Complementary medicine describes a range of pharmaceutical-type preparations, which are not licensed as medicines, and therefore evidence of quality, efficacy and safety is not required before marketing. As reported in the Health Technology Assessment in Homeopathy¹⁰, the profession is “currently unregulated and there are no restrictions on who can practice it”, although it should be stated that regulation via an individual’s accrediting body has now been introduced. Patients may seek treatment using complementary therapies, but may not have good access to information on their risks.

Educational development should be available to those affected by neurological conditions; the patient, families and carers. As outlined in Self care, carers, volunteering and the voluntary sector: towards a more collaborative approach¹¹, the culture of healthcare in Scotland is moving away from “a passive, dependent attitude amongst patients” to the “emergence of a patient who is better educated and more informed, enquiring and confident...”. This highlights the requirement for appropriate educational methods to encourage and develop a model of interactive care and collaborative partnerships between patients and health and care professionals. NHS research has shown that appropriate training and educating of carers produces a better quality of life for the carer and the person being cared for, as well as “tangible economic savings from reduced NHS and social care intervention, and prevention of repeated hospital admission.”²

Information

It is important that all patients, families and carers have access to information that should be:

- up to date
- timely
- written in a language the patient can understand, ie where possible the patient’s first language
- accessible via different sources in order to make informed choices related to their medical conditions, and
- reviewed on a regular basis.

Such objectives have been incorporated into SIGN guidelines (eg Diagnosis and management of epilepsy in adults (SIGN guideline: 70)¹² and National Care Standards: short breaks and respite care services for adults⁹).

Access to information about neurological services is vital to those adults affected by neurological conditions, including their families and carers. NHS personnel are key in providing information to patients. To be able to do this, they need to have adequate opportunities for CPD.

Literature and anecdotal evidence from patients and carers suggest that service users perceive that front-line healthcare professionals lack adequate understanding of health problems encountered by people with neurological conditions. Attention to such issues would improve provision of timely intervention and advice, as well as improved care.

There is much information produced by the voluntary sector for patients with neurological conditions, which is used widely within the NHS. Unfortunately, funding is limited within the NHS. The group felt that this is ultimately an NHS responsibility, one that could be discharged either directly or by commissioning (eg from the voluntary sector).

The group reported variability in access to information and inconsistencies in the information provided, in particular on availability of services and referral pathways.

7 Recommendations

From group discussions and information received from other parties, some major issues and areas of disparity have been identified. Recommendations to the NHS QIS Board on how NHS QIS can best support services in improving the quality of care for those affected by neurological conditions in Scotland are set out below.

Principal recommendations

- The commissioning of a 'stocktaking' exercise to provide an accurate picture of services available nationally, regionally and locally to patients with neurological disorders in Scotland.
- The development of high level/generic standards for the provision of services for those affected by neurological conditions, building upon the existing Department of Health's National Framework (NSF) for Long-term Conditions. The standards should be developed relating to key aspects of care for people with neurological disorders in Scotland, as identified in this report.
- The development of a mechanism to assess the link between the provision of services for those affected by neurological conditions and the NSF and, in particular, its relevance and applicability to NHSScotland.

In addition to the principal recommendations, the group agreed the following secondary recommendations. It should be noted, however, that these recommendations will not necessarily fall within the remit of NHS QIS.

- Development of a mechanism to retain and maintain current information on the provision of services for those affected by neurological conditions throughout Scotland.
- There is an increase in numbers of newly-qualified specialist neuropsychologists and an opportunity to create more posts. Services should be expanded and improved.
- Links should be formed between NHSScotland and NHS Education for Scotland (NES) for the purpose of developing training needs analysis for AHPs.
- Education for healthcare professionals, patients and carers should be the subject of a separate scoping exercise.

Further details of the recommendations are provided below. Each has been categorised with a priority level of high or medium and are not listed in any particular order for action.

Audit (stocktaking exercise)

On completion of the literature review, the group suggested audit should be widely encouraged. This process could be supported in a range of ways (eg by organisations working across NHSScotland or be locally driven). Audit would not necessarily be the sole responsibility of NHS QIS.

The issues categorised as **high** priority for action on audit include:

- waiting times
- access to investigations (imaging, neurophysiology, neuropsychiatry and liaison psychiatry)
- specific and generic rehabilitation services, and
- respite care.

Issues categorised as **medium** priority for action:

- access to emergency and acute management across NHSScotland, and
- inpatient neurological bed capacity (access as outpatient and as transfer from other units).

Best practice statements

Best practice statements are individual reports providing guidance on best and achievable practice on specific topics. Neither the advice given nor compliance is compulsory. The issues below are all regarded as **high** priority for action for the development of best practice statements and include:

- outflow to the community - a co-ordinated approach to management of physical, psychological, social and vocational issues
- transition from child to adult services
- CPD and specialist education programmes; access to training and development opportunities
- palliative care in relation to neurological conditions, and
- complementary medicine; reporting of adverse events for dissemination to homeopathic centres around Scotland.

SIGN guidelines

SIGN guidelines are practical guidelines of recommendations based on evaluation and synthesis of available evidence derived from a systematic literature review. One key area identified by the group for the development of such a guideline is:

- cognitive impairment.

NHS QIS standards

The setting of standards is a national system of quality assurance of clinical services, whereby NHS QIS assesses performance throughout NHSScotland against set standards, and publishes the findings. The standards, which are mandatory, are based on the patient's journey as they move through different parts of the health service. Standards must be clear, measurable and achievable, and apply equally to every NHS board area in Scotland.

The group suggested the following issues for inclusion. Each issue is rated as a **high** priority:

- access to follow-up
- care of disabled people in non-neurological acute settings
- information, advice and support for patients, families and carers
- communication of diagnosis, and appropriate information and advice at point of diagnosis
- respite care: access and quality, and
- training and education (specifically specialist education).

In the development of standards, the group recommended that a mechanism be set in place to build upon the existing National Services Framework for Long-term Conditions covering England and Wales in order to determine aspects which have relevance and are applicable to Scotland.

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10 Glossary

Term	Definition
accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
acute sector	Hospital-based health services which are provided on an inpatient or outpatient basis.
adverse event	Any occurrence which is not routine, and which causes physical or psychological harm, loss, or damage.
agencies (other than NHS)	Public bodies, organisations and stakeholders, such as local authority social work departments, local authority housing departments and the emergency services, with which NHS health boards must liaise and work in partnership to deliver joint services.
AHPs	See allied health professionals.
allied health professionals (AHPs)	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dietitians, etc. Formerly known as professions allied to medicine (PAMs).
audit	Systematic review of the procedures used for diagnosis, care, treatment, rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient.
CAM	See complementary and alternative medicine.
carer	A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.
CCI	See Centre for Change and Innovation.
Centre for Change and Innovation (CCI)	Provides NHS staff with practical support and expertise to improve patient care. The role of CCI role is to bring a stronger focus to bear on improvements and to help staff learn from each other. Website: http://cci.scot.nhs.uk/cci/cci_BaseHomeTemplate.jsp
CHP	See community health partnership.
chronic	Present over a long period of time.
clinical governance	<p>Ensures that patients receive the highest quality of care possible, putting each patient at the centre of his or her care. This is achieved by making certain that those providing services work in an environment that supports them and places the safety and quality of care at the top of the organisation's agenda.</p> <p>Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk.</p>

clinical neurosciences	Relating to the observation and treatment of actual patients, and any of the sciences, such as neurochemistry and experimental psychology, which deal with the structure or function of the nervous system and brain.
cognitive impairment	A reduced ability to know, think, learn or make decisions.
community health partnership (CHP)	A way of organising non-acute care where NHS boards maximise their ability to support integration across health and between health and other agencies such as social services. A CHP covers a geographical area and the number within an NHS board depends on the distribution and size of the population. Website: www.show.scot.nhs.uk/sehd/chp/index.htm
compensatory techniques	Ways of making up for an impairment which are similar to common sense approaches. The techniques can be both external (eg memory book) or internal (eg 'stop-think-act').
complementary and alternative medicine (CAM)	Any of a range of medical therapies that fall beyond the scope of scientific medicine but may be used alongside it in the treatment of disease and ill health.
computerised tomography (CT)	An X-ray imaging technique used in diagnosis that can reveal many soft tissue structures not shown by conventional radiography.
conceptual reasoning	Thinking in a theoretical, abstract way.
continuing professional development (CPD)	An ongoing commitment to learning in various forms, which maintains and enhances professional standards of work, and develops the ability to recognise good practice.
CPD	See continuing professional development.
CT	See computerised tomography.
curative	Tending to overcome disease and promote recovery.
diagnosis	Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and possible causes for the symptoms.
disparity	A difference between.
dissemination	To spread or give out (especially news, information, ideas) to many people.
epidemiological	Relating to or involving epidemiology; the study of the distribution and determinants of health-related states and events in populations and the control of health problems, the study of epidemic disease.
episode of care	An episode of care can be of various types: in-patient; day case; day patient; haemodialysis patient; outpatient or AHP. Each episode is initiated by a referral (including re-referral) or admission, and is ended by a discharge. Each patient type, with a few minor exceptions, is associated with a type of episode of care. These episodes comprise a series of service contacts. It is important to note that a person may be in more than one episode

	at a time.
generic	Characteristic of or relating to a class or group of things; not specific.
guidelines	Systematically developed statements which help in deciding how to treat particular conditions.
healthcare professional	A person qualified in a health discipline.
homeopathy	A system of complementary medicine in which small, highly diluted quantities of medicinal substances are given to cure symptoms, when the same substances given at higher or more concentrated doses would cause those symptoms.
imaging	The production of images of organs or tissues using radiological procedures, particularly using scanning techniques.
interactive	Any process, or source which allows those using it to help shape the way in which the contact develops. For example, a source of information where input from the user determines the type, focus and depth of information given.
liaison psychiatry	Provides psychiatric treatment to patients attending general hospitals, whether they attend out-patient clinics or accident & emergency departments or are admitted to inpatient wards. It deals with the interface between physical and psychological health.
magnetic resonance imaging (MRI)	A special imaging technique used to image internal structures of the body, particularly the soft tissues. An MRI image is often superior to a normal X-ray image. It uses the influence of a large magnet to polarise hydrogen atoms in the tissues and then monitors the summation of the spinning energies within living cells. Images are very clear and are particularly good for soft tissue, brain and spinal cord, joints and abdomen. These scans may be used for detecting some cancers or for following their progress.
managed clinical network (MCN)	A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions. Each MCN is required to have a quality assurance framework describing the standards the service will meet. The framework has to be accredited by NHS QIS, and an annual report on progress is also required.
MCN	See managed clinical network
Medically unexplained symptoms (MUS)	Physical symptoms without organic basis.
Medicines and Healthcare Products Regulatory Agency (MHRA)	From 1 April 2003, the Medicines and Healthcare Products Regulatory Agency (MHRA) replaced the Medical Devices Agency (MDA) and the Medicines Control Agency (MCA). The MHRA is an Executive Agency of the Department of Health with trading fund status.

	The Agency is committed to safeguarding public health by ensuring that medicines, healthcare products and medical equipment meet appropriate standards of safety, quality, performance and effectiveness, and are used safely. Website: www.mhra.gov.uk
MHRA	See Medicines and Healthcare Products Regulatory Agency.
MRI	See magnetic resonance imaging.
multidisciplinary team	A group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition; the scale of the service being provided; and geographical/socio-economic factors in the local area.
MUS	See medically unexplained symptoms.
National Institute for Clinical Excellence (NICE)	NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patients and their carers, to help them make decisions about treatment and healthcare. NICE guidance and recommendations are prepared by independent groups that include healthcare professionals working in the NHS and people who are familiar with the issues affecting patients and carers. Website: www.nice.org.uk
neurophysiology	The study of how living organisms function; physiology of the nervous system.
neuropsychiatry	Psychiatry relating mental or emotional disturbance to disordered brain function.
neuropsychology	A branch of psychology that aims to understand how the structure and function of the brain relates to specific psychological processes.
NHS board	There are 23 NHS boards of two types: 15 territorial boards responsible for healthcare in their areas and eight special health boards which offer supporting services nationally. See NHS board (territorial) and special health board.
NHS board (territorial)	There are 15 territorial boards, the mainland being covered by 12 and the island groups (Orkney, Shetland and the Western Isles) by three. They are responsible and accountable for strategic planning, service delivery, performance management and governance within their local areas. Each NHS board uses the organisational building blocks of NHS direct care, such as community health partnerships or operating divisions, in a way which suits its geography and population. NHS boards work together in regional planning arrangements for those services which require that wider perspective. See community health partnership, NHS operating division and single system working. Website: www.show.scot.nhs.uk/organisations/orgindex.htm

NHS QIS	See NHS Quality Improvement Scotland.
NHS QIS products	Documents or initiatives produced by NHS QIS in conjunction with experts, which are distributed nationally.
NHS Quality Improvement Scotland (NHS QIS)	NHS QIS has been established (January 2003) to lead in improving the quality of care and treatment delivered by NHSScotland. To do this it sets standards and monitors performance, and provides NHSScotland with advice, guidance and support on effective clinical practice and service improvements. Website: nhshealthquality.org
NHSScotland	The National Health Service in Scotland
NICE	See National Institute for Clinical Excellence.
palliative care	Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment.
patient	1. A person who is receiving care or medical treatment. 2. A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes a patient is referred to as a user.
patient pathways	Patient pathways provide evidence-based and best practice recommendations for appropriate referral of patients from GPs to specialist outpatient care and appropriate follow-up care. They also provide diagnostic and management tips, act as an educational tool and provide sources of patient information. The Centre for Change and Innovation's patient pathways are not mandatory but are offered to NHS boards as a national resource for local adaptation and implementation. Web: www.cci.scot.nhs.uk/cci/files/Pathways%20Final%20Report%2020Mar06.pdf
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS QIS approach, all members of a review team are equal.
pharmacological	To do with the properties of drugs and their effects on the body.
policy	The highest level statement of intent and objectives within an organisation. A policy can also be a required process or procedure within an organisation.
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.
procedure	Operational instructions to regulate activity.
protocol	Set of perational instructions to regulate activity. Protocols may be

	national, or agreed locally to take into account local requirements.
referral	The process by which a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
respiration	The action of breathing.
respite care	Respite care is available in health and social care settings and at home, so that the patient and the carer can have a short break.
review	Examine or assess (something) formally with the possibility or intention of bringing about change if necessary. See peer review.
Scottish Executive Health Department (SEHD)	The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website: www.show.scot.nhs.uk/sehd
Scottish Intercollegiate Guidelines Network (SIGN)	To help improve the quality of healthcare SIGN develops national clinical guidelines aimed at reducing variations in clinical practice and in outcomes for patients. Founded in 1993 by the Academy of Royal Colleges and Faculties in Scotland, SIGN became part of the national clinical effectiveness body, NHS QIS, on 1 January 2005. The evidence base for many of the clinical standards developed by NHS QIS has been drawn from SIGN guidelines. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, 28 Thistle Street, Edinburgh, EH2 1EN. Website: www.sign.ac.uk
secondary care	Care provided in an acute sector setting. See acute sector.
SEHD	See Scottish Executive Health Department.
SfH	See Skills for Health.
SIGN	See Scottish Intercollegiate Guidelines Network.
Skills for Health (SfH)	Established in April 2002, SfH are part of the NHS, with own board and management, covering the whole health sector – NHS, independent and voluntary employers to help the whole sector develop solutions that deliver a skilled and flexible UK workforce in order to improve health and healthcare. Website: www.skillsforhealth.org.uk/
spasticity management	The treatment of muscle spasticity, which focuses on finding ways to provide relief from muscle tightness and stiffness caused by chronic conditions like cerebral palsy, multiple sclerosis, spinal cord injury, brain injury and stroke.
special health board	The name given to health boards with a national remit. These boards are focused on specific areas, for example NHS Education for Scotland, or NHS Quality Improvement Scotland. Special Health boards match regional NHS boards in terms of administrative grading. Web link: www.show.scot.nhs.uk/organisations/specialhbs.htm

standard	Required level of quality.
transition	Moving or preparing to move from one thing/situation to another.
whole time equivalent (WTE)	The approach by which headcount staff figures are adjusted to take account of part-time staff.
World Health Organisation (WHO)	A United Nations agency dealing with issues concerning health and disease around the globe. Website: www.who.int/en/
WTE	See Whole Time Equivalent.

Appendix 1: Steering group membership

Dr Roderick Duncan (Chair)	Consultant Neurologist, NHS Greater Glasgow
Mrs Sheena Bevan	Epilepsy Specialist Nurse, NHS Grampian
Ms Airlie Bryce	Pharmaceutical Care Model Schemes Co-ordinator, NHS Grampian
Dr Ali El-Ghorr	Project Manager, Centre for Change and Innovation, SEHD
Dr Donald Farquhar	Clinical Director (Medicine), NHS Lothian
Dr Eleanor Guthrie	General Practitioner, NHS
Mr Mark Hazelwood	Director, Multiple Sclerosis Society Scotland/Chair, Neurological Alliance of Scotland
Ms Thérèse Jackson	Consultant Occupational Therapist (Stroke), NHS Grampian
Ms Kitty Mason	Planning & Commissioning Officer, Health & Social Care Department, City of Edinburgh Council
Ms Norma McIndoe	MS MCN Manager, NHS Forth Valley
Mr David McNiven	Head of Neurological Services, Sue Ryder Care/Trustee of the UK Neurological Alliance
Dr Lance Sloan	Consultant in Rehabilitation Medicine, NHS Fife
Mr Craig Stockton	Chief Executive, Scottish Motor Neurone Disease Association/Vice Chair, Neurological Alliance of Scotland
Professor Charles Warlow	Professor of Medical Neurology, NHS Lothian

Support from NHS QIS was provided by:

Mr Michael Bews	Director of Guidance and Standards
Ms Hilary Davison	Standards Development Unit Team Manager
Mrs Paula Leggat	Team Support Administrator
Miss Ali McAllister	Project Officer
Mr Neill O'Shaughnessy	Senior Project Officer

Appendix 2: Terms of reference

1 Objectives

- 1.1 To scope the current provision of neurological services available to those affected by neurological conditions in NHSScotland, identifying main issues and areas of disparity that may exist.
- 1.2 To identify key policy documents, guidelines and initiatives in relation to services available to those affected by neurological conditions.
- 1.3 To recommend a programme of work for NHS QIS for the services available to those affected by neurological conditions throughout NHSScotland.

2 Scope

- 2.1 The group will work within the remit of NHS QIS aims and objectives.
- 2.2 The group will consider services available to adults affected by conditions that commonly present to neurological services.
- 2.3 The drafting of recommendations will take account of related activities and initiatives in NHS QIS and other organisations.
- 2.4 The recommended programme of work may include the following range of NHS QIS activities – audit, best practice statement, health technology assessment (HTA), standard setting.

3 Constraints

- 3.1 Existing NHS QIS work programme.
- 3.2 Existing programmes belonging to other organisations (avoiding conflict and duplication).

4 Assumptions

- 4.1 Appropriate representation on the group.
- 4.2 Sufficient NHS QIS resources to support the work of the group.
- 4.3 Members of the group representing external organisations will actively communicate with those organisations.
- 4.4 The work of the group will be patient focused.
- 4.5 The group will meet approximately 4 times in 5 months.
- 4.6 Recommendations to be identified and drafted by November 2005.

5 Reporting

- 5.1 The group's pre-scoping report will be a public document, available upon request from NHS QIS and on the internet.

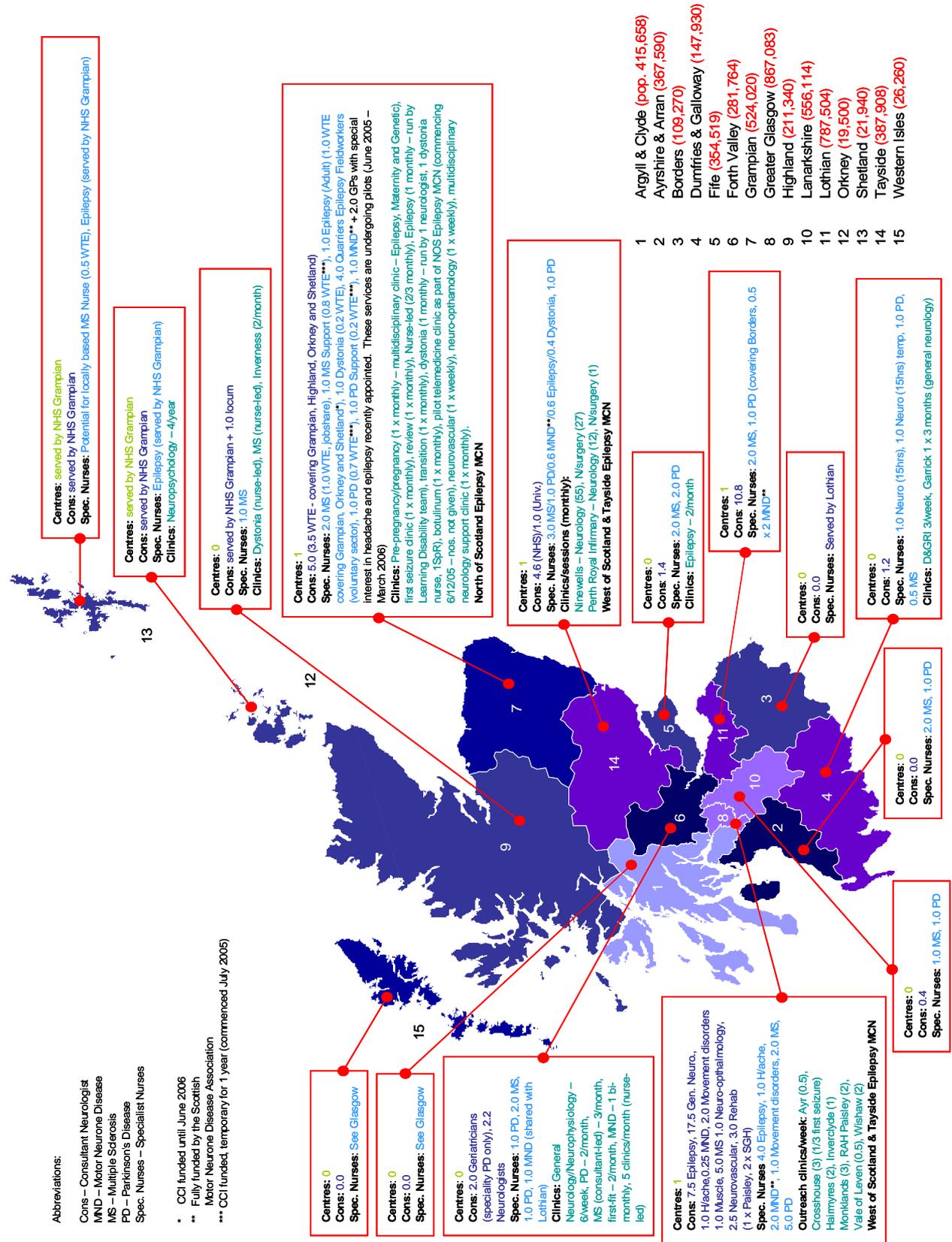
6 Deliverables

- 6.1 Final report, for presentation to NHS QIS Board in December 2005.

The report will include:

- an introduction
- a service map for core neurological services for NHSScotland
- key issues
- specific issues
- recommendations detailing a NHS QIS work programme
- summary
- any other relevant information, and
- appendices.

Appendix 3: Neurological services – a snapshot of service mapping in NHSScotland



Appendix 4: NHS QIS product list

Product name	Audits
Description	Individual audit projects or co-ordinated programmes of work with a national focus addressing specific topic areas and funded by NHS QIS. Final reports peer reviewed and published. Previously overseen by the Clinical Effectiveness Programmes Subgroup (CEPS) of Clinical Resource and Audit Group (CRAG). (Project-based planned work)
Product name	Best practice statements
Description	Individual reports providing guidance on best and achievable practice on specific topics identified by nurses and midwives as being priorities. Blend of evidence and professional consensus compiled by multi-disciplinary working groups of relevant experts. Disseminated widely within NHSScotland. (Project-based planned work)
Product name	Clinical governance/effectiveness support
Description	Widely varied work supporting clinical governance activities in NHSScotland including networks, training, conferences and workshops, expert groups, surveys and feedback, provision of advice and guidance, educational activities, library and information services. (Non-project-based, responds to demand)
Product name	Clinical outcome indicators
Description	Annual report of outcome indicators on a range of health topics, varying from year to year, showing trends over time and geographical variation at NHS board level. Overseen by Clinical Outcomes Working Group; data analysis by ISD using national data. All topics are published at the same time.
Product name	Comments on NICE guidance
Description	An email alert about issuing the NICE guidance to Scotland and highlighting any important contextual differences affecting its use in Scotland such as: principles and values of NHSScotland, epidemiology, structure and provision of services in Scotland and other implications, eg rural issues, predicted update, existing advice from Scottish Medicines Consortium (SMC). (Project based, planned work)

Product name	Evidence notes
Description	A one page note which highlights key issues for health service planners and practitioners and directs them to robust sources of evidence (or lack of evidence) on a particular topic or clinical area which is believed important for NHSScotland. (Non-project-based, responds to demand)
Product name	Frameworks
Description	(Non-project-based, responds to demand)
Product name	Health technology assessments (full)
Description	Advice on the clinical effectiveness, cost effectiveness, patient issues and organisational issues associated with using a health technology in NHSScotland. (Project-based planned work)
Product name	Health technology assessments (short)
Description	Advice on the clinical and cost effectiveness of a health technology in NHSScotland. (Non-project-based, responds to demand)
Product name	Managed clinical networks
Description	Advice and support in the development of each managed clinical network's Quality Assurance (QA) Framework, in accordance with NHS QIS guidance manual, followed by formal endorsement of the QA Framework which is valid for 3 years. During the 3-year endorsement period, annual reports are reviewed, and at its conclusion the revised framework is evaluated. (Non-project-based, responds to demand)
Product name	Quality indicators and local reviews
Description	Quality indicators for learning and physical disability services, mental health and services for the frail and elderly. Reviews are carried out on an area-wide basis every 2–4 years and findings are published. Visits are routinely followed up by an action plan or revisit if required. (Project-based planned work)

Product name	SIGN guidelines
Description	A practical guideline of recommendations based on evaluation and synthesis of available evidence derived from a systematic literature review. The draft is consulted on publicly and within the Service, after which the guideline is distributed for implementation at local level. (Project-based planned work). NHS QIS funds and approves the SIGN programme of work, but guideline content is the responsibility of the SIGN Council.
Product name	SMC product assessments
Description	Advice to NHS Boards and their Area Drug and Therapeutics Committees (ADTCs) across Scotland about the status of all newly licensed medicines, all new formulations of existing medicines and any major new indications for established products. This advice will be made available as soon as practical after the launch of the product involved. (Non-project-based, responds to demand). NHS QIS facilitates the work of the SMC, but the assessments are the responsibility of the SMC Chair and the Consortium.
Product name	Standards and reviews
Description	The development of draft standards which are finalised after extensive public consultation (the standards phase). Following a period during which the standards are assimilated into NHSScotland working practice, all providers of the relevant service are assessed against the standards. Individual reports and a national overview reporting the assessment of performance against the standards are published (the review phase). (Project-based planned work)

Appendix 5: Presentation topics

- 1 Topic: NHS Quality Improvement Scotland**
Presented by: Mr Michael Bews, Director of Guidance and Standards, and Ms Hilary Davison, Standards Development Unit Team Manager, NHS Quality Improvement Scotland
Date: 6 July 2005
- 2 Topic: Neurological Services Pre-scoping Steering Group: Principal Recommendations (Executive Summary)**
Presented by: Dr Roderick Duncan, Consultant Neurologist, NHS Greater Glasgow/Chair of the neurological services pre-scoping steering group
Date: Presented to the NHS QIS Board, 2 February 2006

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