



*The National Service  
Framework for  
Long-term Conditions*

March 2005

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Long-term Conditions*

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<b>Circulation List</b>	
<b>Description</b>	This NSF sets 11 quality requirements to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. Although the NSF focuses on people with long-term neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition.
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<b>For Recipient's Use</b>	

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# Ministerial foreword



This *National Service Framework (NSF) for Long-term Conditions* marks a real change in the way health and social care bodies and their local partners will work with people with long-term conditions to plan and deliver the services which they need to make their lives better.

The NHS has a tremendous record in saving lives and combating illness. Deaths from cardiovascular disease and cancer have fallen by 27% and 12% respectively<sup>i</sup>. But that is not enough. For many people living with conditions such as multiple sclerosis or Parkinson's disease the main issue, until science can find a cure, is improving the quality of their lives, supporting them to manage their symptoms and live as independently as possible. We now need to build on what the NHS and social services have achieved and develop services which can respond better to the needs of this group of people. The *NHS Improvement Plan: Putting People at the Heart of Public Services* sets a new strategic model for management of long-term conditions through self care, disease management and case management. This NSF is a further demonstration of the priority health ministers attach to improving the lives of people with long-term conditions by:

- giving people choice, through services planned and delivered around their individual needs;
- supporting people to live independently and play their full part in society;
- co-ordinating partnership working between health and social services and other local agencies.

This NSF also builds on *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration*, which introduces new management arrangements for transforming service delivery for people living with long-term conditions. The NSF aims to make this new approach a reality for people living with long-term neurological conditions. It is a very important step in delivering this strategic shift in the way in which health and social care organisations work together to support people with long-term conditions.

The NSF focuses on neurological conditions and its quality requirements are based on evidence from services for people with neurological conditions. But that focus on neurology highlights and sets in clear context issues which are also relevant to the millions of people living with other long-term conditions such as arthritis. For instance, in showing the difference which can be made by putting people with long-term neurological conditions at the heart of their own care, the NSF demonstrates the importance of the person-centred approach for everyone who uses health and social care services. Similarly, the evidence in the NSF about the value of improving access to assistive technology and of opening up palliative care for people with neurological conditions can also apply to other people living with disabilities and persistent pain.

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i Department of Health statistics supplied in January 2005 show that the death rate from cardiovascular disease in people under 75 years of age has fallen by 27% since the 1995–1997 baseline. The death rate from cancer in people under 75 years of age has also fallen by 12.2% compared with the 1995–1997 baseline.

Change cannot happen overnight. It will take time to train staff and develop new facilities and services. That is why we are giving commissioners and providers up to 10 years to implement fully the recommendations of this NSF. However, there are changes which can be made to bring improvements in the shorter term. The *NSF Good Practice Guide* we are providing for care service professionals, together with the report of the Modernisation Agency Action on Neurology programme, will provide practical help to transform services. We will ensure that everyone living with a long-term condition, and their families and carers, will be able to understand what help and support they can expect. Finally, we are working with the Health Care Commission and the Commission for Social Care Inspection to help them review and monitor service change.

A handwritten signature in black ink, reading "John Reid". The signature is written in a cursive style with a long horizontal stroke at the end.

**John Reid**  
Secretary of State for Health

# Executive summary

## Introduction

1. This *National Service Framework (NSF) for Long-term Conditions* is a key tool for delivering the government's strategy to support people with long-term conditions outlined in the *NHS Improvement Plan: Putting People at the Heart of Public Services*.
2. The NSF aims to build on proposed changes in NHS management and commissioning to bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions. It should be read alongside *National Standards, Local Action: The Health and Social Care Standards and Planning Framework 2005/6 – 2007/8*, which promises consistently high standards of NHS care across the country, and *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration*. The forthcoming Green Paper on the future of social care for adults in England will consult on how more joined-up, responsive social care services may be achieved to enable people to live independently in the community. The NSF applies to health and social care services working with local agencies involved in supporting people to live independently, such as providers of transport, housing, employment, education, benefits and pensions.
3. At the heart of this NSF are the 11 quality requirements (QRs) set out in detail in Chapter 2. These are drawn from and mapped against the core and developmental standards in *National Standards, Local Action*, and are to be fully implemented by 2015.
4. Chapters 3, 4 and 5 explain how these QRs could be delivered. They cover models for clinical neuroscience networks for commissioning and service delivery, initiatives to support local delivery and guidance on taking the next steps. Further advice is available in the accompanying *NSF Good Practice Guide* (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).
5. The NSF does not address individual neurological conditions separately as there are so many elements of service provision common to different conditions. However, where appropriate, the QRs have a separate section addressing the needs of people with rapidly progressing neurological conditions, such as motor neurone disease, because of the need for services to respond quickly.
6. Although this NSF focuses on people with neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition. Commissioners are therefore encouraged to use this NSF in planning service developments for people with other long-term conditions.
7. Implementing this NSF will contribute to the following Public Service Agreement targets:
  - to improve health outcomes for people with long-term conditions by offering a personalised care plan for vulnerable people most at risk;
  - to reduce emergency bed days by 5% by 2008 through improved care in primary care and community settings for people with long-term conditions;
  - to improve access to services, ensuring that by 2008 no one waits more than 18 weeks from GP referral to hospital treatment, including all diagnostic procedures and tests.

8. The NSF fully supports the concept of choice set out in *Building on the Best: Choice, responsiveness and equity in the NHS*. This aims to ensure that all people have a choice of when, where and how they are treated from onset of illness until the end of life.

## The quality requirements (QRs)

9. The QRs are based on currently available evidence<sup>i</sup>, including what people with long-term neurological conditions told us about their experiences and needs.
- **Quality requirement 1: A person-centred service**  
People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.
  - **Quality requirement 2: Early recognition, prompt diagnosis and treatment**  
People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.
  - **Quality requirement 3: Emergency and acute management**  
People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.
  - **Quality requirement 4: Early and specialist rehabilitation**  
People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home<sup>ii</sup> for ongoing community rehabilitation and support.
  - **Quality requirement 5: Community rehabilitation and support**  
People with long-term neurological conditions living at home<sup>ii</sup> are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.
  - **Quality requirement 6: Vocational rehabilitation**  
People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.
  - **Quality requirement 7: Providing equipment and accommodation**  
People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

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i The evidence base for the NSF as a whole is described in Annex 2.

ii 'Home' in this context means the place where the individual **chooses** to live, which may be their own accommodation or may be a residential or care home.



- **Quality requirement 8: Providing personal care and support**  
Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home<sup>i</sup>.
- **Quality requirement 9: Palliative care**  
People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.
- **Quality requirement 10: Supporting family and carers**  
Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.
- **Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings**  
People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

## Delivering change

10. These QRs are designed to put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate at every stage from diagnosis to end of life. The emphasis throughout this NSF is on supporting people to live with long-term neurological conditions, improving their quality of life and providing services to support independent living. The Department of Health (DH) is committed to ensuring policies are properly funded. As the NSF places no new requirements on local authorities and they, with their partners, are able to set their own pace of change within the 10 year implementation period according to local priorities, DH expects individual local authorities to take the NSF forward within their existing spending plans.
11. Implementing this NSF by 2015 will improve services significantly, not just for those with neurological conditions but also for many other people living with long-term conditions.
12. This NSF is supported by a web-based *NSF Good Practice Guide*, a *NSF Information Strategy*, a leaflet for the public and glossary of terms (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).

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i 'Home' in this context means the place where the individual **chooses** to live, which may be their own accommodation or a residential or care home.

# 1 Setting the scene

## Introduction

1. This *National Service Framework (NSF) for Long-term Conditions* has been developed with the advice of an independent External Reference Group<sup>i</sup>. It sets out quality requirements (QRs) and evidence-based markers of good practice which suggest how the NSF could be implemented locally to improve health and social care services for people with long-term neurological conditions and their carers. It aims to promote quality of life and independence by ensuring they receive co-ordinated care and support that is planned around their needs and choices. The QRs cover treatment, care and support from diagnosis to end of life. A *NSF Good Practice Guide*, a *NSF Information Strategy*, a leaflet for the public and glossary of terms are available online (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).
2. The NSF applies to health and social care services. However, people with long-term neurological conditions also need support with a range of issues including transport, housing, employment, education, benefits and pensions. For this reason, arrangements for working together with a full range of other agencies are vital to support people to live independently and to deliver key elements of the NSF.
3. The NSF does not address individual neurological conditions separately as there are so many elements of service provision that are common to different conditions. However, where appropriate, the QRs have a separate section addressing the needs of people with rapidly progressing neurological conditions (eg motor neurone disease) because of the need for services to respond quickly.
4. Although this NSF focuses on people with neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition. Commissioners are therefore encouraged to use this NSF in planning service developments for people with other long-term conditions.

## How this NSF fits into the changing NHS

5. The NSF is a key element within a wider package of initiatives to improve services for people living with long-term conditions. In particular, the NSF should be viewed in the context of:
  - *The NHS Improvement Plan: Putting People at the Heart of Public Services;*
  - *National Standards, Local Action – The Health and Social Care Standards and Planning Framework 2005/6 – 2007/8;*
  - *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration;*
  - The Prime Minister’s Strategy Unit’s project: *Improving the Life Chances of Disabled People;*
  - The Public Health White Paper: *Choosing Health;*
  - The forthcoming Green Paper on the future of social care for adults in England.

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i Details of the External Reference Group, including terms of reference, are given in Annex 1.

6. Chapter 3 of *The NHS Improvement Plan: Putting People at the Heart of Public Services and Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration* demonstrate the high priority that the government gives to improving care and support and quality of life for people with long-term conditions. This NSF is the next step in delivering real change in services.
7. The NSF builds on the management strategy described in *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration* in exploring how person-centred care planning, information and support, self care, disease management and case management can be put into practice to transform services for people living with long-term neurological conditions. Although there is substantial common ground between the NSF and this strategy, it is important to preserve the neurological focus in implementing the NSF and make sure that it retains its own discrete identity under the umbrella of the broader long-term conditions programme.
8. The NSF fully supports the concept of choice set out in *Building on the Best: Choice, responsiveness and equity in the NHS*. This aims to ensure everyone has a choice of when, where and how they are treated and the right to choose where they wish to die. The NSF will also help to deliver *Choosing Health*, the government's White Paper on improving public health in England. *Choosing Health* aims to provide information, advice and support to give people the opportunity to make healthy choices and change their lifestyles to improve their physical, sexual and mental health and their well-being.
9. This NSF concentrates on adult services but also takes account of other relevant NSFs, particularly those for children and older people. As a result, it highlights the fact that transition issues (eg when someone needing ongoing care moves from children's to adult services) need to be properly addressed to ensure continuity of care, support through life changes and that access to services is based on need, not age.

## Standards, targets and assessment

10. The NSF supports the NHS in working with social services and their partners at local level to plan and deliver services for people with long-term neurological conditions in line with the national standards set out in *National Standards, Local Action – The Health and Social Care Standards and Planning Framework 2005/6 – 2007/8*.
11. These standards include a requirement (Standard D2 on clinical and cost effectiveness) for people to receive effective treatment and care that conforms to nationally agreed best practice, particularly as defined in NSFs. Other standards particularly relevant to this NSF include those cited under 'Patient Focus' (access to information, care planning and self care) and 'Accessible and Responsive Care'. The QRs in this NSF are drawn from and mapped against these national core and developmental standards and this is indicated in a footnote on the first page of each QR.
12. *National Standards, Local Action* emphasises that all health and social care organisations, including NHS Foundation Trusts, should regard NSFs as part of their developmental standards. Their performance will be assessed not just against how they do on national targets but increasingly on whether they are delivering high quality standards across a range of areas, including NSFs. This NSF is for implementation over 10 years and local bodies can set their own pace of change within this period, according to local priorities. However, the *Planning Framework* makes clear that the NHS and local authorities will need to demonstrate that they are making progress in planning and developing the levels of service quality described in the NSF over the course of the three year planning period (2005/8). In due course, the Healthcare Commission and the Commission for Social Care Inspection (CSCI) may undertake thematic reviews of progress, jointly where appropriate.

13. Implementing this NSF will contribute to the following Public Service Agreement (PSA) targets:
  - to improve health outcomes for people with long-term conditions by offering a personalised care plan for vulnerable people;
  - to reduce emergency bed days by 5% by 2008 through improved care in primary care and community settings for people with long-term conditions;
  - to improve access to services ensuring that, by 2008, no one waits more than 18 weeks from GP referral to hospital treatment (with all diagnostic procedures and tests completed during this period).
14. The NSF is supported by a web-based *NSF Good Practice Guide*, a *NSF Information Strategy*, a leaflet for the public and glossary of terms (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).
15. This NSF is based on the current body of evidence. Randomised controlled trials and other quantitative methodologies are not necessarily best suited to research questions about quality of life. Therefore, a new typology has been developed (and agreed with the Department of Health's Research and Development Division) for this NSF to review the evidence available. It separates judgements of research quality from descriptions of research design. This research typology is set out in detail in Annex 2 and a full list of references that support the QRs is in Annex 3. Evaluating services over time will be crucial to delivery, including considering the need for a primary research programme where appropriate. This evaluation will be most effective if it is based on sharing expertise within and between agencies and on building user and carer experience into service review and development.

## Background

### What are long-term neurological conditions?

16. A 'long-term neurological condition' results from disease of, injury or damage to the body's nervous system (ie the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life.
17. Long-term neurological conditions can be broadly categorised as follows:
  - **sudden-onset conditions**, for example acquired brain injury or spinal cord injury, followed by a partial recovery. (Note: stroke for all ages is covered in the NSF for Older People);
  - **intermittent and unpredictable conditions**, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed;
  - **progressive conditions**, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (eg motor neurone disease) deterioration can be rapid. (Note: dementia for all ages is covered in the NSF for Older People);
  - **stable neurological conditions, but with changing needs due to development or ageing**, for example post-polio syndrome or cerebral palsy in adults.
18. There is a wide variety of long-term neurological conditions and people have very different experiences. Conditions may be present at birth (eg cerebral palsy) and some of these may be associated with varying degrees of learning disability. Other conditions appear in childhood (eg Duchenne's muscular dystrophy) or develop during adulthood (eg Parkinson's disease).

19. The time course of conditions also varies widely. The average time between diagnosis and death for someone with motor neurone disease is 14 months, while someone with multiple sclerosis may live with the condition for decades. Even within specific conditions, the needs of individuals, for example for social care support, vary widely. A key feature of this NSF, therefore, is supporting people with long-term neurological conditions to live independently, often for many years.

## How many people are affected?

20. Taken together, neurological conditions are common. For example, 8 million people in the UK suffer from migraine<sup>i</sup>. Altogether, approximately 10 million people across the UK have a neurological condition<sup>ii</sup>. These account for 20% of acute hospital admissions and are the third-most common reason for seeing a GP. Around 17 people in a population of 100,000<sup>iii</sup> are likely to develop Parkinson's disease, and two people in a population of 100,000 experience a traumatic spinal injury every year<sup>iv</sup>. An estimated 350,000 people across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition<sup>ii</sup>.

## How are people affected?

21. The diagnosis or onset of a long-term neurological condition generally marks the beginning of profound changes in the life of the person and the lives of their carer, family and friends. It may affect relationships, career prospects, income and expectations for the future.
22. Long-term neurological conditions can cause a range of different problems for the individual, including:
- **Physical or motor problems**, such as paralysis, inability to walk, fatigue, incontinence, sexual difficulties and, for some people, impairment of all motor functions.

*John (30) lives in Sheffield and was diagnosed with motor neurone disease in March 2001. He now uses a wheelchair full-time because his balance is very poor. John also has major muscle wasting in his shoulders, arms and hands and has little use left in them.*

Motor Neurone Disease Association

- **Sensory problems**, such as loss of vision or hearing, pain and altered sensation.

*Gary was a young, active tetraplegic for nine years before developing appendicitis leading to peritonitis and death. Because of the lack of feeling associated with paralysis, he was unable to feel or complain of pain in the abdomen. He was admitted to a district general hospital. Like all individuals with tetraplegia, he did not exhibit the usual symptoms and signs associated with appendicitis and peritonitis. The diagnosis was made on post-mortem.*

Midlands Centre for Spinal Injuries

i See the epidemiological table at Annex 4. Note: stroke and dementia for all ages are covered in the NSF for Older People.

ii *Neuro numbers – a brief review of the numbers of people in the UK with a neurological condition*. April 2003. The Neurological Alliance.

iii *Journal of Neurology*, March 2002, Vol 249, number 3, pp. 260–265.

iv Spinal Injury Association reports 666 new patient admissions (equivalent to about 2/100,000) to spinal injury centres in the UK and Ireland in 2000.

- **Cognitive/behavioural problems**, such as: lapses in memory and attention; difficulties in organisation, planning and problem-solving; confusion; apathy; disinhibition and lack of insight into difficulties. People with these problems may need additional support to make decisions and take responsibility for their own care.

*Four years ago, Louise noticed that Robert's behaviour was becoming uncharacteristically erratic. He was verbally aggressive, and his behaviour in company and at work was insensitive. Robert denied there was anything untoward. After a year, multiple sclerosis was diagnosed, by which time Robert's confusion was more marked and his mobility was affected. Robert and Louise both stopped work as Robert couldn't be left alone. Robert continues to deny that anything is seriously amiss. Their daughter has become withdrawn and is badly affected by Robert's temper outbursts.*

*We're in This Together, Carers UK, 1999*

- **Communication problems**, such as difficulties in speaking or using language to communicate and in fully understanding what is said or written. People with these problems may need additional support to access information or to communicate their needs and wishes.

*"Sometimes people found it difficult to understand me. I got very frustrated – especially when they just smiled, or nodded and pretended they knew what I was saying. In the end I just stopped trying – I wouldn't answer the phone and I stopped going out. That was before I started speech therapy. Now I've learned techniques to help me control my breathing and I speak more clearly. I'm much more confident and last month I re-joined the local bowls club."*

*Parkinson's Disease Self-care Manual, 2000*

- **Psychosocial and emotional effects** of the condition for the individual, such as potential personality changes after a brain injury and the emotional and psychological effects of living with a long-term condition generally on the individual, their carer and family. These can include stress, depression, loss of self-image and cognitive/behavioural issues, which may lead to relationship breakdown if not addressed.

*"I wish I could still say that I felt something for John, but he's a completely different person to the husband I married... I feel like I'm sharing a bed with a complete stranger ... I don't know how long I can bear it."*

*Wife of a man with severe brain injury*

## Who will benefit from this NSF?

23. Although this NSF focuses on the needs of people living with neurological conditions, it will make an important contribution to delivering the government's overall strategy to improve NHS and social care support for all people living with long-term conditions.
24. The quality requirements are derived from research and expert evidence specific to neurological conditions, but many elements of them are relevant to people with other long-term conditions, for example:
  - prompt diagnosis;
  - providing information and support;
  - person-centred care and choice;



- providing information and support for the safe and effective use of medicines;
- care planning and integrated service provision involving different agencies, including closer working between health and social services;
- planning and liaison when people make transitions between services;
- supporting self care and considering health promotion needs;
- prompt access to treatment which complies with National Institute for Clinical Excellence (NICE) guidelines and timely referral for appropriate specialist intervention;
- rehabilitation and support in the community and vocational rehabilitation;
- providing equipment and adapted accommodation;
- equitable assessment for fully funded NHS continuing care and adult social care under *Fair Access to Care Services*;
- providing palliative care to people who have conditions other than cancer;
- supporting carers;
- managing long-term conditions effectively when in hospital (or other settings) for other problems.

## Improving service delivery

### Specialised services

25. In the Department of Health's guidance for commissioning specialised services, certain elements of neurological services are designated as 'specialised'. These include neurology, neurosurgery, rehabilitation for adults with brain injury and complex disability.
26. In many areas, this has resulted in the concentration of such services in specialist centres. There are several 'hub-and-spoke' and outreach models where staff from the specialist centres spend part of their time working in local hospitals and in the community. In some cases this has led to a clinical network which supports the development of local expertise and enables more treatment to be delivered closer to home, while still retaining access to specialist services for those who need them.

### Local services

27. Other services are commissioned and provided locally. These include community rehabilitation (and sometimes specific neuro-rehabilitation); community equipment services; personal care services and respite provision. Close collaboration between health and social services is key to assessing local needs and commissioning co-ordinated care.
28. General practice plays an important role in service delivery along the entire care pathway. Wherever primary care is mentioned in this NSF, it includes all health and social care professionals who are involved with people with long-term neurological conditions in community settings.

## The bigger picture

29. Consultation with service providers, people with long-term neurological conditions and their carers has revealed examples of high quality services (see the *Long-term Conditions NSF: Good Practice Guide*) but also great variation in levels of provision across the country. There is also evidence that people within black and minority ethnic communities experience greater difficulty in accessing neurological services.
30. Recent snapshot information from four local authorities (Richmond, West Sussex, Bath and Northeast Somerset and Essex) suggests that 50% of people aged 18–65 receiving social services support have a neurological condition. If this were representative across England, it would equate to about 63,000 people aged 18–65 with a neurological condition getting such help. This extrapolated figure suggests a significant level of unmet need across the country<sup>i</sup>. Supporting people with long-term neurological conditions to apply for Direct Payments; assessments for social care services in line with guidance on *Fair Access to Care Services* and prompt and fair assessment of eligibility for fully funded NHS continuing care could help meet this need and is addressed in QR8. Steps to ensure equity and consistency of criteria and assessment processes, which include taking account of the needs of people with long-term neurological conditions, will be part of ongoing work to improve the provision of NHS continuing care.

## Improving services

31. One of the distinguishing characteristics of this NSF is that it is about supporting people with long-term neurological conditions to *live* as independently as possible. The need to address some fundamental issues about how people wish to live – whether at home, with their families or in residential care – has guided the development of the QRs. These QRs set out a clear vision of how to improve the quality, consistency and responsiveness of services and personalised care. They cover:
  - providing information and co-ordinated person-centred care (QR1);
  - improving access to neurological services for diagnosis and treatment (QR2);
  - improving care of people experiencing a neurological or neurosurgical emergency (QR3);
  - improving access to rehabilitation services so that people disabled as a result of a neurological condition can achieve and maintain the greatest possible level of independence and social inclusion (QR4–6);
  - providing flexible services and packages of care to help people live as independently as possible according to their own choices (QR7–8);
  - improving palliative care services for people in the later stages of their illness (QR9);
  - supporting families and carers (QR10);
  - providing appropriate neurological care in hospital and other health and social care settings (QR11).
32. Underpinning all of these QRs is the need at all times to:
  - challenge discrimination and reduce inequalities, including those faced by black and minority ethnic communities, who may find it difficult to access neurological services;
  - treat people with long-term neurological conditions with respect and dignity and listen to and act on their views regardless of their age, disability, race, gender, sexual orientation and religion or beliefs.

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i Source: Jeff Jerome, Director of Social Services, Richmond Social Services.



# 2 Quality requirements

## Introduction

1. This NSF aims to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. It puts the people who have these conditions, along with their family and carers, at the centre of care by setting out evidence-based quality requirements (QRs) from diagnosis to end-of-life care. These are underpinned by evidence-based markers of good practice which suggest how the NSF could be implemented locally. These QRs, together with the *NSF Good Practice Guide*, *NSF Information Strategy*, leaflet for the public and glossary (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)), will help health and social care professionals and their partners plan and deliver responsive, person-centred services, taking into account the needs and choices of individuals.
2. The QRs focus on the needs of people living with long-term neurological conditions but much of their content applies equally to people with other long-term conditions. Anyone involved in care and service planning and provision for this larger group will find this document useful.
3. Where appropriate at the end of each of the QRs, there is a short section setting out how the markers of good practice apply to people with rapidly progressing conditions because of the need for services to respond quickly.

## An overview of the quality requirements

### QR1: A person-centred service

4. QR1 underpins all the other QRs. The delivery of this ‘core’ requirement will improve the co-ordination of services and address many of the key issues service users and voluntary organisations have identified. These include information and the need for a holistic, integrated, interdisciplinary approach to care planning, review and service delivery involving a range of agencies.

### QR2 and QR3: Prompt diagnosis, appropriate referral and treatment

5. QR2 and QR3 set out how people with long-term neurological conditions are identified and referred to appropriate specialist healthcare services as quickly and with as few intermediate steps as possible. Prompt action at this stage can reduce neurological damage, slow down the rate of disease progression, increase survival rates and improve the person’s quality of life. In particular, these QRs aim to ensure that:
  - a. there is early recognition of neurological symptoms both in primary care and acute and emergency settings;
  - b. people who present with neurological symptoms are referred to specialist services quickly and the care pathway allows direct referral to a specialist in accordance with locally agreed protocols;
  - c. people receive a prompt diagnosis;

- d. people receive emergency care from staff with appropriate neurological and resuscitation skills and facilities;
- e. appropriate treatment is jointly agreed with individuals and begins as soon as possible;
- f. people receive safe and effective medicines, the use of which has been jointly agreed between healthcare professionals and the person.

#### **QR4 to QR6: Rehabilitation, adjustment and social integration**

- 6. Neurological conditions can result in profound life changes. Skilled rehabilitation teams can help people make major physical, emotional, social and environmental adjustments so they can become more independent and enjoy a better quality of life. Rehabilitation can also prevent deterioration and secondary complications such as pressure sores.
- 7. Multidisciplinary teams of health and social care professionals usually deliver rehabilitation<sup>i</sup>. These teams can work in different ways depending on the setting and person's needs:
  - a. **Multidisciplinary working:** some teams consist of a group of different professionals working alongside one another towards a common goal, for example, a review clinic offering a thorough reassessment of needs by a multidisciplinary team. Their interventions are delivered in parallel rather than in close collaboration.
  - b. **Interdisciplinary working:** this involves teams taking a more integrated approach. They work together towards a set of agreed goals, often undertaking joint sessions. Team members have a fuller understanding of other members' roles and skills and can work together in a holistic way, ensuring the various treatments complement each other. This approach is often seen in settings where staff are able to collaborate on a regular basis, for example, working in specialist neuro-rehabilitation teams, either in inpatient rehabilitation units or in the community.
- 8. QR4 addresses early and specialist neuro-rehabilitation in the context of inpatient or residential settings, with planned, co-ordinated transfer to the community and re-access as needed. QR5 addresses rehabilitation at home and in the community. It includes supporting people as they adjust to change and take part in leisure and other social activities. QR6 addresses work and vocational rehabilitation. It includes supporting people to remain in, begin or return to employment or other occupational activity.

#### **QR7 to QR11: Life-long care and support for people with long-term neurological conditions, families and carers**

- 9. People often live with their condition for decades, so providing well co-ordinated, long-term support is at least as important to their quality of life as prompt diagnosis and early treatment of the condition.
- 10. Many people find it difficult to maintain an independent life, particularly in the face of increasing disability. This can lead to long-term social and psychological difficulties for them and their families and carers. Providing personal care, support, equipment and accommodation planned around their needs and wishes can help them to retain their independence and remain in their own homes. QR7 addresses the provision of equipment and home adaptations.
- 11. QR8 addresses assessment of personal care and support. The assessment needs to take account of the person's physical, cognitive, psychological and emotional difficulties. It also needs to cover family circumstances, religious, cultural and ethnic needs. People's preferences about care setting, the scope for help and support to prevent deterioration, social isolation and increased dependence will also be important.

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<sup>i</sup> Health and social care professionals on the team can include: doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, social workers, pharmacists, dietitians, psychologists, chiropodists, podiatrists, orthoptists, art, drama and music therapists, clinical scientists, prosthetists, orthotists and counsellors. This list is not exhaustive.

12. QR9 addresses the need for palliative care services for people in the advanced stages of neurological conditions and the importance of enabling people to make choices about end-of-life care.
13. QR10 addresses the need to offer information, advice and support to families and carers.
14. QR11 addresses the provision of care in other settings, for example, during treatment for non-neurological health problems. Good planning can ensure that the management of the neurological condition and the person's self care are not compromised.

## Quality requirement 1: A person-centred service<sup>i</sup>

### Aim

1. To support people with long-term neurological conditions in managing their condition, maintaining independence and achieving the best possible quality of life through an integrated process of education, information sharing, assessment, care planning and service delivery.

### Quality requirement

2. People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

### Rationale

#### Integrated assessment and care planning

3. People with neurological conditions can experience a wide range of complex physical, sensory, cognitive, psychological, emotional, behavioural and social difficulties<sup>1-4</sup>, with a broad range of needs. An integrated approach to assessment of care and support needs and to the delivery of services is key to improving the quality of life of people with long-term neurological conditions. There is evidence that:
  - a. the most effective support for people with long-term neurological conditions is provided when local health and social services teams communicate; have access to up-to-date case notes and patient-held records and work together to provide co-ordinated services<sup>5-9</sup>. Social services tend to provide the greater part of support for people with relatively severe disabilities;
  - b. an integrated system of assessment and care planning can prevent unnecessary reassessment and repetition of basic information. It also helps to ensure that case notes are complete and people are receiving appropriate services<sup>10,11</sup>;
  - c. broad-based and holistic assessment by health and social care services<sup>6,12</sup> can lead to successful interventions, rehabilitation and care. These can: limit the development of predictable secondary consequences of disease<sup>13,14</sup>; increase the effectiveness of earlier rehabilitation; promote improved quality of life for people, their families and carers<sup>15,16</sup> and improve opportunities for social participation; and
  - d. people with long-term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing their medicines; treatment of specific symptoms; help to understand their condition and its current and future management<sup>17</sup>. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve well-being<sup>18-21</sup>.

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<sup>i</sup> This quality requirement supports Standards: C9, C11, D5, D6 and D7 – Governance; C13, C16, D8, D9 and D10 – Patient focus; C5a, C6 and D2 – Clinical and cost effectiveness; C17, C18 and D11 – Accessible and responsive care; C20 – Care environment; C22a, C23 and D13 – Public health. Public Service Agreement Objective II: improve health outcomes for people with long-term conditions and; Objective IV: improve the patient and user experience.

### **Developing integrated care planning and review**

4. The care planning process needs an integrated multidisciplinary team of people who have the appropriate training, expertise and skills and who are able to cross-refer to provide co-ordinated care<sup>12,17,22,23</sup>.
5. Successful care planning is person-centred and recognises that needs will change over time<sup>10,11,24–28</sup>. It may be a simple or complex process depending on the condition and the range of services needed<sup>9,26,27</sup>. The care plan needs to be developed and agreed with the person and, subject to their agreement, with their carers and/or an advocate. The care plan is owned by the person, and the relevant multidisciplinary team members review it regularly with them. The professional developing the care plan has a role to help the person navigate their way around the health and social care system<sup>29</sup>.
6. The care planning process is likely to include:
  - a. assessing immediate needs and potential future needs, including risk assessment;
  - b. assessing support needed to:
    - maintain opportunities for independent living;
    - delay deterioration in physical or mental health; and
    - prevent social exclusion;
  - c. reviewing treatment plans (see QR2);
  - d. considering services and support to enable people to play a full, inclusive role in society, including housing, transport, benefits, education, careers advice, employment and leisure;
  - e. reviewing information provision, including its timing and level of detail to ensure it is useful and appropriate;
  - f. considering health promotion issues such as sexual health, weight management and smoking cessation and providing access to a full range of health promotion services;
  - g. taking account of identified non-neurological health issues;
  - h. considering any care and support provided by family members/carers and how this might change over time (see QR10).
7. Some people with more complex needs requiring skilled multidisciplinary input from a number of different agencies will need an identified person who co-ordinates care. The job title of such people currently varies (eg a care co-ordinator, case manager or community matron). This role includes developing a comprehensive care plan involving a range of agencies and may involve arranging access to appropriate health and social care services. Ideally, services need to be commissioned from a pooled budget with the care plan acting as a 'passport' to services.
8. Assessment and care planning are ongoing processes, dictated by the changing needs of the person and their family and carers. Regular monitoring and review processes are needed to ensure that:
  - a. people know how to access services through self-referral if their needs change. This may be through a practitioner with a special interest or another named contact;
  - b. no equipment or services are withdrawn before a thorough reassessment of a person's needs has been undertaken;

- c. there is continuity of health and social care services when a person's needs change or they move between services (eg between children's and adult services or when they move home to another area). For example, the transition of people with childhood-onset conditions such as muscular dystrophy or cerebral palsy from children's to adult services needs detailed care planning (see Standard 4 of the NSF for Children, Young People and Maternity Services<sup>30</sup>). Commissioners and service providers need to ensure appropriate services are in place to meet these people's continuing needs and to provide support for making life transitions. Standard 1 of the NSF for Older People<sup>31</sup> states that people will access services based on need, not their age – so that, for example, older people who have or develop neurological conditions have access to specialist neurological services as well as to services for older people;
- d. there is enough flexibility to allow for both planned reviews and unplanned reviews when a person's condition suddenly deteriorates or their circumstances change (eg due to the illness of a carer);
- e. people's information needs are reviewed regularly, recognising that the need for information will change over time (see below);
- f. people have timely, regular medication reviews (see QR2).

### **Information, advice, education and support**

- 9. To become full partners in care, people have said that they need information, advice, education and support. People often live with a long-term neurological condition and its impact for decades. Over that time many become experts in their condition and its management. Their knowledge, based on personal experience, can help professionals to support them<sup>32</sup>.
- 10. The Expert Patient programme<sup>33</sup> is a self management programme which aims to improve quality of life by developing the confidence and motivation of people to use their own skills and knowledge to take effective control over life with a long-term condition. In general, these 'experts' report that their health is better, they cope better with fatigue, feel less limited in what they can do and are less dependent on hospital care. The programme suggests that such people will need to know how to:
  - a. recognise and act on symptoms;
  - b. make most effective use of medicines and treatments, including those approved by the National Institute for Clinical Excellence (NICE);
  - c. understand the implications of professional advice;
  - d. access social and other services including transport;
  - e. manage work and access the resources of the employment services;
  - f. access chosen leisure activities;
  - g. develop strategies to deal with the psychological effects of illness.
- 11. Not everyone with a long-term neurological condition will want to participate actively in their own care or be capable of managing their condition to this extent, particularly in the later stages when they may develop physical or communication difficulties. However, most will want to be involved in decisions about their care; to choose which treatment best suits their needs, and to share responsibility for managing their own condition in partnership with professional staff.

12. Providing good information and education benefits the person by improving opportunities for choice and levels of independence<sup>34</sup> and can reduce consultation rates<sup>33,35</sup>. However, for any information and education to be effective, they need to be tailored to suit people's needs and circumstances and to be assessed at every review or interaction with health and social care professionals. Evidence from research and people's experience when they use services shows that:
  - a. providing good quality information (eg, on the condition, its treatment and progression and on relevant local services) is most effective if it is available at diagnosis or onset and on an ongoing basis as necessary<sup>32,36</sup>;
  - b. people value having a single point of contact to help them access appropriate information and advice about their condition and the services available, at each stage of the care pathway<sup>37-39,40(G20)</sup>. This contact could be one of a range of professionals in the specialist neurological or rehabilitation team, or a care co-ordinator;
  - c. some people, particularly those with cognitive problems or relatives who may still be in a state of shock, may not understand or retain information at diagnosis<sup>40,41</sup>. They may value the chance to discuss this information later with a doctor, nurse or allied health professional or with voluntary organisations;
  - d. information also needs to be updated over time (eg when new treatment options become available<sup>32,42,43</sup>, when the person's service needs or circumstances change<sup>41,44</sup>, or at times of transition, eg from children's to adult services);
  - e. staff at all levels benefit from training to ensure that they give information effectively and sensitively<sup>45-47</sup> (eg taking into account language and cultural needs of people from black and minority ethnic groups<sup>48,49</sup> and the needs of people with sensory and cognitive impairments<sup>32,39,45</sup>);
  - f. information works best when it is available in a range of different formats for people with long-term neurological conditions and their carers;
  - g. local education and training programmes such as 'newly diagnosed courses' organised by health and social care professionals and voluntary sector organisations can improve people's knowledge about their condition and treatment options and support independence.

### **Special needs of people with rapidly progressing conditions**

13. The timing and appropriateness of information is particularly important in cases where the disease progresses rapidly (eg motor neurone disease). The challenge is to ensure that the person and their family are informed about the current stage and prepared for how rapidly their care and support needs may change.
14. People with rapidly progressing conditions may benefit from specialised services, including nutritional management, home ventilatory support, communication aids and electronic assistive technology. Good care planning across all agencies will ensure a rapid and flexible response to changing needs so that these services can be provided promptly.

## Evidence-based markers of good practice for QR1

		Evidence grade
1	<p>There is timely integrated assessment involving all relevant agencies leading to individual care plans<sup>9,12,17,50,51</sup> which:</p> <ul style="list-style-type: none"> <li>cover current and anticipated needs (including health, social, emotional and cultural needs);</li> <li>are held by the person and regularly evaluated and reviewed with them by the clinical team. Review is based on clinical need, including self-assessment (see QR2); and</li> <li>ensure that staff have access to all relevant records and background information about the person's condition, test results and previous consultations.</li> </ul>	<p><b>RA</b> <b>Expert</b></p>
2	<p>Arrangements are in place to ensure that:</p> <ul style="list-style-type: none"> <li>all people with long-term neurological conditions have a named point of contact for advice and information.</li> <li>people with complex needs who require skilled input from a number of professionals have a named individual (eg a care co-ordinator<sup>i</sup>, case manager or community matron) who is responsible for co-ordinating the input from all relevant agencies and producing a care plan<sup>37-39,40(G20)</sup>.</li> </ul>	<p><b>Expert</b></p>
3	<p>The care assessment and planning process ensures that appropriate services are available to provide support for life transitions and to enable people with long-term neurological conditions to receive continuity of care (eg when they transfer to adult health or social care services or across geographical service boundaries<sup>51-55</sup>, or following a change in circumstances such as the death of a carer).</p>	<p><b>RC</b> <b>Expert</b></p>
4	<p>Local arrangements for providing information ensure that:</p> <ul style="list-style-type: none"> <li>people receive timely, quality-assured, culturally appropriate information in a range of formats<sup>40,41,45,46,48,51,56</sup> on: <ul style="list-style-type: none"> <li>all relevant aspects of service provision;</li> <li>the condition and how best to manage it<sup>43,44,56,57</sup>;</li> <li>wider social inclusion issues (eg employment and transport<sup>58</sup>).</li> </ul> </li> <li>health and social care professionals, people with long-term neurological conditions and carers receive appropriate training on effective ways to provide and use information. Assessment of information needs is part of review and any interaction with health and social services.</li> </ul>	<p><b>RC</b> <b>Expert</b></p>
5	<p>People with long-term neurological conditions and their carers can access education and self management programmes, tailored to their individual needs<sup>51,59,60</sup> and these are available at different stages of the condition<sup>33,36,42,61</sup>.</p>	<p><b>RA</b> <b>Expert</b></p>

i A care co-ordination role has been described in Department of Health guidance, *Effective Care Co-ordination: Modernising the Care Programme Approach*, which integrated the Care Programme Approach with care management in mental health (see [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4009221&chk=k0eztB](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4009221&chk=k0eztB)).



## Quality requirement 2: Early recognition, prompt diagnosis and treatment<sup>i</sup>

### Aim

1. To ensure that people presenting with neurological symptoms or a neurological condition receive the correct diagnosis and appropriate treatment as soon as possible.

### Quality requirement

2. People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

### Rationale

#### Recognition and diagnosis

3. There is evidence that people with long-term neurological conditions have improved health outcomes and better quality of life when they are able to access prompt specialist expertise to obtain a diagnosis and begin treatment<sup>1-3</sup>.
4. *The NHS Improvement Plan: Putting People at the Heart of Public Services* and *National Standards, Local Action: The Health and Social Care Standards and Planning Framework 2005/6 – 2007/8* state that, by December 2008, no one should wait longer than 18 weeks from GP referral to hospital treatment.
5. Every year around one person in ten consults their GP about a neurological symptom<sup>4</sup>. Their first point of contact may be by other routes (eg NHS Direct, a walk-in centre, or other health and social care professionals in the community, such as nurses, allied health professionals and pharmacists).
6. Most neurological symptoms will have a non-serious cause and it is important that those people who are showing early symptoms of a neurological condition are diagnosed quickly and accurately. Individuals and their families and carers can experience distress and anxiety while waiting for a diagnosis. Early diagnosis can reduce this and lead to earlier treatment and effective management. This can slow disease progression and, in some cases, may even prevent death<sup>5</sup>.
7. Some neurological conditions can present a particular challenge for early identification as they lack clear, simple diagnostic features (eg early Parkinson's disease is often mistaken for arthritis, normal ageing or stroke<sup>6</sup>). It is, therefore, important for people who may have a long-term neurological condition to have a specialist assessment in line with national guidelines<sup>3,7-9</sup>. This can help prevent wrong or delayed diagnosis in conditions such as epilepsy, which has been shown to be misdiagnosed in around one in four cases<sup>10,11</sup>.

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<sup>i</sup> This quality requirement supports Standards: C5a and D2a – Clinical and Cost Effectiveness; and D11a – Accessible and Responsive Care. It also supports the Public Service Agreement: Objective III: Improve access to services to ensure that by 2008 no one waits more than 18 weeks from GP referral to hospital treatment.

8. Improved diagnosis can result from:
  - a. primary care teams collaborating more closely with their linked neurologists;
  - b. improved training in recognising important symptoms for all staff likely to have contact with people first presenting with neurological problems<sup>12</sup>;
  - c. triage of patients so that clinicians with the most appropriate skills, including practitioners with a special interest, evaluate people<sup>13,14</sup>;
  - d. agreed protocols for timely referral for specialist neurological assessment and diagnostic tests as appropriate, which allow tests to be pre-booked and avoid unnecessary duplication of tests;
  - e. specialist clinics (eg in primary care settings) as close to people's homes as possible.
9. Some conditions (eg multiple sclerosis or motor neurone disease) will need further investigations before a final diagnosis can be made. In this situation, a plan can be agreed with the person for their investigations at the same time as booking appointments for the tests. All tests need to be completed as soon as possible and the person seen again by the neurologist without delay.
10. Some conditions may be genetic in origin (eg Huntington's disease). Whenever a genetic condition is diagnosed, or when a genetic opinion can inform a diagnosis, the person needs to be referred to a geneticist<sup>15</sup>. The person and their family can then be offered counselling and information about the implications of their condition so that they can make informed decisions about testing, treatment and other life choices (eg issues around having children).

### Information at diagnosis

11. As part of the process of diagnosis, people need information about their condition and an opportunity to talk through the implications for them. This may involve attending a 'newly diagnosed' course run by health and social care professionals and voluntary sector organisations. Giving information at diagnosis is part of an ongoing process of meeting information needs and encouraging people to manage their condition themselves (see QR1).
12. The way in which a diagnosis is given can significantly affect the psychological well-being of the person and their family. Training for staff in the sensitive breaking of bad news<sup>3(R1,R2)</sup> can make a difference to how people and their family cope. Adopting a communications policy can also improve the way bad news is delivered<sup>16,17</sup>.

### Treatment

13. Once the person has a diagnosis, early treatment can often reduce or delay the impact of the condition on their life. The process of multidisciplinary assessment and care planning needs to begin as soon as it is required (see QR1)<sup>3,7-9</sup>. People need access to the full range of treatment and support services identified as best practice in NICE guidance<sup>3,7,18,19</sup>. People need information about treatment options, their effectiveness and any potential problems and side effects so they can make informed choices.
14. Using medicines effectively is vital to managing many long-term neurological conditions, particularly Parkinson's disease and epilepsy. However, research shows that around 50% of medicines for long-term conditions are not taken as prescribed<sup>20</sup> and that people's beliefs and preferences about medicines are the most important factor in how they use them<sup>21</sup>. Therefore, as well as providing information, it is essential that health professionals:
  - a. discuss the person's views and preferences with them;
  - b. reach a shared agreement about the proposed form of treatment;

- c. make sure that people have the physical and cognitive skills to manage their medication themselves, or that there are appropriate arrangements to ensure that people take their medicines correctly;
  - d. provide contact details so that the person can get in touch straight away if they experience any problems with their medicines;
  - e. contact the person soon after treatment is started to ensure that there are no problems in taking their medicine.
15. People may also need advice and support in managing side effects or if they are considering stopping treatment, for example during pregnancy, and should have the opportunity to discuss this with their health professional<sup>22-24</sup>. Regular reviews of medication are important. These may be face to face for those who need them, especially those taking three or more medicines, with a skilled reviewer (eg an appropriately trained pharmacist). This is to assess: how they are taking their medicines; whether they are tolerating them and the impact (both positive and negative) of medicines on their condition and on other aspects of their lives. The reviewers can agree adjusting medication with the person<sup>25</sup>.
16. The multidisciplinary team in the neurology clinic (eg neurologists, specialist nurses, social workers, and a range of therapists and psychologists) can support people, help them manage their symptoms and refer them for rehabilitation, if necessary before the diagnosis is confirmed. The team can also identify what emotional and spiritual support people might need.
17. Some people with long-term neurological conditions may need planned clinical reviews to monitor their condition and unplanned reviews if they deteriorate suddenly or develop complications. The need for review can be agreed as part of the care planning process (see QR1).
18. People tell us that they value ongoing specialist advice from people who understand their condition. Specialist practitioners could provide this. Specialist nurses are shown to provide effective and cost effective advice and care for people with progressive conditions such as multiple sclerosis or Parkinson's disease<sup>1,26,27</sup>.

### **Special needs of people with rapidly progressing conditions**

19. Recognising symptoms is a particular problem in rapidly progressing conditions. Early diagnosis can significantly improve the person's quality of life in terms of access to appropriate support, treatment and other healthcare and social services<sup>28,29</sup>. Referral protocols for diagnosis, such as non-standard referral routes (eg telephone, e-mail, and rapid access neurology assessment clinics), are needed when a GP suspects a rapidly progressing condition, in order to speed up both the referral and diagnostic processes. After initial diagnosis, fast-tracked referral to specialist multidisciplinary services experienced in the needs of people with rapidly progressing conditions can improve the person's quality of life. People need treatment, care and equipment to be provided quickly, with services responding flexibly to changing needs.
20. People with rapidly progressing long-term neurological conditions may develop respiratory difficulties and respiratory failure. Staff can prepare them for this by discussing with them the possibility of early referral and treatment options. These could include non-invasive ventilation, tracheostomy ventilation and relieving symptoms with drugs. People with these conditions may also need support with advance directives on preferred treatment for symptoms towards the end of their life.

## Evidence-based markers of good practice for QR2

		Evidence grade
1	<p>There is improved access to specialist neurological expertise through:</p> <ul style="list-style-type: none"> <li>• training for front-line staff to improve recognition of neurological symptoms<sup>3,6,7,10-12</sup>;</li> <li>• shared protocols for referral for further specialist assessment so that people receive appropriate priority within locally agreed target times<sup>14,30-32</sup>;</li> <li>• guidelines on the management of genetic disorders including referral to genetic services<sup>15</sup>;</li> <li>• multidisciplinary neurology clinics run in hospital and community settings where possible;</li> <li>• communication routes for GPs to obtain rapid specialist neurological advice about urgent clinical problems.</li> </ul>	<p><b>RB</b> <b>Expert</b></p>
2	<p>Diagnostic services are effectively designed and have sufficient capacity to enable prompt diagnosis. Services should be delivered according to NICE guidelines and take account of agreed national guidance<sup>3,7,9,18</sup> and protocols for delivering diagnosis, using staff trained in delivering 'bad news'.</p>	<p><b>RA</b> <b>Expert</b></p>
3	<p>There is improved access to appropriate treatments and:</p> <ul style="list-style-type: none"> <li>• treatment available to people includes all those approved by NICE<sup>3,7</sup>;</li> <li>• early integrated assessment and care planning (see QR1) ensure timely access to treatment and to multidisciplinary support, if necessary before diagnosis is confirmed;</li> <li>• individuals receive appropriate information before starting medication to enable informed choice and are supported to manage side effects or any other problems they may be having<sup>22-24</sup>.</li> </ul>	<p><b>RA</b> <b>Expert</b></p>
4	<p>All people with long-term neurological conditions have prompt access to ongoing specialist neurological advice and treatment. Specialist nurses and practitioners with specific knowledge of long-term neurological conditions are available to support people in the community<sup>1,26,27</sup>.</p>	<p><b>RB</b> <b>Expert</b></p>
5	<p>There is improved access to treatment review that ensures:</p> <ul style="list-style-type: none"> <li>• processes are in place to provide review and monitoring of treatment appropriate to individual need (see QR1);</li> <li>• people taking medicines on a long-term basis have access to regular medication reviews to enable them to get the most out of treatment<sup>25</sup>. For some people, especially those taking three or more medicines, it may be appropriate to have a face-to-face review.</li> </ul>	<p><b>Expert</b></p>

## Quality requirement 3: Emergency and acute management<sup>i</sup>

### Aim

1. To improve the treatment of people who develop a neurosurgical or neurological emergency, preventing avoidable illness and death.

### Quality requirement

2. People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

### Rationale

3. Over one million people attend accident and emergency departments each year with a head injury. Trauma is the most common cause of death in people under 40. Approximately 50% of deaths in this group are due to head injury. Severe head injury has a 20–30% mortality rate. Variations in service provision to manage head injuries and other neurosurgical emergencies<sup>1</sup> can lead to complications, avoidable death, increased disability and greater dependence<sup>2,3</sup>.
4. Evidence shows that people who experience neurosurgical and neurological emergencies have better outcomes in terms of survival rates, fewer avoidable complications and impairments and less risk of death and as a result achieve better independence, when:
  - a. they receive early and effective initial resuscitation<sup>2,4-9</sup>;
  - b. they receive early treatment, for example admission to a specialist spinal cord injury centre within one day of injury reduces both mortality and overall length of stay<sup>4</sup>;
  - c. there is timely access to appropriate neuro-imaging (eg MRI and CT scans) which meets local and national standards<sup>3</sup>.
  - d. they receive care on wards staffed by teams who have themselves, or have rapid access to, neurological expertise and skills and where protocols are in place to monitor their condition and identify potentially lethal progressive complications, such as blood clots or raised pressure in the brain<sup>2,7,8,10</sup>;
  - e. they receive early assessment in the acute setting by a multidisciplinary neurological rehabilitation team to identify rehabilitation needs and a care plan which includes providing appropriate early treatment and support to prevent secondary complications such as contractures<sup>11,12(G43, G43-77)</sup> (see QR1 and QR4);
  - f. those needing more complex specialist interventions have timely access to a specialist neuroscience centre where prompt intervention can be made (within four hours or less for head injuries) and where neurosurgical and neuro-critical care with protocol based treatment are available<sup>4,11,13-16</sup>. This has been shown to increase favourable outcomes from 40% to 60%<sup>15</sup>;

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<sup>i</sup> This quality requirement supports Standards: C5a and D2a – Clinical and Cost Effectiveness; and Standard C19 and D11 – Accessible and Responsive Care.

- g. protocols are in place so that people who are *not* admitted to hospital for conditions such as head injury and who do not make a complete recovery know how and when to access services. Referral for multidisciplinary assessment, including psychometric testing, to detect and treat ongoing cognitive and emotional difficulties may be appropriate<sup>3,12(G33-38),17</sup>. Referral for further assessment and support from mental health services may be needed;
  - h. treatment is provided according to NICE guidelines and takes account of nationally agreed standards and guidelines<sup>3,12,18</sup>;
  - i. neurologists and neurosurgeons are available to give timely, expert advice to accident and emergency departments.
5. Increased capacity at spinal cord injury centres<sup>1,19-21</sup> and specialist neuroscience centres, including an increase in dedicated neurosurgical and neurological critical care beds, can result in better outcomes for people by:
- a. speeding up transfer or reducing the current wait for admissions to facilities that provide specialist management and care<sup>19,22</sup>; and
  - b. preventing people being returned too early or transferred to inappropriate wards and facilities in district or local services following specialist intervention. This is estimated to apply to more than 50% of people<sup>1</sup>.

### **Information**

6. In an emergency situation, people and their families need information about their condition to be given quickly and calmly so that they can become involved, as appropriate, in planning their treatment and ongoing care. When they are transferred between settings, both the person and their family need to know whom to contact for information.

## Evidence-based markers of good practice for QR3

		Evidence grade
1	Acute and emergency management of sudden onset neurological conditions complies with NICE guidelines and takes account of nationally agreed standards and guidelines <sup>3,12,18</sup> .	<b>RA Expert</b>
2	Local hospitals accepting people with a neurosurgical or neurological emergency have appropriate resources to treat, manage and review individuals presenting with a sudden onset neurological condition, including <sup>2,4,6-9,11,15,16</sup> : <ul style="list-style-type: none"> <li>trained staff/teams (A&amp;E, medical assessment, acute medical, neurological) to ensure that people with acute neurological symptoms receive prompt neurological assessment;</li> <li>appropriate facilities and links to a specialist neuroscience centre and spinal cord injury centre for prompt expert opinion if necessary;</li> <li>protocols of care agreed with specialist spinal cord injury, neuroscience and neuro-rehabilitation centres.</li> </ul>	<b>RA</b>
3	There are protocols in place which comply with NICE guidelines on head injury and take account of nationally agreed standards and guidelines, for people with acquired brain injury not admitted to hospital <sup>3,12(G33-38),17</sup> .	<b>RA Expert</b>
4	Transfer to specialist centres is available when needed, and: <ul style="list-style-type: none"> <li>specialist neuroscience centres and spinal cord injury centres have the capacity, staff and facilities to accept prompt transfer of people who need more specialist management and to conform to national standards<sup>4,11,15,16,20,22</sup>;</li> <li>protocols are in place to support prompt transfer of people to district or local services when specialist intervention is no longer needed.</li> </ul>	<b>RA Expert</b>
5	Local hospitals admit people transferred from specialist neuroscience centres to suitable wards or facilities where any necessary ongoing neurological care, supervision or rehabilitation can be appropriately provided <sup>22</sup> , involving senior specialist medical staff and other staff with neurological expertise.	<b>Expert</b>

## Quality requirement 4: Early and specialist rehabilitation<sup>i</sup>

### Aim

1. To ensure that people who develop a neurological condition achieve the best possible recovery and rehabilitation.

### Quality requirement

2. People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home<sup>ii</sup> for ongoing community rehabilitation and support.

### Rationale

3. People who suddenly become disabled as a result of a neurological condition may initially be unable to manage safely at home and may need the services of a specialist inpatient unit to help them make the best possible recovery. Timely, good quality rehabilitation offers these people the chance to achieve goals for independent living. Early rehabilitation also reduces the risk of developing preventable secondary complications and reduces length of stay in hospital and re-admission rates.
4. People benefit most from specialist neuro-rehabilitation if they are:
  - a. assessed by a multidisciplinary specialist neuro-rehabilitation team as early as possible in the acute care setting, to provide specialist support and advice to prevent secondary complications developing<sup>1(G39,G43)</sup>;
  - b. transferred without delay to an appropriate neuro-rehabilitation facility<sup>1(G41),2-4</sup>; and are
  - c. able to re-access specialist inpatient neuro-rehabilitation to meet their changing needs<sup>1(G8, G13)</sup>.

### Benefits of specialist inpatient neuro-rehabilitation

5. Evidence shows that:
  - a. rehabilitation in specialised settings for people with traumatic brain or spinal cord injury is effective and provides value for money in terms of reducing the length of stay in hospital and reducing the costs of long-term care<sup>2,5-7</sup>;
  - b. early transfer to specialist centres<sup>2</sup> and more intense rehabilitation programmes<sup>8-10</sup> are cost effective, the latter particularly in the small group of people who have high care costs due to very severe brain injury<sup>5,11</sup>;
  - c. continued co-ordinated multidisciplinary rehabilitation in the community improves long-term outcomes<sup>12</sup> and can help to reduce hospital re-admissions<sup>13</sup>. Benefits are similar for people with severe behavioural problems following brain injury<sup>14,15</sup>.

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i This quality requirement supports Standards: C5a and D2 – Clinical and Cost Effectiveness; and Standard D10 – Patient Focus.

ii 'Home' in this context means the place where the individual **chooses** to live, which may be their own accommodation or may be a residential or care home.



6. Providing adequate properly staffed and resourced neuro-rehabilitation services can help to avoid:
  - a. bed closures, waiting lists and difficulties in providing appropriate services for people with more complex needs<sup>1,16</sup>;
  - b. premature discharge home from acute wards or inpatient neuro-rehabilitation settings, which can mean increased levels of dependence and risk of re-admission<sup>1</sup>;
  - c. prolonged occupancy of acute beds by people waiting for admission to a neuro-rehabilitation unit<sup>17-19</sup>;
  - d. preventable secondary complications, which bring further health problems and increased length of stay in hospital<sup>20,21</sup>.

### **Effective specialist inpatient neuro-rehabilitation**

7. Specialist inpatient neuro-rehabilitation services form a vital link with both acute hospital care and the community as they can:
  - a. support staff to deliver early rehabilitation in the acute setting before transferring the person to the specialist inpatient unit; and
  - b. provide programmes after a period of inpatient neuro-rehabilitation to support transition back into the community through co-ordinated care planning in close collaboration with providers of community rehabilitation and support (see QR5).
8. People with complex needs may require ongoing access to specialist neuro-rehabilitation as their needs change. For some people, planned re-admissions to the inpatient unit over a number of years may be the most appropriate way of meeting their changing needs. Those who have additional health conditions may also need to access specialist neuro-rehabilitation and special arrangements may be necessary to meet their full range of needs (eg renal dialysis).
9. A few people with very severe and complex disabilities (eg those in persistent vegetative or low-awareness states, or with severe cognitive or behavioural problems) may need highly specialised and structured service provision over a prolonged period. Such highly specialised inpatient facilities are likely to serve the populations of several strategic health authorities, or may have national status<sup>22</sup>.
10. An effective specialist neuro-rehabilitation facility will:
  - a. be staffed by a team of expert professionals who work as a co-ordinated interdisciplinary team to enable people to transfer the skills acquired during therapy sessions to their daily living activities<sup>1(G14-16,G23),23-25</sup>;
  - b. deliver well planned, goal-orientated<sup>1(G24-26),26</sup> neuro-rehabilitation at the appropriate intensity for the person<sup>9,10,27,28</sup>;
  - c. support the person, their family and carers to contribute to planning the rehabilitation process<sup>1(G21,G23,G88),26</sup>;
  - d. have strong links to the community, including social services and housing departments to provide a co-ordinated transition of care. Good practice can include flexible admission policies to allow graded transition to the community with practice periods at home<sup>1(G8, G86)</sup> and inreach/outreach arrangements<sup>29,30</sup>;
  - e. work with wheelchair centres and integrated community equipment services to co-ordinate provision of specialist equipment to meet people's changing needs (see QR7)<sup>1(G145-148),31</sup>;

- f. involve housing, social services and other relevant agencies in early discharge planning and ensure that appropriate services are available<sup>1(G169-171)</sup>.

### **Information**

11. People and their carers need information on the services and support available so they can take part in setting and meeting rehabilitation goals and manage the impact of their condition on their lives<sup>1(G30-32)</sup>.

### **Special needs of people with rapidly progressing conditions**

12. People with rapidly progressing conditions may need brief periods of inpatient neuro-rehabilitation to help with the rapid and co-ordinated provision of:
- multidisciplinary assessment, integrated care planning and training of carers; and
  - highly specialist equipment (eg integrated electronic technology), which they can use to control their environment, their ability to move around within it and to communicate with the outside world.

## Evidence-based markers of good practice for QR4

		Evidence grade
1	Rehabilitation is provided which complies with NICE guidelines and takes account of other nationally accepted guidance <sup>1,32-36</sup> .	<b>RA Expert</b>
2	<p>There is improved access to rehabilitation and:</p> <ul style="list-style-type: none"> <li>• rehabilitation is provided: <ul style="list-style-type: none"> <li>– early<sup>2-4</sup>;</li> <li>– at high intensity appropriate to need<sup>9,10,27,28</sup>;</li> <li>– by a co-ordinated interdisciplinary team<sup>23,24</sup>;</li> <li>– in an appropriate specialist setting<sup>1(G40, G84),34(R51)</sup>; and</li> <li>– on an ongoing or re-accessible basis to people with changing needs<sup>1(G13)</sup>;</li> <li>– with specialist equipment (including wheelchairs and seating support systems) where required<sup>1(G145-148)</sup>;</li> </ul> </li> <li>• trained rehabilitation, nursing or allied health professions staff support people to apply the skills acquired during therapy sessions in routine daily living activities<sup>1(G14-16),25</sup>;</li> <li>• the person, their family and the rehabilitation team all work towards the same agreed goals<sup>1(G21,G23-26),26</sup>;</li> <li>• inpatient rehabilitation programmes are followed by ongoing rehabilitation and support in the community for those who need them<sup>1(G8,G86,G166,G169),12,29,30</sup> (see QR5).</li> </ul>	<b>RA Expert</b>
3	<p>Seamless transition of care is provided through:</p> <ul style="list-style-type: none"> <li>• integrated working with other care professionals/teams<sup>1(G7-9)</sup>;</li> <li>• inreach/outreach arrangements between: <ul style="list-style-type: none"> <li>– specialist neuro-rehabilitation and acute care services; and</li> <li>– inpatient and community based specialist neuro-rehabilitation services<sup>1(G86,G170),29,30</sup>.</li> </ul> </li> </ul>	<b>RA Expert</b>
4	<p>Specialist rehabilitation services are provided to meet the needs of people with very severe and complex disabilities<sup>1(G4),22</sup>, including:</p> <ul style="list-style-type: none"> <li>• profound and complex disabilities (eg vegetative or low-awareness states, high or complete spinal cord injury or severe brain injuries);</li> <li>• severe cognitive and behavioural problems needing a structured environment;</li> <li>• other long-term medical problems needing intervention.</li> </ul>	<b>Expert</b>

## Quality requirement 5: Community rehabilitation and support<sup>i</sup>

### Aim

1. To enable and support people with long-term neurological conditions to lead a full life in the community.

### Quality requirement

2. People with long-term neurological conditions living at home<sup>ii</sup> are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

### Rationale

#### Benefits of high quality community rehabilitation

3. People with long-term neurological conditions face many complex challenges in attempting to live as they would wish. At different times, they can experience physical, emotional, psychological and social difficulties. These can limit their ability to participate in society<sup>1-5</sup> and can lead to social isolation, anxiety and depression<sup>6-9</sup>. These problems can cause increased dependency on care services and can affect partner and sexual roles<sup>10-14</sup>, as well as placing an additional burden on family and friends. These effects are long-term and people and their families may need ongoing intervention and support appropriate to their needs<sup>15-17</sup>.
4. Research shows that:
  - a. community rehabilitation centred on a person's home<sup>18</sup> and employing the full range of disciplines can provide cost effective services that help people reintegrate into the community. Increased independence can mean lower care costs overall<sup>19</sup>. Improved well-being and adjustment<sup>20</sup> lessens the burden on carers and reliance on services, prevents unnecessary hospital admissions and can lead to substantial savings over the long term;
  - b. community rehabilitation for people with long-term neurological conditions reduces the restrictions they experience in daily living, maintains their independence and enables social participation<sup>18,21-23</sup>;
  - c. intensive day rehabilitation programmes delivering holistic management of cognitive, behavioural and emotional problems following acquired brain injury help people to cope better at home and in the community<sup>20,22,24,25</sup>;
  - d. targeted rehabilitation programmes can increase participation in social and leisure activities<sup>26,27</sup> and reduce inappropriate behaviour<sup>28</sup>. Counselling and psychological support to help people adjust to altered personal, family and social circumstances<sup>29,30</sup> are highly valued by people with long-term neurological conditions and their families<sup>31</sup>.

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i This quality requirement supports Standards: D2b and c – Clinical and Cost Effectiveness; and Standard C22a – Public Health.

ii 'Home' in this context means the place where the individual **chooses** to live, which may be their own accommodation or may be a residential or care home.

5. There are many different models for providing multidisciplinary health and social services rehabilitation and support in the community. They include:
  - a. outreach from specialist centres;
  - b. day centre and outpatient programmes;
  - c. rehabilitation in the home and local environment provided by specialist community neuro-rehabilitation teams;
  - d. community teams providing rehabilitation and support to people with many different conditions.
  
6. Good community rehabilitation has a lot in common with good social care support. Rehabilitation is most effective in helping people live as independently as possible and improving their quality of life when health and social care bodies work collaboratively with each other<sup>32</sup>, with people and their families and with other agencies.
  
7. In developing responsive and high quality rehabilitation in the community, key issues to consider include:
  - a. integrating health and social care provision. This will help, in particular, to develop care co-ordination, a single point of contact for people and communication between agencies;
  - b. providing staffing levels to enable more people to benefit from specialist neuro-rehabilitation and long-term rehabilitation and support in the community;
  - c. improving levels of knowledge, expertise and skills among generic community teams to enable them to support people with long-term neurological conditions;
  - d. organising services to provide specialist support, perhaps by making staff with neurological expertise an integral part of the community team or by providing support through networking arrangements with specialist community neuro-rehabilitation teams and outreach services (see Chapter 3);
  - e. developing links with specialist rehabilitation/neurology services and GP services;
  - f. providing care and support in the longer-term based on clinical need delivered by care professionals with appropriate experience (see QR8).
  
8. Existing good practice and evidence suggest that good quality, fully integrated rehabilitation and social care includes:
  - a. providing appropriate information and education about the condition, practical advice, support and skills training for the person, their family and carers<sup>33–35,36(G32,G82),37(R4)</sup>, and access to family or sexual counselling if needed (see QR1);
  - b. co-ordinating health and social care resources to support people who have specially-designed programmes to prevent them developing secondary complications and to help them maintain their current skills and abilities and provide specialist equipment<sup>35,36(G3,G5)</sup>;
  - c. providing appropriate social care support, including appropriate personal care both in and outside the home, which takes account of cognitive or behavioural problems that may affect the person's ability to care for themselves<sup>36(G133–135),38</sup> (see QR8);
  - d. interventions that focus on wider social participation, such as leisure and recreational activities including those provided by the voluntary sector<sup>36(G149–151),39(R70),40</sup>;

- e. supporting the person with practical problem-solving (including joint working across agencies) to: increase their participation in the local community; develop their local support networks and help them to access housing-related support services<sup>36(G170),39(R79)</sup>;
- f. developing protocols to help co-ordination and collaboration with other specialist health services (eg mental health) to provide appropriate support for vulnerable people<sup>36(G123–125),39(R144, R145)</sup>.

### **Special needs of people with rapidly progressing conditions**

- 9. The needs of people with rapidly progressing conditions can change almost overnight<sup>9</sup>. For this reason, community rehabilitation providers need to offer a rapid and co-ordinated service to provide care and support, including specialist emotional support, for the person and their family as their needs and circumstances change.

## Evidence-based markers of good practice for QR5

		Evidence grade
1	<p>There is improved access to community rehabilitation through:</p> <ul style="list-style-type: none"> <li>• flexible, individualised programmes of community rehabilitation and support which are focused on individual goals beyond basic daily care and promote participation in a full range of life roles<sup>33,36(G141–157),39(R70–80)</sup>;</li> <li>• interventions provided according to individual need may include:                             <ul style="list-style-type: none"> <li>– rehabilitation and support centred on the person's home and environment<sup>18,26,31</sup>;</li> <li>– holistic outpatient or day rehabilitation programmes<sup>21–25,40</sup>.</li> </ul> </li> </ul>	<p><b>RA</b> <b>Expert</b></p>
2	<p>Local multidisciplinary rehabilitation and support are provided in the community<sup>36(G166–169)</sup> by professionals with the right skills and experience<sup>36(G14,G15,G18)</sup>; and:</p> <ul style="list-style-type: none"> <li>• involve health and social services working together;</li> <li>• include access to specialist neurological expertise (eg neuro-rehabilitation, neuro-psychology) to address the full range of practical and emotional challenges<sup>18,29,30,36(G16),39(R70–80)</sup>;</li> <li>• are available in the longer term based on clinical need<sup>36(G13),39(R76–78)</sup>.</li> </ul>	<p><b>RB</b> <b>Expert</b></p>
3	<p>Providers of community rehabilitation and support services support people and their family members and carers<sup>36(G166–170),39(R3–6)</sup> to:</p> <ul style="list-style-type: none"> <li>• live with a long-term neurological condition<sup>17,18</sup>;</li> <li>• develop knowledge and skills to manage their condition<sup>17,18,31</sup>;</li> <li>• achieve a sense of well-being and make long-term psychological adjustments to altered personal, family and social circumstances<sup>17,18,29,30</sup>;</li> <li>• provide proactive intervention, where relevant, to maintain function and prevent deterioration as the condition progresses.</li> </ul>	<p><b>RA</b> <b>Expert</b></p>

## Quality requirement 6: Vocational rehabilitation<sup>i</sup>

### Aim

1. To enable people with a long-term neurological condition to work or engage in alternative occupation.

### Quality requirement

2. People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

### Rationale

3. Returning to work is extremely important to many people with long-term conditions. It can improve their quality of life and help them maintain their independence. People may need vocational rehabilitation or support to:
  - a. enter training or work opportunities;
  - b. remain in or return to their existing job;
  - c. identify and prepare for suitable alternative work options;
  - d. plan withdrawal from work at an appropriate time, conserving pension and other rights;
  - e. access appropriate alternative occupational and educational opportunities.
4. People with long-term neurological conditions often experience major restrictions in their ability to work and can find it difficult to find suitable employment that offers the flexibility and understanding that they need. Some conditions may also have subtle effects on a person's fine motor skills, cognitive functioning and organisational abilities which may limit their capacity to work in the competitive job market<sup>1-3</sup>.
5. Vocational rehabilitation for people with long-term neurological conditions needs to include both local rehabilitation services and more specialised neurological rehabilitation services.

### Local rehabilitation services

6. Local community rehabilitation providers, working closely with appropriate professionals, eg Jobcentre Plus, employers, NHS Plus and other providers of occupational health services and other agencies, eg independent and voluntary organisations, need to provide:
  - a. a basic vocational assessment with the aim of helping people to develop work-related skills;
  - b. informed guidance about available options, including advice on welfare rights and benefit entitlements;

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<sup>i</sup> This quality requirement supports Standards: C5, C6 and D2 – Clinical and Cost Effectiveness; C7e, C11, D4 and D5 – Governance; C16 – Patient Focus; C17, C18 and D11 – Accessible and Responsive Care. It also supports Public Service Agreement Objective II: improve health outcomes for people with long-term conditions.



- c. practical support to manage problems in the workplace;
- d. liaison and advice to employers to adjust work duties, patterns or environments as appropriate;
- e. advice on retiring on health grounds;
- f. referral to specialist vocational services.

### **Specialist vocational rehabilitation**

- 7. Vocational rehabilitation for some people with long-term neurological conditions works best when it includes services specifically designed for this group. Ideally, this involves specialist multi-agency rehabilitation services that can address more complex needs that cannot be met by local rehabilitation services alone and provide ongoing personalised support over a longer period.
- 8. There is evidence that:
  - a. specialist brain injury vocational programmes are successful (50–70% of people in work)<sup>4–8</sup>. Such programmes are demonstrably cost-effective<sup>4,8</sup>, with costs recovered in around 20 months, and there are long-term benefits over seven years or more<sup>9,10</sup>;
  - b. holistic intensive day rehabilitation programmes improve the chances of people with acquired brain injury returning to work<sup>5,11–13</sup>;
  - c. while the strongest research evidence has been gathered in people with brain injuries, there is corroborative evidence for the benefits of vocational rehabilitation in people with spinal cord injury<sup>14</sup>, epilepsy<sup>15</sup>, and multiple sclerosis<sup>16,17</sup> (eg Job Raising Program in USA with 71% of participants employed at long-term follow-up)<sup>18</sup>.
- 9. Specialist vocational rehabilitation services of this kind can work alongside and in partnership with local rehabilitation services. They can provide a specific programme of vocational support, including specialist assessment, training, counselling, job preparation and job retention services for those who need them. They may also provide occupational and educational opportunities as an alternative to paid employment. They have a valuable role to play in advising, supporting and training local employment and rehabilitation services in recognising and addressing the needs of people with long-term neurological conditions.
- 10. Vocational rehabilitation and support can be improved with<sup>19(R65–69),20(G158–165),21</sup>:
  - a. better co-ordination of services and information sharing across relevant agencies involved in vocational rehabilitation/support (including health, social services, Department for Work and Pensions/Jobcentre Plus, and the independent/voluntary sectors);
  - b. more vocational rehabilitation services specifically designed to meet the needs of people with a long-term neurological condition to avoid referral to inappropriate and unsuitable services (a recent survey mapping specialist vocational rehabilitation services for people with brain injuries in the UK indicated that current provision may be only 10% of the estimated requirement<sup>22</sup>);
  - c. a greater focus within the NHS and other agencies on helping people remain economically active;
  - d. more local authority ‘Welfare to Work’<sup>i</sup> initiatives to provide opportunities for disabled people<sup>23,24</sup>;

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i Department for Work and Pensions programmes which offer practical advice and support to disabled people and their employers to overcome work-related obstacles resulting from disability.

- e. more sheltered or adapted work environments for people who are unable to engage in competitive employment<sup>23,24</sup>;
- f. recognition of the role of voluntary services in helping people into work or alternative occupation, in partnership with other agencies<sup>21</sup>.

### **Special needs of people with rapidly progressing conditions**

11. People with rapidly progressing long-term neurological conditions need prompt access to appropriate vocational advice. People who are in work may need particular advice about leaving work on medical grounds and about pension arrangements, to ensure their and their family's financial arrangements remain secure.

## Evidence-based markers of good practice for QR6

		Evidence grade
1	Co-ordinated multi-agency vocational rehabilitation is provided which takes account of agreed national guidance and best practice <sup>19(R65–69),20(G158–165),21</sup> .	Expert
2	Local rehabilitation services are provided which: <ul style="list-style-type: none"> <li>• address vocational needs during review of a person's integrated care plan and as part of any rehabilitation programme (see QR5 and QR6)<sup>11–14,16,17,25</sup>;</li> <li>• work with other agencies to provide:               <ul style="list-style-type: none"> <li>– vocational assessment;</li> <li>– support and guidance on returning to or remaining in work;</li> <li>– support and advice on withdrawing from work;</li> </ul> </li> <li>• refer people with neurological conditions who have more complex occupational needs to specialist vocational services<sup>19(R65–69),20(G158–165),21</sup>.</li> </ul>	RA Expert
3	Specialist vocational services are provided for people with neurological condition to address more complex problems in remaining in or returning to work or alternative occupation including <sup>4–10,14,16–18</sup> : <ul style="list-style-type: none"> <li>• specialist vocational assessment and counselling;</li> <li>• interventions for job retention, including workplace support;</li> <li>• specific vocational rehabilitation or 'work preparation' programmes;</li> <li>• alternative occupational and educational opportunities;</li> <li>• specialist resources for advice for local services<sup>21</sup>.</li> </ul>	RA Expert
4	Specialist vocational rehabilitation services routinely evaluate and monitor long-term vocational outcomes, including the reasons for failure to remain in employment <sup>3,5,26,27</sup> .	RA

## Quality requirement 7: Providing equipment and accommodation<sup>i</sup>

### Aim

1. To provide people with long-term neurological conditions with appropriate equipment and adaptations to their accommodation to give them greater independence and choice about where and how they live.

### Quality requirement

2. People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

### Rationale

3. People with long-term neurological conditions can find it difficult to maintain their independence in the face of increasing disability. Providing up-to-date and appropriate assistive technology/equipment and home adaptations can help people to live with their condition and promote social inclusion and independence<sup>1</sup>.
4. New ways of delivering services such as integrated occupational therapy services, joint assessment by health and social care and the single assessment process are examples of how appropriate assessment can help with effective care planning, provide co-ordinated and timely equipment and adaptations, and avoid unnecessary duplicate assessments.

### Providing equipment

5. Assistive technology/equipment for people with long-term neurological conditions falls into three main categories<sup>2,3</sup>:
  - a. equipment to help with mobility, sensory impairment or daily living activities (eg walking, bathing or reaching aids, telecare)<sup>4</sup>;
  - b. more specialist, custom-built equipment for those with complex needs to support independence and participation in the home or work place (eg environmental controls, computer equipment, communication aids or other electronic assistive devices)<sup>2,3,5-7</sup>;
  - c. equipment to prevent deterioration (eg special seating or standing aids).
6. There is evidence in adult populations and people with brain injury that assistive technology/equipment and home environmental interventions improve independence and quality of life<sup>8-11</sup> and reduce frustration<sup>11</sup>. Providing appropriate equipment is also cost effective: it can reduce the costs of care at home and in residential care settings<sup>9-11</sup>; it can reduce the development of further health problems (eg immobility and contractures) at low cost compared with other forms of healthcare<sup>1</sup> and in some cases it can improve the opportunities for employment<sup>12</sup>.

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i This quality requirement supports Standards: C4b and c – Safety; C5a and c, D2a–d – Clinical and Cost Effectiveness; D10 – Patient Focus. It also supports PSA Objective II: supporting people with long-term conditions through a personalised care plan and IV: support for older people to live independently in their own homes with an improved quality of life including provision of equipment and adaptations.

7. In addition, specific types of equipment have particular benefits for people with long-term neurological conditions. Providing communication aids can support social participation and prevent the potential development of depression. Providing appropriate seating systems can prevent unnecessary complications (eg spasticity, deformity and pressure sores) developing which can leave the person confined to bed or result in hospital admission<sup>13</sup>, causing distress and reduced quality of life. For people with paralysis in the legs who cannot stand unsupported, using a standing frame regularly reduces bone demineralisation<sup>14</sup>; improves the management of spasticity and provides psychological benefits<sup>6,15</sup>. Where two people are needed to transfer and position the person in a standing frame, the additional cost of providing an electric standing frame may be offset by savings in care costs. Providing a fall detector as part of a telecare package means people with epilepsy know that if they have a seizure when they are alone, a call centre would be alerted.
8. Holistic assessment needs to take account of the home environment, lifestyle and the need for practical advice on how to use assistive technology/equipment. This can ensure that people use any larger, expensive or more complex items regularly, appropriately and effectively<sup>16,17</sup>.
9. In assessing the needs of people with long-term neurological conditions for assistive technology/equipment, local and specialist equipment services need to consider:
  - a. providing specialist professional assessment and assistive technology/equipment to meet complex needs co-ordinated with other interventions (eg rehabilitation: see QR4 and QR5) to maintain people's abilities and prevent deterioration. This may include providing equipment on trial. Equipment requirements need to be included in the integrated care plan<sup>18</sup> (see QR1), together with a record of who is responsible for each item of equipment and whom to contact for repairs and maintenance;
  - b. training and support for people and carers to use the equipment. People with cognitive problems may need more time to learn how to use new equipment and more intensive support or practice to use it effectively<sup>5,7</sup>;
  - c. how to respond to changing needs over time (eg people with rapidly progressing conditions need regular review and equipment provided flexibly)<sup>13</sup>;
  - d. providing a responsive collection and repair service and a loaned replacement if equipment breaks down<sup>13</sup>. Loans can be provided at very little extra cost if services have enough equipment resources and if equipment is efficiently tracked and recycled;
  - e. the changing needs of carers due to ageing, illness and the demands of paid employment (see QR10).
10. The Integrating Community Equipment Services (ICES) project has resulted in joint health and social services community equipment stores which address inequities of equipment provision. Some models of good practice support an advisory/information service to encourage people to assess their own needs and advise them on using Direct Payments to buy their own basic items of equipment where appropriate, or using vouchers for wheelchairs. This promotes people's choices and allows professional assessment and statutory provision to focus on more complex items of assistive technology/equipment.

### **Providing accommodation**

11. While providing equipment can improve some aspects of a person's environment, providing suitable housing (eg a single storey building) or modifications to the current home (eg specially adapted showers and toilets, kitchen worktops and appliances at wheelchair height, elevators and stair lifts) can meet other specific needs<sup>18,19</sup>. Appropriate or appropriately adapted accommodation can improve the person's independence and comfort. It can also reduce the need for statutory care and support; the risk of injury (eg from falls) and the amount of time spent in residential or hospital care and the resulting loss of independence.

12. Social services need to work closely with housing/accommodation and Supporting People<sup>i</sup> services to provide suitable adapted or purpose-built accommodation and/or support in making adaptations, including:
  - a. timely access to assessment and provision of Disabled Facilities Grants and ‘supported living’ schemes (see QR8);
  - b. facilities appropriate for ‘supported living’ schemes (see QR8).
13. A ‘lifetime homes’ approach to new building, ie houses that already are, or can be adapted to meet the person’s need as the condition progresses, has benefits and authorities may wish to look to see whether this approach can be incorporated easily into their schemes.
14. The government also believes that there are benefits in compiling a register held by the local authority (including those owned and managed by registered social landlords, voluntary and private sector providers) of all adapted accommodation and their facilities, which can be matched against the needs of individuals, for the most effective recycling of adapted properties. The government is revising the *Code of Guidance on the Allocation of Accommodation* to make it clearer that under the choice based lettings schemes local authorities need to carefully consider the needs of disabled tenants.

### Information

15. People with long-term neurological conditions need information about how to get assessment and funding for:
  - a. assistive technology/equipment and training in how to use, maintain and repair it safely;
  - b. adaptations to current accommodation;
  - c. alternative, more suitable accommodation.

### Special needs of people with rapidly progressing conditions

16. Rapidly progressing conditions can present a particular challenge for services that provide home adaptations and assistive technology/equipment. Services need to anticipate, identify and regularly review the needs of people with rapidly changing conditions. Providing fast-track equipment can make sure that specialist equipment is prescribed and delivered promptly; maintained in full working order and exchanged flexibly as a person’s needs change.

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<sup>i</sup> The Office of the Deputy Prime Minister’s (ODPM’s) Supporting People programme promotes strategically planned, housing-related support services. The programme offers vulnerable people the opportunity to improve their quality of life through maintaining or increasing their ability to live independently. It also helps to prevent problems that can lead to social exclusion, hospitalisation, institutional care or homelessness by providing high-quality, cost effective and timely support (see Chapter 4).

## Evidence-based markers of good practice for QR7

		Evidence grade
1	Assistive technology/equipment is provided and maintained in accordance with nationally agreed standards and guidelines <sup>13,20</sup> .	Expert
2	<p>People with long-term neurological conditions have access to integrated community and specialist assistive technology/equipment services which work closely with neurology and rehabilitation services to provide<sup>1,2,5-11,13</sup>:</p> <ul style="list-style-type: none"> <li>• specialist assessment and advice to help them select the most appropriate assistive technology/equipment for their needs and lifestyle;</li> <li>• support in using direct payments for equipment and vouchers for wheelchairs;</li> <li>• assistive technology/equipment to maintain their health, help with their care, and support independence;</li> <li>• more specialist equipment on temporary loan or trial;</li> <li>• systems for tracking and recycling equipment to increase cost efficiency or temporary provision;</li> <li>• regular and ongoing review of their assistive technology needs, especially in response to changing need, including the needs of their carers, where appropriate.</li> </ul>	RA Expert
3	Assistive technology/equipment needs are documented in a person's integrated care plan <sup>18</sup> (see QR1).	Expert
4	There are specific arrangements for joint funding of specialist assistive technology provision (eg communication aids, electric standing frames and special seating aids) <sup>1</sup> .	Expert
5	Social services work closely with housing/accommodation and Supporting People services to provide timely, suitably adapted or purpose-built accommodation <sup>21</sup> .	Expert

## Quality requirement 8: Providing personal care and support<sup>i</sup>

### Aim

1. To ensure that people with long-term neurological conditions are able to choose where and how they live.

### Quality requirement

2. Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home<sup>ii</sup>.

### Rationale

#### Choice and supported living

3. Exercising choice and control over one's own life is fundamental to a sense of dignity and independence. Whatever physical or cognitive limitations people with long-term neurological conditions may have, they retain preferences, ambitions and commitments which they hope to fulfil.
4. The availability of a wide range of care and support options allows people with long-term neurological conditions to make choices and select the services that suit them and will meet their changing needs<sup>1,2</sup>. Any practical help needs to be based on supporting their individual aspirations to live independently and take part in society<sup>3</sup>.
5. People with greater care needs or those in the later stages of illness often prefer to stay at home and use community support services, rather than having to go into a care home.
6. Health and social care services need to follow guidance issued on choice of accommodation<sup>4</sup>. In addition, people need to be offered a range of accommodation options which can include:
  - a. reliable, flexible short or long-term care in the person's home tailored to their needs;
  - b. appropriate respite care at home or in specialised settings. Respite care is a key factor in enabling care to be provided at home over a long period<sup>1,5</sup>. User organisations have also drawn attention to the need for appropriate respite care<sup>3</sup>;
  - c. longer-term care settings (eg specialised care homes suited to the needs of people with long-term neurological conditions and which also meet their individual cultural and personal requirements); and
  - d. supported living options where people are enabled to live in individual accommodation, or with peers in group homes, with support available on site or nearby. Evidence shows these schemes offer good community integration and quality of life for both the person and their family/carers, while avoiding the need for more expensive options<sup>2,6-10</sup>.

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i This quality requirement supports Standards: C5a-c and D2a-c – Clinical and Cost Effectiveness; C11 – Governance; Standard; C22 a and c – Public Health. It also supports PSA Objective II: supporting people with long-term conditions through a personalised care plan and improved care in primary care and community settings and IV: support for older people to live independently in their own homes through person-centred, needs-based care services.

ii 'Home' in this context means the place where the individual **chooses** to live, which may be their own accommodation or may be a residential or care home.



7. Direct Payments schemes have also proved effective in allowing people greater choice over the nature and timing of care, as well as over who provides it. It is a legal requirement that everyone receiving community care services should be offered Direct Payments.

### **Improving access to support in the community**

8. The holistic assessment described in detail in QR1 will identify people's needs for community care and support. The assessment also needs to take account of the type and amount of care which carers are willing and able to provide and how this might change over time (see QR10).
9. It is easier to deliver continuity of care and provide appropriate support at identified times during the day and night when all the agencies involved (social care, the NHS and the voluntary and independent sectors) work together to support the person in the home. Care staff need to be aware of the person's care plan and deliver care in a way that allows them to retain as much independence, choice and control as possible.
10. The following are key elements of successful home care:
  - a. providing rehabilitation and support in the community (see QR5) with a range of therapies (eg physiotherapy, occupational therapy, speech and language therapy and clinical psychology). Providers of community rehabilitation and support services can train those providing day-to-day support (eg healthcare staff, personal care staff or carers), to make sure that rehabilitation (eg wearing splints to manage spasticity) becomes part of everyday life and helps to maintain the person's health and well-being and prevent their condition deteriorating;
  - b. providing appropriate support from general practice and community nursing teams;
  - c. co-ordinating planned home care between all agencies involved, including social care and the NHS and voluntary and independent sectors;
  - d. specialist neurological and rehabilitation services, experienced care providers and people with long-term neurological conditions and carers providing training and supervision for care staff in the needs of people with long-term neurological conditions;
  - e. developing close links with palliative care services;
  - f. providing a range of community and domiciliary healthcare services including (eg dentistry, ophthalmology, psychology, chiropody and pharmacy) to help people maintain their basic health and well-being at home.

### **Improving access to care**

11. People with long-term neurological conditions also need:
  - a. greater flexibility in the nature and timing of care and who provides it to meet their own and their family's varying needs and active support to operate Direct Payments through Direct Payment support services to increase this flexibility;
  - b. active support to ask for an assessment for community care services in line with guidance on *Fair Access to Care Services* (introduced in April 2003 to determine eligibility for adult social care)<sup>11</sup>. Assessments of community care needs should be holistic, determining the person's overall level of need by taking into account their physical, cognitive, behavioural and emotional requirements and what support they need to participate in society and to fulfil family roles. Risk assessment can also be an integral part of the process to identify the extent to which providing support could prevent a decline in the person's physical or mental health;

- c. removing any eligibility barriers to receiving a prompt initial or screening assessment for fully funded NHS continuing care which will normally identify whether it is appropriate to proceed to fuller assessment;
- d. prompt and fair assessment of eligibility for fully funded NHS continuing care, based on clinical and care needs<sup>12</sup>. This assessment should be holistic, taking into account the many complex needs of people with long-term neurological conditions (eg daily care needs, spasticity management, communication, cognitive, emotional and behavioural problems). Assessors need to be trained to take account of the needs of people with long-term neurological conditions when they are assessing for NHS continuing care. Steps to ensure equity and consistency of criteria and assessment processes, which include taking account of the needs of this group, will be part of ongoing work to improve the provision of NHS continuing care;
- e. prompt reassessment of eligibility for both social and healthcare when needs change;
- f. access to the Supporting People programme which provides housing-related support for vulnerable people.

### **Information**

- 12. People with long-term neurological conditions, their carers and families need to have information about the full range of personal care and supported living options available to them locally. It is important to inform people that they are entitled to have their needs assessed and to explain how to get an assessment. They also need to be aware of and supported in accessing Direct Payments where appropriate.

### **Special needs of people with rapidly progressing conditions**

- 13. People with rapidly progressing conditions find their care needs increase over a short period of time. Specific plans drawn up at an early stage need to ensure flexible care and respite arrangements; continuity in and training of care staff (eg to manage ventilation at home and other specialist equipment or particular care needs) and close communication between care teams and specialist neurological and palliative care services.

## Evidence-based markers of good practice for QR8

		Evidence grade
1	Health and social services work together to provide the full range of accommodation, care and support options and facilities to maximise choice <sup>4</sup> ; and where day or residential care or supported living are provided, they are in suitable settings for people with neurological conditions <sup>3,8,9,13</sup> .	RA Expert
2	Care in all settings is provided by appropriately trained nursing, therapy and care staff with experience in managing long-term neurological conditions; and care staff receive support and advice from community rehabilitation and support providers (see QR5) and other specialist neurological, palliative care and rehabilitation services as appropriate <sup>3</sup> .	Expert
3	Health and social care services work together to provide programmes of care that help the person to remain as independent as possible as their condition progresses <sup>13-15</sup> .	RA Expert
4	<p>People with long-term neurological conditions have equitable access to services and assessments based on their need for health and social care support (with prompt reassessment when needs change), and are supported in applying for:</p> <ul style="list-style-type: none"> <li>• Direct Payments<sup>16,17</sup>, to increase their control and choice over their care;</li> <li>• fully funded NHS continuing care that takes account of the particular needs of long-term neurological conditions, including physical, communication, cognitive, behavioural and emotional problems<sup>12</sup>;</li> <li>• adult social care delivered under the <i>Fair Access to Care Services</i> scheme based on need<sup>11</sup>;</li> <li>• help from the Supporting People Programme which provides housing-related support for vulnerable people; and</li> </ul> <p>staff administering these assessments and schemes are aware of the particular needs of people with neurological conditions (eg for social inclusion, independent living, preventative care).</p>	Expert

## Quality requirement 9: Palliative care<sup>i</sup>

### Aim

1. To provide people in the advanced stages of long-term neurological conditions with high-quality palliative care services.

### Quality requirement

2. People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care<sup>1</sup>.

### Rationale

3. People of all ages who are in the advanced stages of long-term neurological conditions may need specialised palliative care services<sup>ii 2,3</sup>. These services promote physical, psychosocial and spiritual well-being and emphasise quality of life and good symptom control<sup>4-7</sup>. Palliative care services take a whole-person approach, respect patient autonomy and favour open and sensitive communication. They can also support a person's family and carers in bereavement. Because of the protracted nature of long-term neurological conditions, people may need palliative care over an extended period of time to alleviate distressing symptoms and improve their quality of life. The situation is particularly difficult for younger adults nearing the end of their lives. Families and staff may need additional personal support in caring for them.
4. The NICE guidance for supportive and palliative care for adults with cancer<sup>1</sup> sets out the benchmark of palliative care services. While this guidance is orientated towards cancer, many of the principles and recommendations apply to other long-term conditions. Many of the symptoms experienced in the advanced or final stages of certain long-term neurological conditions are similar to those in other conditions such as cancer<sup>8</sup> (eg in terms of pain and breathlessness)<sup>3,5,9</sup>. However, there are some issues and interventions that are specific to long-term neurological conditions. For example:
  - a. managing pain arising from spasticity or neuropathic pain needs a different approach from managing cancer pain<sup>9,10</sup>;
  - b. non-invasive ventilation may be needed to improve breathing<sup>3,5,9</sup>;
  - c. cognitive and communication problems may limit the person's ability to describe their experience, express their choices and take part fully in counselling or other support and staff need training to communicate with them effectively<sup>3,4,7</sup>;
  - d. there may be issues around mental capacity and consent and the need for advance directives.

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i This quality requirement supports Standards: C5a and c and D2 – Clinical and Cost Effectiveness; and D9 and 10 – Patient Focus. It also supports the PSA Objective II: supporting people with long-term conditions through a personalised care plan.

ii Specialised palliative care is delivered by professionals who specialise in this field and who work with patients and families with complex needs (eg consultants in palliative care medicine, palliative care nurse specialists and staff working in hospices). Other staff also provide care for patients and their families (eg GPs, district nurses, hospital doctors, social workers, allied health professionals and staff in care homes). These staff are often considered to be 'generalist' in relation to palliative care.

5. Research shows that palliative care is effective in improving both symptom control and quality of life in cancer<sup>1</sup> and is cost-effective in comparison with standard hospital and community care at the end of life<sup>11–15</sup>. There is also evidence that similar approaches are effective in long-term neurological conditions<sup>3,4,16,17</sup> and that people and their families value this care. There is evidence for the effectiveness of interventions to control pain<sup>9,10,16,18,19</sup>, breathlessness<sup>3,9,20</sup> and specific neurological symptoms such as spasticity<sup>4,5,19</sup>.
6. Currently only a small number of services and facilities offer specialised and comprehensive care for people in the advanced stages of neurological conditions. Social care staff, domiciliary or care home staff, rather than NHS staff provide most day-to-day care in the community. These staff would benefit from training in palliative care to support them in caring for people with severe motor, sensory, cognitive and/or communication impairments<sup>17</sup>.
7. Therefore, people in the advanced stages of long-term neurological conditions, as well as their families and carers, need access to specialised services and teams like those caring for people with cancer. Hospices, specialist palliative care hospital teams, day hospitals offering mainstream and complementary treatments and respite beds within a hospice setting could provide this care<sup>2,6,17,21–23</sup>. Because of the protracted nature of some neurological conditions, services need to be designed in a way which acknowledges that people will often need a longer, though initially less intensive engagement with palliative care services<sup>17</sup> than people with cancer.
8. NICE guidance on palliative care emphasises the importance of co-ordinated planning and care between all agencies to provide continuity of appropriate care<sup>1</sup>. Professionals working in neurology, rehabilitation and palliative care need to work closely together and with primary care staff and care providers, including non-NHS care staff (social care, domiciliary and home care staff), combining their expertise to support people in the advanced stages of long-term neurological conditions. This could be achieved by:
  - a. specialist palliative care teams (medical/nursing/allied health professionals/pharmacy) working alongside specialist neurology and neuro-rehabilitation teams (eg in joint clinics). This would help promote more consistent shared practice;
  - b. providing training in:
    - palliative care skills for neurologists, neurology specialist nurses and neuro-rehabilitation teams;
    - relevant aspects of neurology and neuro-rehabilitation for specialised palliative care teams and general practice and community nursing teams (eg how to deliver care for people with severe motor, sensory, cognitive and communication impairments);
    - palliative care skills for staff providing care in people's own homes, in hospitals, and in care homes<sup>24</sup>;
    - pain control and the medicines to control pain;
  - c. involving palliative care services in the networks described in Chapter 3.
9. The government's Command Paper *Building on the Best: Choice, Responsiveness and Equity* supports people's right to choose where they want to die. There is evidence that palliative care for people with neurological conditions can be provided effectively in a home environment if a co-ordinated team approach is adopted<sup>25</sup> and recent studies have highlighted that most people would prefer to die at home<sup>26</sup>. However, current information suggests that the proportion of end-of-life care provided at home is comparatively low and decreasing, although levels vary across the country<sup>27</sup>. It is important that people with long-term neurological conditions are able to exercise choice on this issue.

10. It is also important that people with long-term neurological conditions benefit from the innovations in generalised palliative care practice that are being implemented in the community, hospitals and in other care settings. The Department of Health's NHS End of Life Care Initiative<sup>28</sup> will invest £12 million over three years (2004/2007) to improve care for people coming to the end of their lives and will extend palliative care services to meet the needs of all people regardless of diagnosis. This initiative aims to spread existing best practice identified in the NICE guidance in improving end-of-life care including:
  - a. the Macmillan *Gold Standards Framework*<sup>29</sup> in GP practices, community nursing teams, other primary care settings and care homes which describes good practice guidelines for the last 12 months of life;
  - b. the *Liverpool Care Pathway for the Dying*<sup>30</sup> in district general hospitals, all primary care settings and care homes which deals with the last 72 hours of life; and
  - c. the *Preferred Place of Care*<sup>24</sup> in district general hospitals, all primary care settings and care homes which empowers people to choose where they would prefer to die.

### **Information**

11. It is important that people with long-term neurological conditions and their carers have information about the full range of palliative care services that are available to them locally and how to access them throughout their illness. Professionals need this information to support people effectively.
12. When people are considering their choices about end-of-life issues, it is essential that information to support their decision making is conveyed with sensitivity.

### **Special needs of people with rapidly progressing conditions**

13. People with rapidly progressing conditions benefit from early referral to palliative care services soon after diagnosis as symptoms may arise very quickly and survival may be short. This is particularly important for people with motor neurone disease who may lose their ability to speak, making it much more difficult for them to take part in full discussions about their care plan.

## Evidence-based markers of good practice for QR9

		Evidence grade
1	Specialised neurology, rehabilitation and palliative care multidisciplinary teams and providers work together to provide care for people with advanced long-term neurological conditions <sup>2,6,17,21-23</sup> .	<b>RA Expert</b>
2	People with advanced long-term neurological conditions have access to specialised and generalised palliative care services which support them in their home or in a specialised setting according to their choice and needs <sup>3,4,9,15,16</sup> and in line with national best practice guidelines <sup>1,24,29</sup> ; and specialised neurological and community rehabilitation services (see QR5) provide support, advice and training for all staff delivering palliative care in the community.	<b>RA Expert</b>
3	Staff providing care and support in the later stages of a long-term neurological condition have appropriate training so that: <ul style="list-style-type: none"> <li>neurologists and neuro-rehabilitation teams are trained in palliative care skills<sup>17,24</sup>.</li> <li>all staff providing care for people in the advanced stages of neurological illness are trained in both the management of long-term neurological conditions and palliative care<sup>17,24</sup>.</li> </ul>	<b>RB Expert</b>

## Quality requirement 10: Supporting family and carers<sup>i</sup>

### Aim

1. To provide support and services to carers<sup>ii</sup> of people with long-term neurological conditions, which recognise their needs both in their role as carers and in their own right.

### Quality requirement

2. Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

### Rationale

3. Family members and friends who care for and support people with long-term neurological conditions are often vital to the progress, well-being and quality of life of the person<sup>1,2</sup>. Most choose to take on this role willingly but it is important that health and social care services enable them to exercise choice, support them effectively and protect their health and independence.
4. Family relationships and roles change and carers can be put under severe financial and psychological pressure, particularly where there are cognitive, emotional and behavioural problems<sup>3-14</sup>. The whole family can become increasingly isolated<sup>8,9,12,13,15-17</sup>. Partners in particular often become the sole financial provider and organiser of care and support as well as coping with the responsibilities of running a family. This can result in deterioration in their own physical and mental health. Children can be profoundly affected and may also need support<sup>8,17-22</sup>. It is important to ensure that children do not take on inappropriate caring responsibilities.
5. Some conditions (eg multiple sclerosis and brain and spinal cord injuries) typically affect younger people. The person often has a normal life expectancy, so will need long-term care and support (for up to 40–50 years)<sup>1,23</sup>. This may mean planning alternative support systems as the carers themselves get older<sup>24</sup>.
6. Carers often need training and support to acquire new skills (eg in moving and handling the person, using equipment to help daily living activities<sup>9,25,26</sup> and managing cognitive and behavioural difficulties<sup>2</sup>). They may need the opportunity to work in partnership with specialist teams<sup>1,2,17,27-29</sup>. Carers may also need information on the role of medicines in the management of long-term neurological conditions and pharmacists can play an important role in providing this support.
7. Family members and other carers may need help to adjust to changes, especially those of a cognitive or behavioural nature. A whole-family approach, which includes siblings and children, may be helpful<sup>2,9,10,24,27,29-33</sup>. Current service models include designated family-specialist clinicians, carers' support workers and peer-support networks including those provided by the voluntary sector<sup>29,33-37</sup>.

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i This quality requirement supports Standards: D2b – Clinical and Cost Effectiveness; D9 – Patient Focus. It also supports compliance with the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004.

ii Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid (definition: Carers UK). See also the Carers Recognition and Services Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004.



8. The importance of the role and needs of carers has been recognised and reflected in legislation and government initiatives since 1995<sup>38–40</sup>, in reports by national carers' organisations<sup>41–43</sup> and in a range of good practice guidelines<sup>40,44–46</sup>.
9. The Carers (Equal Opportunities) Act 2004 will be implemented from April 2005. It places on local councils a duty to inform carers of their right to an assessment and stipulates that all assessments need to take account of the carer's needs or wishes to work or participate in training or leisure activities. The Act will promote better joint working between councils and the health service to ensure support for carers is delivered coherently. Improvements to services for carers of people with long-term neurological conditions need to be made in this context. There is scope to:
  - a. identify more carers who need support (eg carers from black and minority ethnic communities report significant problems in accessing carers' services)<sup>16,44,47,48</sup>;
  - b. develop voluntary sector and local authority carers' projects that focus specifically on the needs of carers of people with long-term neurological conditions<sup>9,37,45,48,49</sup>;
  - c. improve the training of health and social care professionals in awareness of the needs of carers, in the effects of cognitive impairments and in person-centred care planning<sup>9,24,47,50</sup>.
10. Evidence shows that there is a lot that can be done to reduce stress levels and improve carers' quality of life, including:
  - a. offering an integrated assessment of carers' health, social care and other needs, as well as the support they need in their caring role, together with a designated contact person (irrespective of whether the person with the long-term neurological condition recognises or accepts their own need for statutory services)<sup>1,13,17,23,38–40</sup>. This assessment needs to form the basis of a written care plan drawn up and implemented in discussion with the carer and reviewed regularly. The assessment identifies each person's needs and takes account of how providing services to one member of the family could benefit the family as a whole;
  - b. giving carers a choice about the nature and extent of their caring and support role<sup>1,38–40</sup>;
  - c. involving carers in planning and implementing (with appropriate training) the care plan for the person for whom they provide care. This would be done with the consent of the person to any disclosure of personal information<sup>1,25,48,51</sup>(see QR1);
  - d. providing timely information about the condition and its effects<sup>1,9,16,24,48,51–55</sup>;
  - e. providing information about condition-specific rehabilitation and support networks<sup>1,6,9,15,16,24</sup> and other services which are available both for the carer(s) and the person for whom they are caring (see QR1);
  - f. providing support and advice on relationships, physical and emotional well-being; bereavement; safety; welfare benefits; employment; education; training; leisure and breaks<sup>1,3,6,9,10,13,24,49,51,53,54</sup>;
  - g. providing regular breaks and breaks at short notice during emergencies when usual care arrangements have broken down (see QR8). The support offered during these breaks needs to be flexible and able to meet the needs of people with long-term neurological conditions, including highly dependent people. The service also needs to be available across a range of settings on a long-term or short-term basis as needed<sup>9,16,24</sup>;
  - h. establishing more culturally appropriate and accessible<sup>16,44,47,48</sup> services that specifically address the needs of carers of people with long-term neurological conditions;

- i. providing carer awareness training as an integral part of training and ongoing professional development for all those working with carers of people with long-term neurological conditions (see also 9c above)<sup>9,24,47,50</sup>.

### **Special needs of people with rapidly progressing conditions**

11. Where the condition progresses rapidly, it is important that the response from services acknowledges the urgency of carers' needs and the physical and emotional demands that are placed on them. Protocols will need to be in place to support carers of people with rapidly progressing conditions, including regular planned respite care<sup>6,49</sup>.

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i Services for carers must meet the requirements of the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004.

## Evidence-based markers of good practice for QR10

		Evidence grade
1	<p>Carers of people with long-term neurological conditions:</p> <ul style="list-style-type: none"> <li>• can choose the extent of their caring role and the kinds of care they provide<sup>1,38-40</sup>;</li> <li>• are offered an integrated health and social care assessment at diagnosis and all future interactions<sup>1,17,38-40</sup>, together with information that addresses their needs;</li> <li>• are offered a written care plan agreed with them and reviewed regularly;</li> <li>• have an allocated contact person.</li> </ul>	<p><b>RB</b> <b>Expert</b></p>
2	<p>Involving carers is part of the planning process so that:</p> <ul style="list-style-type: none"> <li>• all carers are treated as partners in care and helped to acquire appropriate skills to support them in their caring role<sup>9,25</sup>, including how to move and handle the cared-for person and how to use equipment to help in daily living<sup>9,25,26</sup>.</li> <li>• carers are given the opportunity to work in partnership with specialist teams<sup>1,2,17,27-29</sup>.</li> </ul>	<p><b>RA</b> <b>Expert</b></p>
3	<p>A range of flexible, responsive and appropriate services<sup>1</sup> is provided for all carers which:</p> <ul style="list-style-type: none"> <li>• deals effectively with emergency situations<sup>16</sup>;</li> <li>• can support highly dependent people at short notice;</li> <li>• provides appropriate support for children in the family<sup>8,17-21</sup>;</li> <li>• provides carers with breaks across a range of settings<sup>16,24</sup>;</li> <li>• is culturally appropriate (eg to the needs of black and minority ethnic communities)<sup>16,44,47,48</sup>.</li> </ul>	<p><b>RA</b> <b>Expert</b></p>
4	<p>Carers who need help to adjust to changes especially of a cognitive or behavioural kind have access to support based (where appropriate) on a whole-family approach and delivered (where necessary) on a condition-specific basis and in partnership with the voluntary sector<sup>2,10,24,27,29-33,35,37</sup>; and</p> <p>current service models are evaluated to inform future good practice<sup>7,10,11,27,33,37</sup>.</p>	<p><b>RB</b> <b>Expert</b></p>
5	<p>Staff working with people with long-term neurological conditions receive carer awareness education and training which involves carers in planning and delivery<sup>9,24,47,50</sup>.</p>	<p><b>Expert</b></p>

## Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings

### Aim

1. To provide people with appropriate neurological care at all times while they are having treatment or care in any health or social care setting.

### Quality requirement

2. People with long-term neurological conditions are to have their specific neurological needs met while receiving care for other reasons in any health or social care setting.

### Rationale

3. People with long-term neurological conditions often have complex problems needing a carefully integrated care plan for their condition and any secondary complications (see QR1). When a person is admitted to hospital or another unfamiliar care setting (eg for an unrelated illness or for respite care), it is important that their normal neurological care plan continues as far as possible. For example:
  - a. people with Parkinson's disease need their medication at specific times to control their symptoms properly. Failure to achieve this can result in poorer control of their symptoms and further medical problems developing<sup>1,2</sup>;
  - b. people who normally self-medicate will need help to continue to do so while in hospital or other care settings if they are able to;
  - c. people with spinal cord injury may need to follow certain procedures to maintain bladder and bowel continence. These may be different from local or national continence guidance because of the specific nature of their problem. Failure to follow these particular procedures can result in incontinence and constipation leading to increased spasticity and other neurological problems;
  - d. some people with long-term neurological conditions may need specialist aids and equipment (eg communication aids, equipment for non-invasive ventilatory support or for alternative feeding, walking aids, or specialist wheelchairs) to help them continue to function effectively during their stay in a hospital or care facility<sup>3</sup>;
  - e. people who have behavioural, cognitive and/or communication problems (eg due to a brain injury) have particular needs of which staff may have little experience <sup>3,4,5(R1,R2)</sup>;
  - f. certain people with progressive conditions may have written advance directives specifying those interventions they do not want during the later stages of their illness<sup>6</sup>.

4. Making sure that neurological needs are met will help to avoid unnecessary complications like contractures<sup>7</sup> and pressure sores which can result in delayed discharges home<sup>8</sup>; the need for more health and social care support at home and in extreme cases death. Neurological needs can be met by:
  - a. recognising the person's (and their carer's) understanding and experience of their own needs and consulting them on managing their condition<sup>9,10</sup>. Interpreter services may be needed in some instances to enable the person or their carer to communicate (eg if English is not their first language or if they have a sensory impairment);
  - b. in the case of planned admissions, making the person's neurological care plan (which might include information on current medication<sup>2</sup>, care programme, handling procedures<sup>11</sup>, and advance directives) available to all staff so that appropriate arrangements can be made before the admission<sup>12</sup>. Where appropriate, the person's *own* specialist equipment can go with them to the hospital/care facility and staff there need to be adequately trained in how to use it<sup>3,12</sup>;
  - c. in the case of emergency admissions, having clear protocols for liaison with specialist teams (eg spinal cord injuries centres (SCICs), neuroscience centres or community teams);
  - d. getting advice about meeting the specific needs of people with neurological conditions from specialist staff or people who will be familiar with the disease, its impact and management and the person themselves<sup>2,4,5,11,12</sup> (eg the identified key named person such as a care co-ordinator or case manager; members of the family or a carer; the neurological team; staff involved with the individual in the community and in specialist neuroscience centres and SCICs<sup>13</sup>). These specialists could be invited to provide support, information and training to generalist staff so they can develop a better understanding of the needs of people with long-term neurological conditions<sup>11,12</sup>;
  - e. providing non-neurological treatment in neurological settings for people with particularly complex neurological needs (eg some people with spinal cord injuries may prefer to have investigations and treatment in SCICs<sup>14</sup> where they know their neurological needs will be met).

### **Information**

5. People with long-term neurological conditions who need treatment for other unrelated conditions need to know how their neurological needs will be met in the non-specialist setting and who will be co-ordinating their care. They also need to be offered the opportunity to discuss any implications of their treatment on their neurological condition<sup>11</sup>.

### **Special needs of people with rapidly progressing conditions**

6. In addition to the above, if people with rapidly progressing conditions experience respiratory difficulties while they are in hospital, staff need to get advice from the neurological and respiratory care teams. They need to discuss treatment options and implications with the person and their carers. Emergency tracheostomies need to be avoided if possible.

## Evidence-based markers of good practice for QR11

		Evidence grade
1	Whenever the person is managed in a non-neurological setting (eg a general hospital ward or care facility) <sup>12,13,15</sup> : <ul style="list-style-type: none"> <li>• the integrated neurological care plan is available to all staff (see QR1);</li> <li>• there is close liaison with their usual neurological care team.</li> </ul>	<b>RB Expert</b>
2	Arrangements are in place to ensure that neurological needs can be met in all settings: <ul style="list-style-type: none"> <li>• planned admission:               <ul style="list-style-type: none"> <li>there are pre-admission interviews to establish any special needs, including equipment provision, communication aids<sup>4</sup> and transport<sup>12,16</sup>.</li> </ul> </li> <li>• emergency admission:               <ul style="list-style-type: none"> <li>protocols are in place for liaison with:                   <ul style="list-style-type: none"> <li>– the person's community care team; and</li> <li>– any relevant specialist team (eg neurosciences centre or SCIC<sup>15</sup>).</li> </ul> </li> </ul> </li> <li>• there is evidence of appropriate consultation between teams.</li> </ul>	<b>RA Expert</b>
3	There is effective consultation with the person about their management <sup>2-5,11,12,15</sup> and, where appropriate, involvement of family/carers who are familiar with the person's care needs; and interpreters are available for people who need them.	<b>RA Expert</b>
4	Specialist neurosciences, rehabilitation and spinal cord injury services are involved in providing advice and training for staff in general hospital and other care settings <sup>11,17,18</sup> .	<b>RC Expert</b>

# 3 Commissioning and clinical neuroscience networks

## Introduction

1. The quality requirements (QRs) have clearly shown that people with long-term neurological conditions frequently have complex needs requiring intervention or support from a range of different services. Some services are commissioned locally and others through specialised commissioning arrangements. Implementing this NSF successfully and providing good quality services depend on:
  - a. co-ordinating service commissioning and delivery;
  - b. working collaboratively;
  - c. sharing information.

## Neuroscience Networks

2. Establishing neuroscience networks to co-ordinate the planning, commissioning and provision of services will contribute to implementing this NSF successfully. The networks need to:
  - a. engage all stakeholders, including clinical and other staff, commissioners, managers, voluntary organisations, people with long-term neurological conditions and their carers;
  - b. work across traditional service boundaries and models of care;
  - c. have clear leadership, management and accountability arrangements.
3. Networks of this type can provide a structure for service planning and delivery, promote continuity of care and support staff by targeting resources where they are most needed. The aims of such networks are usually:
  - a. integrated care;
  - b. improved clinical outcomes;
  - c. cost effective services;
  - d. improved experience for people using health and social care services;
  - e. equity of service provision.

## Managed clinical networks

4. This chapter suggests key features of a neuroscience network, including:
  - arrangements for commissioning integrated services;
  - clinical network groups, which enable clinicians to work collaboratively to provide access to a wide range of services, support each other through training and the development of clinical skills and improve quality of care through systematic audit and evaluation of clinical practice.

These functions could combine to become a 'managed neuroscience clinical network', bringing together both commissioners and providers in the delivery of high quality integrated services (see optional model of network on page 67).

- Stakeholder or partnership groups can support the network and provide a forum to work together to address a range of related issues and help identify and develop network-wide priorities.

5. A collaborative, multi-agency approach to commissioning and delivering services for people with long-term neurological conditions makes it easier to provide co-ordinated and equitable services throughout the care pathway. Existing network models (eg cancer, cardiac and renal) are good examples of collaborative working between a range of key stakeholders. For a neuroscience network these might include:

- primary care trusts (PCTs) and their specialised commissioning groups (SCGs);
- acute trusts;
- foundation trusts;
- mental health trusts;
- neuroscience centres and spinal cord injury centres (SCICs);
- community and home care providers;
- rehabilitation services;
- local authority services (eg social services, housing, transport and education);
- Supporting People Commissioning Body;
- voluntary and independent sector organisations;
- people with long-term neurological conditions and their carers.

Within a managed clinical network all of these stakeholders make up the network board (see optional model of network on page 67).

6. The size and structure of the network will depend on the population served, local circumstances and geography (eg rural, urban or inner city location). Occasionally the network may extend beyond a strategic health authority (SHA) boundary. A PCT explicitly leads such a collaborative network and SHAs are responsible for developing them and ensuring appropriate engagement from organisations. Foundation trusts would be encouraged to join the network. The network needs to take account of current commissioning arrangements and involve all agencies in strategic planning. Networks will need to consider the effects on existing service models of payment by results; the expanded GP commissioning role; the legally binding contracts between PCTs and foundation trusts and their different accountability arrangements and increasing choice. The following features could be incorporated into the managed neuroscience clinical network:

- a. support by a network management team, including a clinical director, manager and administrative support (as with cancer);
- b. one designated lead PCT within an SHA boundary with responsibility for developing the commissioning framework for all services for people with long-term neurological conditions (including joint commissioning arrangements with social services and other agencies). This framework could form part of the annual accountability agreements between PCTs and their SHA;



- c. appropriate collaborative commissioning arrangements for specialised services, set out in the Department of Health's *Guidance on Commissioning Arrangements for Specialised Services* (March 2003). The guidance requires PCTs to adopt a collaborative approach through their SCGs to commissioning neurology, neurosurgery, specialised neuro-rehabilitation and spinal injury services. Collaborative commissioning arrangements allow neurology services to be commissioned from regional centres;
- d. collaborative commissioning to help share costs and reduce both administrative work and the unpredictability of case-by-case commissioning for low-volume, high-cost episodes of care. This would allow funding to be equally distributed across the network and help people with highly complex needs (eg those in a vegetative or low-awareness state) to have fair access to specialist services;
- e. PCT commissioning of local services (eg services provided to people at home). Existing models of joint commissioning (ie arrangements formed between PCTs and social services in local partnership boards and the Supporting People Commissioning Body), could form part of the commissioning network for services in the community and at home;
- f. clear accountability and financial arrangements, which may include pooled budgets and Health Act flexibilities, for all the agencies involved in the network for the delivery of the NSF. Where social services departments do not have separate teams for people with long-term neurological conditions, they will need internal lead management arrangements.

## Network clinical groups

- 7. Within managed neuroscience clinical networks, multi-agency, multidisciplinary clinical groups can support the work of the network and improve integrated service delivery across the whole care pathway from diagnosis to end-of-life through:
  - a. clinical guidelines to promote best practice in primary care, local hospitals, neuroscience centres and SCICs and by GPs and other health and social care professionals;
  - b. referral protocols to achieve appropriate access to hospital-based services, other specialised services (including neuroscience centres) and highly specialist interventions that are not appropriate for every centre (eg epilepsy surgery) and for return to primary care as needed;
  - c. two-way liaison for advice and support through e-mail, telemedicine or other interactive communication;
  - d. close communication between hospital staff and community-based teams (through inreach/outreach working) to promote exchange of experience and good practice and to ensure smooth transition between services;
  - e. flexible hospital admission and discharge policies that allow the person to make a graded transition from hospital to community. This is especially relevant for people adjusting to newly acquired disability and for those who have had a long stay in hospital;
  - f. support from specialist services for generalist services to develop expertise in treating, caring and supporting people with long-term neurological conditions (eg specialist neuro-rehabilitation community teams supporting a community rehabilitation team; or a SCIC or neuroscience centre supporting staff and patients in a local hospital);
  - g. collaboration between networked specialist services and centres which is likely to focus on a particular condition or need.

8. Network clinical groups can:
  - a. link hospital and community services;
  - b. support joint working in the community between all agencies involved;
  - c. allow specialist service providers to work together;
  - d. provide effective support for local, more generalist services.
9. Specialist providers involved in network clinical groups need enough time to fulfil their specialist assessment and consultancy role in addition to managing their own complex caseload. Time will be needed for:
  - a. advice and training for generalist staff;
  - b. specialist assessment and planning to initiate appropriate programmes of care and support to be delivered by generalist teams;
  - c. collaborative working with generalist teams to make sure people with long-term neurological conditions receive appropriate local services;
  - d. consultancy work to help redesign and develop local services.

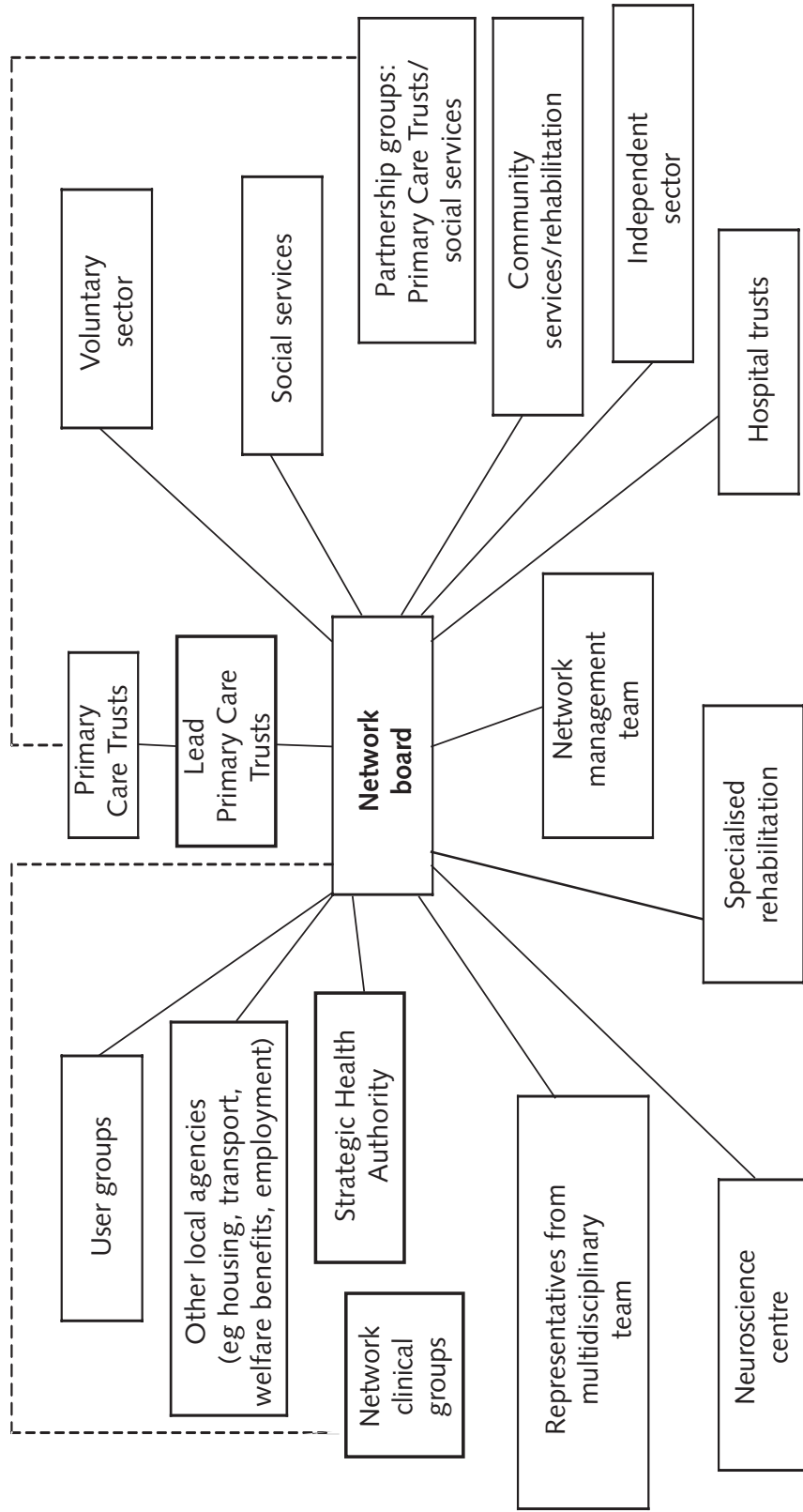
## Measuring performance

10. The Healthcare Commission and the Commission for Social Care Inspection may carry out performance reviews jointly where appropriate to assess progress on local implementation of:
  - a. the NSF, both in terms of its clinical indicators, as defined in *Better Metrics* (see [www.osha.nhs.uk/](http://www.osha.nhs.uk/)) and any locally agreed targets;
  - b. relevant National Institute for Clinical Excellence clinical guidelines and appraisals;
  - c. other national standards and audit measures.

## Summary

11. The key elements of good-quality, managed neuroscience clinical networks for integrated service provision are:
  - a. co-ordination and integration of:
    - multi-agency service commissioning and delivery in a geographical area covering all stages of care;
    - multidisciplinary service provision supported by network clinical groups;
  - b. partnerships between managers from different organisations to promote joined-up services and make the best use of resources;
  - c. collaborative working that recognises the role of specialised neurological services in complementing the work of non-specialised services in delivering appropriate treatment/support to people with long-term neurological conditions in all settings.

Optional network for neurosciences



**Key**

— indicates direct representation on the network board.

- - - indicates that the network board may take clinical/professional advice from this group.

## 4 National support for local action

1. This chapter signposts initiatives that can support local delivery of the *Long-term Conditions National Service Framework (NSF)*.

### National modernisation programmes

#### *Action on Neurology (QRs 1–5, 8 and 10)*

2. The Department of Health (DH) has been working with the NHS Modernisation Agency on the *Action on Neurology* programme to develop new ways of working to improve access and quality of care for people with neurological conditions. The outcomes of the programme will be available in their final report (see [www.modern.nhs.uk/action-on](http://www.modern.nhs.uk/action-on)).

#### *Neuroscience Critical Care Report (QR3)*

3. The Modernisation Agency published the *Neuroscience Critical Care Report – Progress in Developing Services* (August 2004) as part of its Critical Care Programme (see [www.modern.nhs.uk/criticalcare/5021/7117/20040%20DoH-Neurosciences.pdf](http://www.modern.nhs.uk/criticalcare/5021/7117/20040%20DoH-Neurosciences.pdf)).

### National underpinning programmes

#### Finance

4. Record extra resources for the NHS were announced in the 2003 Budget. As a result, DH was able to announce revenue allocations for 2003/06 of £148 billion to primary care trusts (PCTs) over three years – a total cash increase of 30.83%. This gave PCTs three years of certainty of funding for the first time.
5. On 9 February 2005, DH announced a further £135 billion for the next two years 2006/7 and 2007/8 – a cash increase of 19.5%. This will again give PCTs certainty of funding for the next three years.
6. In addition, as part of the recently announced Local Government Finance Settlement, DH notified local authorities (LAs) of £11,448 million of revenue funding for adult personal social services (PSS) for 2005/6. This reflects an 8% increase in the total funds (revenue and capital) allocated for adult PSS when compared with 2004/5 unadjusted figures. PSS allocations are currently made to LAs on an annual basis.

#### Workforce

7. In planning and delivering neurological and community services, it is important that there are enough staff with the right skills and experience who are well led, supported and deliver high quality care. DH has established the Long-term Conditions Care Group Workforce Team (LTC CGWT) which is taking a national view on the health and social care workforce pressures of this NSF. The responsibility for

supporting the CGWTs has been transferred to Skills for Health, who are also developing a competency framework on behalf of the LTC CGWT, defining the skills and knowledge needed to deliver the NSF. It will support service redesign and assessment of skill mix (see [www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingWorkforcePlanningHome/CGWTLongTerm/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingWorkforcePlanningHome/CGWTLongTerm/fs/en)).

## The nursing profession

8. Several initiatives highlight the contribution of nurses to support the delivery of this NSF, including:
  - a. *Making a Difference. Strengthening the nursing, midwifery and health visiting contribution to health and healthcare. The New NHS* (1999) (see [www.dh.gov.uk/nurstrat.htm](http://www.dh.gov.uk/nurstrat.htm)).
  - b. *The Chief Nursing Officer's 10 Key Roles for Nursing* (1999). The *NHS Plan* requires NHS employers to empower appropriately qualified nurses, midwives and therapists to undertake a wider range of clinical tasks.
  - c. *Liberating the Talents* describes continuing care, rehabilitation, managing long-term conditions and delivering the NSFs as core functions for all nurses in primary and community care (see [www.dh.gov.uk/cno/liberatingtalents](http://www.dh.gov.uk/cno/liberatingtalents)).
  - d. Nurse Prescribing, including:
    - Independent Prescribing for Nursing (see [www.dh.gov.uk/nurseprescribing](http://www.dh.gov.uk/nurseprescribing));
    - Supplementary Prescribing (see [www.dh.gov.uk/supplementaryprescribing](http://www.dh.gov.uk/supplementaryprescribing));
    - Patient Group Directions (see [www.groupprotocols.org.uk](http://www.groupprotocols.org.uk)).
  - e. Case Management/Community Matrons. The *NHS Improvement Plan: Putting People at the Heart of Public Services* (2004) sets out the government's intention that by 2008 there will be 3,000 community matrons using case management techniques for planning and co-ordinating the care of people with high-intensity needs. Community matrons will be key to delivering the Public Service Agreement target for long-term conditions.

## Allied health professions (AHPs)

9. A number of initiatives highlight the contribution that AHPs can make to support the delivery of this NSF, including:
  - a. *Meeting the Challenge: A Strategy for the Allied Health Professions* (2000) illustrates how the role of AHPs can be developed and supported and the central role they have to play in delivering the *NHS Plan* and *NHS Improvement Plan* (see [www.dh.gov.uk/PublicationsandStatistics/Publications/Publicationspolicyandguidance](http://www.dh.gov.uk/PublicationsandStatistics/Publications/Publicationspolicyandguidance)).
  - b. *The Chief Health Professions Officer's 10 Key Roles for AHPs* (2003) describes the current roles of AHPs and examines the potential for new roles to be developed (see [www.dh.gov.uk/AboutUs/HeadsofProfession/ChiefHealthProfessionsOffice](http://www.dh.gov.uk/AboutUs/HeadsofProfession/ChiefHealthProfessionsOffice)).
  - c. Extending non-medical prescribing to a range of healthcare professionals including AHPs (see [www.dh.gov.uk/PolicyandGuidance/MedicinesPharmacyandIndustry/PrescriptionsandPrescribing/SupplementaryPrescribing](http://www.dh.gov.uk/PolicyandGuidance/MedicinesPharmacyandIndustry/PrescriptionsandPrescribing/SupplementaryPrescribing)).
  - d. *The National Primary and Care Trust (NatPaCT) Self-Assessment Tool for AHPs* (2003) highlights significant issues for the delivery, modernisation and commissioning of AHP services (see [www.natpact.nhs.uk/cms.php?pid=2](http://www.natpact.nhs.uk/cms.php?pid=2)).

## Pharmacy profession and medicines management

10. Several initiatives have been developed which will increase the contribution that pharmacy can make to support the delivery of this NSF.
  - a. *A Vision for Pharmacy in the New NHS* (July 2003) emphasises the contribution of pharmacy to high quality, person-centred NHS services in community pharmacies, other primary care settings and hospitals  
(see [www.dh.gov.uk/Consultations/ClosedConsultations/ClosedConsultationsArticle/fs/en?CONTENT\\_ID=4068353&chk=Y2fMuy](http://www.dh.gov.uk/Consultations/ClosedConsultations/ClosedConsultationsArticle/fs/en?CONTENT_ID=4068353&chk=Y2fMuy)).
  - b. *The Chief Pharmaceutical Officer's 10 Key Roles* (July 2003) focuses on the role of the pharmacy profession in providing high quality services to people  
(see [www.dh.gov.uk/Consultations/ClosedConsultations/ClosedConsultationsArticle/fs/en?CONTENT\\_ID=4068353&chk=Y2fMuy](http://www.dh.gov.uk/Consultations/ClosedConsultations/ClosedConsultationsArticle/fs/en?CONTENT_ID=4068353&chk=Y2fMuy)).
  - c. Extending prescribing: a framework is being developed for independent prescribing by pharmacists, in particular for people with long-term conditions  
(see [www.dh.gov.uk/PolicyAndGuidance/MedicinesPharmacyAndIndustryServices/Prescriptions/SupplementaryPrescribing/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/MedicinesPharmacyAndIndustryServices/Prescriptions/SupplementaryPrescribing/fs/en)).
  - d. The new contractual framework for community pharmacy, which will be implemented in 2005, will provide services such as repeat dispensing, medicine usage review, signposting and support for self care (see [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?cCONTENT\\_ID=4091867&chk=h2R9wL](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?cCONTENT_ID=4091867&chk=h2R9wL)).
  - e. The medicines management collaborative, which is hosted by the National Prescribing Centre, provides medicines management schemes to help people get the most from their medicines. The collaborative programme currently covers 146 PCTs, involving around 14,000 GPs and 4,900 community pharmacies. It has the potential to ensure over 27 million people across these PCTs can get help to make better use of their medicines (see [www.npc.ppa.nhs.uk/mms/](http://www.npc.ppa.nhs.uk/mms/)).

## Medicines management

11. DH has published *Management of Medicines: A resource to support implementation of the wider aspects of medicines management for the National Service Frameworks for Diabetes, Renal Services and Long-term Conditions* (July 2004). It offers practical support for PCTs and NHS trusts (see [www.dh.gov.uk/assetRoot/04/08/87/55/04088755.pdf](http://www.dh.gov.uk/assetRoot/04/08/87/55/04088755.pdf)).

## Medicines Partnership

12. DH is funding the Medicines Partnership based at the Royal Pharmaceutical Society. It has developed two guides to help people prepare for review consultations (see [www.medicines-partnership.org/medication-review/focus-on-your-medicines](http://www.medicines-partnership.org/medication-review/focus-on-your-medicines)):
  - *Focus on your Medicines*, which is suitable for all conditions;
  - *Focus on your Health for People with Epilepsy*, which includes an epilepsy diary for the person to complete and questions to consider.

13. Medicines Partnership also offers an interactive website to help people with multiple sclerosis who are considering disease-modifying drugs make an informed decision about treatment options (see [www.msdecisions.org.uk](http://www.msdecisions.org.uk)).
14. Medicines Partnership is also running a major study to develop community pharmacists with a special interest in Parkinson's disease who can support people to understand and manage their medicines. The project aims to lead to a framework for pharmacists with a special interest in specific neurological conditions (see [www.medicines-partnership.org/projects/current-projects/pd-project](http://www.medicines-partnership.org/projects/current-projects/pd-project)).

### Medicines information project

15. The Medicines Partnership, NHS Direct Online, the Medicines and Healthcare products Regulatory Agency (MHRA) and the pharmaceutical industry are collaborating on a new, independent, comprehensive source of medicines information for people, linked to information about conditions and treatment options. They have already developed a complete set of 'medicines guides' for epilepsy. Further conditions will be added over the next two to three years. The guides are available through NHS Direct Online (see [www.medguides.medicines.org.uk/](http://www.medguides.medicines.org.uk/)).

### Practitioners with a special interest (PwSI)

16. Practitioners with special interests, including GPs (GPwSI), nurses (NwSI) and AHPs (AHPwSI) and, in future, pharmacists, make it possible to provide a wide range of services in local community settings. The PwSI approach is being extended with further frameworks for healthcare scientists and other key staff (see [www.dh.gov.uk/PolicyandGuidance/OrganisationPolicy/PrimaryCare/GPswithSpecialInterests/fs/en](http://www.dh.gov.uk/PolicyandGuidance/OrganisationPolicy/PrimaryCare/GPswithSpecialInterests/fs/en). NatPaCT has also produced documentation and support on PwSIs: [www.natpact.nhs.uk/cms/165.php](http://www.natpact.nhs.uk/cms/165.php)).

### Research and development

17. DH has funded short-term research studies focusing on user/carer experience and sudden brain injury to support the development of the NSF. There is funding for a longer-term, more intensive programme of research to support implementation of the NSF and examine its impact on the management of long-term neurological conditions.

### *NSF for Long-term Conditions Information Strategy*

18. The *NSF Information Strategy* is a web-based resource for use alongside the NSF. It is designed to signpost tools, evidence and other sources of information which will help implement and deliver the NSF (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).



## Other initiatives

### Supporting people with long-term conditions

19. The *NHS Improvement Plan: Putting People at the Heart of Public Services* and the policy document *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration* (January 2005) demonstrate the government's commitment to improving the care and quality of life for people with long-term conditions.
20. There is a strong emphasis on primary care, particularly on proactive primary care teams and informed patients working together and on multidisciplinary team-working across health and social care partnerships. People with long-term conditions will be supported to manage their condition themselves (self care). By March 2008, 3,000 community matrons will be in place to plan, manage and co-ordinate care for people with highly complex needs who are living at home.
21. There is substantial common ground between the NSF and the long-term conditions strategy (eg, around person-centred care planning, information and support, self care and disease management). However, it is important to preserve the neurological focus in implementation and to ensure that this NSF retains its own discrete identity under the umbrella of the broader long-term conditions programme.

### Information for choice (QR1)

22. Almost 90% of people who responded to the *Building on the Best* patient choice survey stated that they need the right information at the right time in order to make choices and decisions about their personal health and healthcare. The Information for Choice strategy, *Better information, better choices, better health*, sets out a wide range of national and local actions designed to improve, by 2008, the range, quality and accessibility of information and support for users and professionals in giving, receiving and using health information. This will affect the way information around all long-term conditions is generated and communicated.

### Improving the life chances of disabled people

23. This Prime Minister's Strategy Unit project has significant overlaps with the NSF. It addresses the needs of all disabled people and the barriers they face, while recognising that many of these people would not define themselves as disabled. The final report, which is agreed government policy, assesses the extent to which disabled people are experiencing adverse economic and social outcomes in the UK; identifies why this is happening and what the implications are and assesses what can be done to improve the situation. The report emphasises choice and control for independent living, as well as rehabilitation, support and incentives for disabled people to get and retain employment. A new Office for Disability Issues will co-ordinate work on the policy recommendations (see [www.strategy.gov.uk/output/Page5046.asp](http://www.strategy.gov.uk/output/Page5046.asp)).

### Valuing People

24. This is the government's strategy to support all people with learning disabilities including those with epilepsy. Adults with learning disabilities and epilepsy will benefit from both this NSF and Valuing People. The key principles of Valuing People are rights, choice, independence and inclusion (see [www.valuingpeople.gov.uk/](http://www.valuingpeople.gov.uk/)).



## Independence Matters

25. The social model of disability recognises that social and environmental barriers limit opportunities for disabled people to take part in society on an equal basis with other people. Using this model, the Social Services Inspectorate (SSI) (now the Commission for Social Care Inspection, CSCI) published *Independence Matters* in December 2003. This overview report brings together the findings from a national programme of inspections into social care services for physically and sensory disabled people aged 16–64 years provided by local councils with social services responsibilities and the information held by the SSI as part of its performance monitoring process on the progress and achievements of all local councils.
26. The report contains an action checklist of questions to help local councils with social services responsibilities to audit their progress in responding to the national agenda for social care services for physically and sensory impaired people (see [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications) and follow links).

## Equality and human rights

27. DH and the Disability Rights Commission have produced a leaflet called ‘You can make a difference’, to improve disabled people’s experience of hospital services and give practical suggestions for how NHS staff can meet the needs of disabled service users (see [www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/EqualityAndHumanRightsArticle/fs/en?CONTENT\\_ID=4089269&chk=MnDYP/](http://www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/EqualityAndHumanRightsArticle/fs/en?CONTENT_ID=4089269&chk=MnDYP/)).

Further guidance on equality issues, including addressing age discrimination is at:

[www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/fs/en).

[www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/OlderPeopleArticle/fs/en?CONTENT\\_ID=4071271&chk=coj27b](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/OlderPeopleArticle/fs/en?CONTENT_ID=4071271&chk=coj27b).

## Transforming diagnostic services (QR2 and QR3)

28. Work is now under way nationally to address the need to increase speed of access to diagnostic services in the priority areas of pathology, imaging, endoscopy and physiological measurement services.

## General medical services contract (QRs 1, 2 and 9)

29. The new primary care contracting routes introduced a Quality and Outcomes Framework (QOF) to reward practices that provide an enhanced level of care in particular clinical areas. Epilepsy is one of these areas. GP practices can also negotiate with their PCT to deliver enhanced services to a higher specified standard for certain conditions. Multiple sclerosis is one such condition and already has a nationally negotiated specification for enhanced services (see [www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingPay/GPContracts/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingPay/GPContracts/fs/en)).

## The Primary Care Neurology Society (PCNS)

30. PCNS is a new network organisation supporting primary care professionals with an interest in neurology. It will offer information on new developments in clinical management and care across a range of neurological conditions (see [www.p-cns.org.uk](http://www.p-cns.org.uk)).

## Integrating community equipment services (QR7)

31. Community equipment services can provide a wide range of equipment that covers home nursing, minor home adaptations, communication aids and other electronic equipment for people with long-term neurological conditions. The integration of health and social services equipment services across the country is almost complete and will reduce duplication and provide equipment more efficiently (see [www.icesdoh.org](http://www.icesdoh.org)).

## Electronic assistive technology (EAT) (QR7)

32. EAT can contribute to reducing care costs and improving the quality of life for many people with long-term neurological conditions. The EAT project will produce guidance by April 2005 and additional funding for EAT will be available from April 2006.

## Wheelchair services (QR7)

33. From 2002 to May 2004, the DH Wheelchair Service Collaborative (in partnership with the NHS Modernisation Agency and the Audit Commission) involved 44 wheelchair services in England in a programme to improve services. Further information and a good practice guide are available (see [www.modern.nhs.uk/scripts/default.asp?site\\_id=44](http://www.modern.nhs.uk/scripts/default.asp?site_id=44)).

## Direct Payments (QR8)

34. Direct Payments increase people's independence and choice by giving them control over the way the services they receive are delivered. There is now a duty on councils to make a Direct Payment to people who want them. The Direct Payments Development Fund, worth £3 million a year over the next three years supports voluntary and community organisations to increase take-up of direct payments (see [www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en)).

## Fully funded NHS continuing care (QR8)

35. 'Fully funded NHS continuing care' describes a package of care arranged and funded solely by the NHS and provided free to the person. Eligibility is based on assessment of a person's mental and physical healthcare needs, not on the diagnosis of a specific condition. Following national guidance (Health Circular (HSC) 2001/015, Local Authority Circular (LAC) (2001/18), all strategic health authorities (SHAs) are responsible for setting eligibility criteria in their area and have recently reviewed them to ensure their legal compliance.

## Fair Access to Care Services (FACS) (QR8)

36. FACS guidance was introduced in April 2003 to provide those councils with social services responsibilities with a framework for determining eligibility for adult social care. Councils use the framework to describe the circumstances that make people with disabilities, impairments and difficulties eligible for help (see [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/FairAccessToCare/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/FairAccessToCare/fs/en)).

## Palliative care strategy (QR9)

37. DH has allocated £4 million a year over the three years 2004/05 to 2006/07 to support an end-of-life programme. This will enable SHAs to build on work already developed for cancer patients by training and supporting staff to provide high quality end-of-life care to all patients, regardless of diagnosis, who are approaching the end of their life.

## Carers strategy (QR10)

38. The Carers (Equal Opportunities) Act 2004 will come into force on 1 April 2005. It will:
- ensure that all carers know they are entitled to an assessment of their needs;
  - place a duty on councils to consider carers' outside interests (work, study or leisure) when carrying out an assessment; and
  - promote better joint working between councils and the NHS to ensure support for carers is delivered coherently.

## Beacon Councils for Supporting Carers (QR10)

39. The Office of the Deputy Prime Minister (ODPM) leads the Beacon Council Scheme. It aims to identify the best-performing authorities, who then act as centres of excellence in particular fields. Supporting Carers is one of the themes in the sixth round of the scheme (see [www.idea.gov.uk/beacons/](http://www.idea.gov.uk/beacons/)).

## National Institute for Clinical Excellence (NICE)

40. NICE has published clinical guidelines in several areas for people with long-term neurological conditions, including early head injury, multiple sclerosis and epilepsy. It has also produced technology appraisals on drugs for motor neurone disease, multiple sclerosis and epilepsy for adults and children. NICE also offers guidance on interventional procedures in neurosurgery<sup>i</sup>. It has also carried out an audit of epilepsy-related deaths (May 2002). DH's epilepsy action plan in response to this audit is available online (see [www.publications.doh.gov.uk/cmo/epilepsy/intro.htm](http://www.publications.doh.gov.uk/cmo/epilepsy/intro.htm)).
41. Future publications include a clinical guideline on Parkinson's disease (March 2006) and a technology appraisal for multiple sclerosis drugs. Further details can be found on the NICE website (see [www.nice.org.uk](http://www.nice.org.uk)).

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i NICE interventional procedures include: deep brain stimulation for Parkinson's disease; vagus nerve stimulation for refractory epilepsy in children; stereotactic radiosurgery for trigeminal neuralgia using the gamma knife; subthalamotomy for Parkinson's disease; selective peripheral denervation of cervical dystonia, and supraorbital mini craniotomy for intercranial aneurysm; coil embolisation of ruptured and unruptured intracranial aneurysms.

## Other related government initiatives

42. People with long-term neurological conditions have needs that go beyond health and social services, requiring co-ordination within a broader strategic framework. The principal initiatives of this type are Local Strategic Partnerships and Local Area Agreements.

- **Local Strategic Partnerships (LSPs)**

Although not statutory, LSPs exist in almost all parts of the country and represent the key local partnership for bringing together local authorities, service providers and the private, voluntary and community sectors. LSPs aim to co-ordinate local service provision better and will support the delivery of this NSF. Information on LSPs can be obtained on a regional basis from individual government offices or from the Office of the Deputy Prime Minister (ODPM) website (see [www.odpm.gov.uk](http://www.odpm.gov.uk)).

- **Local Area Agreements (LAAs)**

Local Area Agreements represent a radical new approach to improve co-ordination between central government and local authorities and their partners, working through the Local Strategic Partnerships. They will rationalise some funding streams from central government, help join up public services more effectively and provide greater flexibility for local solutions to local circumstances. They will be structured around three blocks: *children and young people; safer and stronger communities and healthier communities and older people*. Outcomes and indicators will be agreed between central government and local authorities and their partners for each block. There are currently 21 pilot LAAs. Government has announced a further phase of 40 agreements to be in place by April 2006. Information on implementation of LAAs is available online (see [www.odpm.gov.uk/localvision](http://www.odpm.gov.uk/localvision)).

- **Housing – Supporting People**

The *Supporting People* programme offers vulnerable members of the community the opportunity to improve their quality of life through increasing or maintaining their ability to live independently. It promotes housing-related support services which are strategically planned, high quality and cost effective. These can help to prevent problems that lead to social exclusion, hospitalisation, institutional care or homelessness by effective and timely support.

The programme is administered at a local level by the 150 top-tier (ie county and unitary) local authorities, who commission and manage housing-related support services based on local needs and priorities through partnerships with Probation and Primary Care Trusts. The latter have a key role to play in ensuring that local Supporting People services complement local relevant care and health services, so that they support health as well as housing objectives and targets.

Through *Supporting People*, people with long-term conditions may be able to access services such as community alarm systems, help in organising adaptations and help in claiming benefits and emotional support. This can have a positive impact on people's lives by enabling them to make choices about where and how they live, improving their quality of life and maintaining their independence for as long as possible. Through this housing related support, there can also be a positive impact on:

- improved health and mobility;
- reducing admissions to hospital;
- reducing length of stay and delayed discharge from hospital;
- reducing visits to A&E;
- improving access to primary care services for vulnerable people;

- increasing use of treatment services; and
- promoting stability in lives which gives the chance to plan ahead. This can reduce psychological distress.

Further details are available online (see [www.spkweb.org.uk](http://www.spkweb.org.uk)).

- **Benefits**

Information about benefits and services for disabled people and carers can be found online (see [www.dwp.gov.uk](http://www.dwp.gov.uk)). The website allows people to claim Carer's Allowance electronically and download claim forms for Attendance Allowance or Disability Living Allowance (see [www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk) for information on all programmes specifically for disabled people).

- **Employment: Access to work/work preparation**

Jobcentre Plus programmes specifically aimed at disabled people can be viewed online (see [www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk) under 'Help for disabled people').

- **Transport**

*Accessible public transport*

The government is committed to ensuring that all public transport is accessible to disabled people, including wheelchair users. Regulations under the Disability Discrimination Act setting access standards for new trains, buses and coaches have already been implemented and similar standards for taxis are being developed.

*Personal mobility*

The government is supporting a network of mobility centres which provide advice, information and assessment to disabled people wanting to start or return to driving or to find out about adapted vehicles to meet their needs either as a driver or a passenger.

*Concessionary travel schemes*

The government has introduced a national minimum standard for local authority concessionary travel schemes in England. This means that there must be, in every area, travel concession arrangements which offer at least half fare reductions for older and disabled people for travel on local buses within the travel concession authority's area. Authorities are free to offer a more generous scheme if they wish.

Further details can be found online (see [www.dft.gov.uk/stellent/groups/dft\\_mobility/documents/sectionhomepage/dft\\_access\\_page.hcsp](http://www.dft.gov.uk/stellent/groups/dft_mobility/documents/sectionhomepage/dft_access_page.hcsp)).

- **Children**

*Every Child Matters: Change for Children*

This is a programme of change to improve the outcomes for all children and young people to be taken forward in 150 local authority areas, supported by a national framework. Further details can be found online (see [www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)).

# 5 Next steps: Implementing the NSF for Long-term Conditions

## Introduction

1. This NSF will form part of the developmental standards set out in *National Standards, Local Action: The Health and Social Care Standards and Planning Framework 2005–2008*. The aim is to implement the NSF over 10 years, with the pace determined by local priorities. Over the course of the three-year planning period covered by the *Planning Framework*, the NHS and local authorities will be expected to demonstrate that they are making progress in planning and developing the levels of service quality described in the NSF and other related national strategies. Both the Healthcare Commission and the Commission for Social Care Inspection may carry out improvement reviews to assess progress, jointly where appropriate.
2. This chapter does not prescribe how local health and social services should implement the NSF but outlines early steps they can take over the next three years in collaboration with a range of agencies and other local stakeholders listed in Chapter 3. The *NSF Good Practice Guide* is available online (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)). It can be used to support local implementation and includes examples of good practice, service models and links to relevant websites. The *NSF Information Strategy* and glossary are also available online at the same address.
3. The key areas to focus on during implementation are:
  - a. making progress in delivering each quality requirement (QR);
  - b. building capacity in staffing, facilities, equipment and range of service providers to ensure access to appropriate services for people with long-term neurological conditions;
  - c. developing a more integrated approach to delivering services with an increase in working with a range of agencies and using joint budgets.
4. All stakeholders will need to draw on:
  - a. ongoing work on service modernisation, including guidance on workforce and role redesign, *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration*, diagnostic services work, the Action on Neurology programme and *Neuroscience Critical Care Report* (see Chapter 4);
  - b. the evidence base for the quality requirements, including the examples of service models and provision in the good practice guidance;
  - c. National Institute for Clinical Excellence (NICE) clinical guidelines on multiple sclerosis, epilepsy, early management of acute brain injury, supportive and palliative care for adults with cancer and guidance for improving outcomes in children and young people with cancer;
  - d. previous NSFs, particularly the *NSF for Older People*, the *NSF for Children, Young People and Maternity Services* and the *NSF for Mental Health*.

## Suggested early action

5. This section outlines a range of possible early actions to help organisations prepare for and start implementing the NSF. Primary care trusts (PCTs) can consider:
  - a. setting up managed neuroscience clinical networks (Chapter 3) involving relevant stakeholders<sup>i</sup> and service users (networks need to be formalised with identified leadership and financial and accountability arrangements in place);
  - b. holding a stakeholder event to identify and agree local implementation priorities;
  - c. setting up a local implementation team to take the agreed NSF priorities forward;
  - d. setting up integrated planning and commissioning arrangements with social services departments and other PCTs, with agreements for shared financial responsibility, including pooled budgets.
  - e. influencing the provision of housing-related support for this group of people through their role on local Commissioning Bodies as part of the Supporting People Commissioning Framework.
6. Other possible early actions across the whole health and social care system include:

### Assessing and auditing local services, skills and training needs

- a. using the long-term conditions self-assessment tool for PCTs and social services developed by the Modernisation Agency to identify services needed for people with long-term neurological conditions and provide an overview of local delivery of the NSF QRs (see [www.natpact.nhs.uk/cms.php?pid=2](http://www.natpact.nhs.uk/cms.php?pid=2)). The *NSF Good Practice Guide* can also inform this audit;
- b. auditing existing local services for people with long-term neurological conditions across all local organisations delivering care to establish a baseline;
- c. analysing and profiling the skills of the local workforce (see Skills for Health long-term neurological conditions project at [www.skillsforhealth.org.uk/content/project.php?p=53](http://www.skillsforhealth.org.uk/content/project.php?p=53));
- d. identifying key training needs for all local agencies working within health, social services and the voluntary sector. As well as taking advantage of any national educational initiatives, this could also lead to a local education programme for all agencies involved, built around the NSF and run with the support of the local workforce development confederation;

### Redesigning services

- e. redesigning services, including developing local protocols and pathways of care and considering new patterns of working and skill mix, perhaps integrating trust and local social services department staff in specific multidisciplinary teams. Relevant strategies include:
  - the National Primary Care Development Team chronic disease ‘collaborative’ process (see [www.natpact.nhs.uk/cms/2.php](http://www.natpact.nhs.uk/cms/2.php));
  - practitioners with special interests initiative;
  - *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration*;

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<sup>i</sup> Including: people with long-term neurological conditions; carers; the voluntary sector; acute trusts; foundation trusts; mental health trusts; social services; care trusts; local authority agencies such as housing, transport, education and vocational training; the independent sector.



- the Department of Health's diagnostic services work to increase diagnostic capacity and reduce waiting times.

### Other actions

7. Other actions that will help to implement the NSF successfully include:
  - a. implementing the NHS Modernisation Agency's Action on Neurology and Neuroscience Critical Care projects;
  - b. implementing existing NICE guidelines and monitoring progress across primary care, local hospitals, neuroscience and spinal cord injury centres. This could be linked with improving medicines management for all long-term neurological conditions;
  - c. developing Expert Patient programmes and 'newly diagnosed courses' with the voluntary sector for people with long-term neurological conditions;
  - d. using the new general medical services (GMS) contract to deliver national enhanced services for multiple sclerosis in the appropriate PCT area and to support epilepsy care using the new GMS quality outcomes framework and future performance indicators;
  - e. using personal medical services (PMS) contracts to develop specific expertise in neurology to meet local needs;
  - f. providing improved information locally for professionals, people who use services and carers on all aspects of long-term neurological conditions;
  - g. liaising with national and local service providers for information technology to ensure that the design of local electronic systems (eg electronic booking), meets the needs of people with long-term neurological conditions;
  - h. reviewing local implementation of the eligibility criteria for fully funded NHS continuing care and adult social care to ensure it is in line with national guidance and meets the needs of people with long-term neurological conditions;
  - i. developing integrated care planning and assessment processes using guidance from the Modernisation Agency (work in progress due for publication in April 2005) (see [www.natpact.nhs.uk/cms/2.php](http://www.natpact.nhs.uk/cms/2.php)).



# ANNEX 1

## Acknowledgements, External Reference Group members and terms of reference



### Acknowledgements

I would like to thank all of the members of the External Reference Group (ERG). I would also like to thank the members of the ERG's Working Groups, Implementation Group, Research and Evidence Group and Focus Groups who have contributed to the development of this National Service Framework (NSF). Their expertise and commitment has made this NSF possible. I am particularly grateful to the Chairs of the ERG: Diana Whitworth and Sarah Mullally; and the Deputy Chair Lynne Turner-Stokes.

Work on the NSF began under the Rt Hon Jacqui Smith MP, who held the post of Minister of State for Community until June 2003. Since then, I have been responsible for the *NSF for Long-term Conditions*. I would like to thank her for her important contribution to developing the NSF.

A great deal of work on projects like this NSF is done behind the scenes by government officials, some of whom have been with this project since the start. Many of them have dedicated a large amount of their time to its successful completion. In particular, I would like to thank:

Robert Anderson, Jerry Bird, Clare Brassington, Mike Davies, Dr Jeffrey Graham, Susan Hanley, Bev Hopcutt (on secondment from Manchester Royal Infirmary), Kate James, Carol Lupton, Elizabeth Lynam, Glynn McDonald (on secondment from the MS Society), Patricia Noons, Zavar Patel, Sue Samples, Judith Sergeant, Rachel Swallow, Sue White, Helen Wiggins and Patience Wilson.

The NSF will deliver a significant change in the health and well-being of people with long-term conditions. Without these officials, and all those who have contributed, it would not have happened.

Thank you.

A handwritten signature in black ink, appearing to read 'Stephen Ladyman'. The signature is written in a cursive style with a long horizontal flourish at the end.

Dr Stephen Ladyman MP, Minister for Community

## ERG members

### Chair

**Diana Whitworth** Former Chief Executive, Carers UK.

### Co-Chair

**Sarah Mullally** Former Chief Nursing Officer, England.

(former Co-chair Andy McKeon, former Director of Policy and Planning at the Department of Health).

### Deputy Chair

**Prof Lynne Turner-Stokes** Professor of Rehabilitation, King's College Hospital, London; Director, Regional Rehabilitation Unit, Northwick Park Hospital, Middlesex.

### Members

**Alan Burns** Chief Executive, Trent Strategic Health Authority.

**Maggie Campbell** Brain Injury Co-ordinator and consultant neurophysiotherapist, Sheffield West PCT.

**Julie Charles** Executive Director, Equalities – The National Council of Disabled People and Carers from Black and Minority Ethnic Communities.

**Dr Chris Clough** Medical Director and consultant neurologist, King's College Hospital, London.

**Marilyn Ekers** Service user.

**Mr Wagih El-Masri** Consultant in spinal injuries and Medical Director, Midlands Centre for Spinal Injuries; Chairman, British Association of Spinal Cord Injury Specialists (BASCIS).

**Mr David G Hardy** President, Society of British Neurological Surgeons; consultant neurosurgeon, Addenbrooke's Hospital, Cambridge.

**Dr Maggie Helliwell** General Practitioner, Ling House Medical Centre; PEC Chair and Medical Director, Airedale PCT, Keighley, West Yorkshire.

**Jackie Holt** Director of Nursing and Clinical Development, Walton Centre for Neurology and Neurosurgery, Liverpool.

**Barbara Howe** Director of Specialised Commissioning, North East Sector, London.

**Jeff Jerome** Director of Social Services and Housing, London Borough of Richmond.

**Glyn Jones** County Manager, Physical Disability Services, Hampshire County Council Social Services Department.

**Norman Keen** Carer.

**Maureen Kelly** Chair, Neurological Alliance; Manager, Glaxo Neurological Centre, Liverpool.

**Barbara Kennedy** Chief Executive, Milton Keynes PCT.

**Helen McCloughry** Head of Rehabilitation and Intermediate Care, Nottingham City PCT.

**David Pink** Chief Executive, Long-term Medical Conditions Alliance.

**Jill Stewart** Policy Manager, Health and Social Care, Disability Rights Commission.

**Dr Andy Tyerman** Consultant clinical neuropsychologist and Head of Service, Community Head Injury Service, Vale of Aylesbury PCT.

**Dr Ian Williams** Neurologist and former Director, North West Clinical Neuroscience Partnership.

## Former members

**Dr Geoffrey Carroll** Former Clinical Director, Eastern Regional Specialised Commissioning Group.

**Prof Pam Enderby** Professor of Community Rehabilitation, University of Sheffield.

For full membership of Working Groups, Implementation Group and Research and Evidence Group (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).

## ERG terms of reference

To advise the Secretary of State in confidence on the development of a *National Service Framework (NSF) for Long-term Conditions* with a focus on neurological services, making recommendations on the areas in which standards might be set and on the content of the implementation guide.

The NSF will:

- set standards and define health and social care models for the diagnosis, treatment and care of people with neurological conditions. This will include identifying and tackling some generic issues that will benefit everyone with a long-term condition;
- provide an implementation guide based on processes, key interventions and service models that have worked in practice (linked wherever possible to National Institute for Clinical Excellence guidelines and appraisals);
- recommend national and local performance indicators and outcome measures as a means of monitoring and benchmarking progress.

The ERG recommendations must be:

- user- and carer-centred, taking into account both health and social care needs and building on the principles of the NHS Plan;
- based on robust evidence or, where robust evidence does not exist, built on the best evidence available or on a broad consensus of best practice;
- affordable and offer best value in the use of resources, making explicit where interventions will be cost and quality effective in both the short and longer term;
- set within the context of other policy initiatives, including the other NSFs, and taking into account the implications of new health and social care organisational arrangements;
- focused primarily within the NHS and social care but linked across to employment and other relevant government department policy areas.

# ANNEX 2

## Research and evidence

1. This National Service Framework (NSF) is based on the current body of evidence. Over the next few years, the body of evidence will grow as new models of service provision are developed and evaluated and new treatments are assessed.
2. Randomised controlled trials and other quantitative methodologies are not necessarily best suited to research questions involving long-term outcomes, varied populations with complex needs and assessment of impact on quality of life rather than cure. Existing tools which put a numerical score on 'quality of life' also often bear little relation to an individual's own definition of actual quality of life. Longitudinal studies and well conducted qualitative research are therefore equally likely to be appropriate methods to evaluate the interventions that are recommended as part of this NSF.
3. In response to these issues, the External Reference Group (ERG), set up to advise ministers on the NSF, developed a new typology to assess systematically the evidence currently available to support the quality requirements (QRs) and agreed this with the Department of Health Research and Development Directorate<sup>i</sup>. The typology:
  - a. reflects the value placed on the opinions of service users and their families/carers, as well as the views of professionals, when assessing the evidence to support the QRs;
  - b. is based on the principle that qualitative, quantitative and mixed studies can have equal validity when used in the appropriate context, rather than suggesting that there is an implicit hierarchy among research designs;
  - c. emphasises the quality of the study design, the integrity of its conclusions, and their relevance to the population served by this NSF.

### Evaluation of evidence

4. Each piece of evidence cited in the NSF has been reviewed and given either an 'E' or an 'R' rating:  
**E:** reflects expert (user/carer/professional) evidence;  
**R:** reflects research-based evidence.

### Expert evidence

5. This is evidence expressed through consultation or consensus processes rather than formal research designs. It could be professional opinion, or that of users and/or carers or other stakeholders. References are described as E1 user expert opinion or E2 professional expert opinion. Where there is expert evidence supporting the markers of good practice, this is indicated as expert in the evidence grade.

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i This aspect of development was undertaken by the Research and Evidence Group chaired by Professor Lynne Turner-Stokes.

## Research evidence

6. This is evidence gathered through formal research processes. Each piece of research-based evidence supporting the markers of good practice has been awarded a rating based on three categorisations: **Design, Quality** and **Applicability**. The first part indicates the category of research design; the second indicates whether the study was of high, medium or low quality, using scoring criteria with a maximum score of 10 and the third indicates whether the study relates directly or indirectly to long-term neurological conditions.
7. **Design** has been classified according to the categories listed in Table 1 below.

Table 1: Categories of research design

Primary research-based evidence	
P1	Primary research using quantitative approaches
P2	Primary research using qualitative approaches
P3	Primary research using mixed methods (qualitative and quantitative)
Secondary research-based evidence	
S1	Meta-analysis of existing data analysis
S2	Secondary analysis of existing data
Review-based evidence	
R1	Systematic reviews of existing research
R2	Descriptive or summary reviews of existing research

8. **Quality** has been assessed using five questions with a possible score on each question of 0, 1 or 2 – giving a maximum score of 10, as indicated in Table 2 below.

Table 2: Quality assessment

Each quality item is scored as follows: Yes = 2, In part = 1, No = 0		Score
1	Are the research question/aims and design clearly stated?	
2	Is the research design appropriate for the aims and objectives of the research?	
3	Are the methods clearly described?	
4	Is the data adequate to support the authors' interpretations/conclusions?	
5	Are the results generalisable?	
<b>Total</b>		<b>/10</b>

High quality research studies are those which score at least 7/10.

Medium quality studies score 4–6/10.

Poor quality studies score 3/10 or less.

9. **Applicability** has been classified as:

<b>Direct</b>	Studies that focus on people with long-term neurological conditions
<b>Indirect</b>	Extrapolated evidence from populations with other conditions

*So, for example:*

- *a well-constructed qualitative study, scoring 8/10 and demonstrating the benefits of a given intervention in people with multiple sclerosis would be classified as: **P2 High Direct**;*
- *an underpowered randomised controlled trial scoring 5/10 on quality assessment, demonstrating the benefits of palliative care in people with cancer would be classified as: **P1 Medium Indirect**.*

## Grade of research evidence

10. Each individual marker of good practice has then been given an overall evidence grade of A, B or C, based on the quality of all the evidence supporting it and how much of it was directly relevant. The overall grade of evidence was calculated using the table below.

**Table 3: Grade of evidence**

Grade of evidence	Criteria
<b>Research grade A:</b>	<ul style="list-style-type: none"> <li>• more than one study of high quality score (<math>\geq 7/10</math>); <i>and</i></li> <li>• at least one of these has direct applicability.</li> </ul>
<b>Research grade B:</b>	<ul style="list-style-type: none"> <li>• one study of high quality score (<math>\geq 7/10</math>) which is of direct applicability.</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>• more than one study of high quality score (<math>\geq 7/10</math>) which are of indirect applicability</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>• more than one study of medium quality score (4–6/10); <i>and</i></li> <li>• at least one of these has direct applicability.</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>• one study of medium quality score (4–6/10) which is of direct applicability; <i>and</i></li> <li>• one study of high quality score (<math>\geq 7/10</math>) which is of indirect applicability.</li> </ul>
<b>Research grade C:</b>	<ul style="list-style-type: none"> <li>• one study of medium quality score (4–6/10) which is of direct applicability.</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>• studies of low quality score (2–3/10) only.</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>• studies of indirect applicability only; <i>and</i></li> <li>• no more than one is of high quality score (<math>\geq 7/10</math>).</li> </ul>

11. The overall weight that can be placed on the available evidence is therefore signposted by an indicator that combines a description of the type of evidence with an overall rating of the quality and applicability of any research-based evidence. Where guidelines which summarise research evidence are quoted to support a marker of good practice, the evidence rating for that specific section of the guidance is used and this may mean that the overall evidence grade is lowered. The development, testing and application of the typology is being written up in detail for publication.

*For example:*

*a marker of good practice might carry the following indicator – **Expert, RA**. This indicates that there is expert opinion to support this statement as well as research of high quality, derived directly within the field of study. This would suggest that considerable weight could be placed on the findings of this evidence.*



# Annex 3

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# ANNEX 4

## Incidence and prevalence of some neurological conditions in the UK<sup>i</sup>

Condition	Incidence (new cases per year per 100,000 of population)	Prevalence (cases per 100,000 of population)	Approximate total numbers
Cerebral palsy	N/k	186	110,000
Charcot-Marie-Tooth disorder	N/k	40	23,600
Dystonia <sup>ii</sup>	N/k	65	38,000
Early onset dementia <sup>iii</sup>	N/k	N/k	18,000
Epilepsy <sup>iv</sup>	24–58	430–1,000	182,750–425,000
Essential tremor	N/k	850	500,000
Huntington's disease	N/k	13.5	6,000–10,000
Migraine <sup>v</sup> (England)	400	15,000	8,000,000
Motor neurone disease	2	7	4,000
Multiple sclerosis <sup>vi</sup>	3–7	100–120	52,000–62,000
Muscular dystrophy	N/k	50	30,000
Parkinson's disease	17	200	120,000
Post-polio syndrome	N/k	N/k	120,000
Spinal cord injury <sup>vii</sup>	2 <sup>viii</sup>	50	36,000
Spina bifida and congenital hydrocephalus	N/k	24	14,000
Young onset stroke <sup>ix</sup>	55 <sup>x</sup>	N/k	N/k
Traumatic brain injury leading to long-term problems <sup>xi</sup>	175 requiring admission to hospital	1,200 with long-term problems	420,000 upto 65 years

i Unless indicated otherwise, this table is based on figures in *Neuro numbers: a brief review of the numbers of people in the UK with a neurological condition*. This table includes a selected number of neurological conditions. See publication for details on other conditions such as ataxia, brain tumour, Guillain-Barré syndrome and narcolepsy. Where additional and comparable information has become available it is added with a footnote.

ii Primary idiopathic, ie not associated with another condition.

iii For Alzheimer's disease/dementia, the incidence is 25,000 per 100,000 in over 65s, prevalence 1,000 per 100,000 in the general population and approximate total numbers 700,000. Alzheimer's disease and other dementias are covered in the *National Service Framework (NSF) for Older People*.

iv Figures for England and Wales from National Institute for Clinical Excellence (NICE) guidelines.

v Steiner TJ et al. (1999) Epidemiology of migraine in England. *Cephalgia*, 19: 305–6.

vi Figures from NICE guidelines for England and Wales.

vii Kurtzke JF (1978) Epidemiology of spinal cord injury, *Neurologia Neurocirurgia Psiquiatria*, 18: 157–91.

viii The Spinal Injury Association gives 666 new patient admissions to spinal cord injury centres in the UK and Ireland in 2000 (equivalent to about 2 in 100,000).

ix For stroke in all ages the incidence is 204, prevalence 800, and approximate total numbers 300,000. Stroke is covered in the *NSF for Older People*.

x Admissions to hospitals in England 2002/03.

xi Figures for working age adults in England from a study by Professor Alan Tennant, Professor of Rehabilitation Science, University of Leeds, commissioned by the NSF Research and Evidence Group.



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