



National Audit Office

**REPORT BY THE  
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**Department of Health**

Services for people with  
neurological conditions

# Summary

**1** Neurological conditions result from damage to the brain, spinal column or peripheral nerves and fit broadly into four groups of conditions:

- sudden-onset: for example, acquired brain injury or spinal cord injury, often from an accident;
- intermittent and unpredictable: for example, epilepsy, certain types of headache or early multiple sclerosis;
- progressive: for example, motor neurone disease, Parkinson's disease or later stage multiple sclerosis; and
- stable: for example, post-polio syndrome or cerebral palsy in adults.

**2** Some neurological conditions are life threatening, many severely affect quality of life and cause lifelong disability. They also have a significant impact on the carers and families of those living with the condition. Approximately two million people have a neurological condition in the United Kingdom, excluding migraine.

**3** People with neurological conditions need a wide range of services across a number of organisations including health, social services, employment, benefits, transport, housing and education. The services a person needs can change, particularly where conditions rapidly deteriorate, or fluctuate. Fluctuation can affect access to services, in particular, when people's entitlement is assessed during periods where their condition has temporarily improved.

**4** The National Service Framework for Long-term Conditions (the Framework) introduced by the Department of Health (the Department) in March 2005, focused on people with neurological conditions. The Framework accurately identified a range of problems faced by people with neurological conditions including: lengthy diagnosis; poor information for patients on their condition and services; variable access to, and little integration of, health and social services; and poor quality of care in hospital. The Framework was developed at a time when accountability and delivery were being devolved to the front line rather than centrally driven, and reflecting this approach, the Framework, allowed local commissioners to determine the speed of implementation according to local priorities.

**5** At the core of the Framework were 11 quality requirements designed to “put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate from diagnosis to end of life”. The quality requirements were to be fully implemented by 2015. While the Framework remains part of the Department’s approach, at the time of our fieldwork in the summer of 2011, there was significant uncertainty about its status amongst the range of stakeholders we talked to. This was for a range of reasons including: the election of a new Government; the cancellation of a planned mid-point review agreed by the previous Government; and the decommissioning of the Long-Term Conditions Delivery Support Team in March 2011 due to the cessation of NHS bundle funding.

**6** Since the introduction of the Framework there has been a significant increase in spending on neurological services (see Key findings section below). It is therefore important to understand the Framework’s impact on services and learn lessons for the Department’s new long-term conditions strategy currently being developed.

**7** This study focuses on the health and social care services for adults with neurological conditions resulting from disease rather than from, for example, sudden brain or spinal cord injury. We have focused on three progressive conditions (Parkinson’s disease, multiple sclerosis and motor neurone disease), affecting approximately 200,000 people, for some of our fieldwork. This includes focus groups with people with these conditions, their carers and supporting charities. All Party Parliamentary Group reports on services for other neurological conditions (e.g. muscular dystrophy and epilepsy) indicate that these people face similar issues to those outlined below.

## **Key findings**

Progress in implementing the Framework has been poor

**8** This was a ‘new style’ Framework, developed to reflect changes in the way that the NHS was managed, significantly devolving decision making. By design, it did not have the traditional levers to support implementation including national monitoring, targets and ring-fenced funding for specific initiatives.

**9** Health spending on neurological services has increased significantly since the introduction of the Framework in 2005. Between 2006-07 and 2009-10, health spending increased by 38 per cent in real terms, from £2.1 billion in 2006-07 to £2.9 billion in 2009-10. This was part of local commissioners’ general budget and was not ring-fenced by the Department. Social services spending on adults with a physical disability, of which a significant proportion will have a neurological condition, has remained flat in real terms since 2005-06.

**10 The Department put in place no specific arrangements for monitoring how commissioners implemented the Framework. As a result, the Department was unable to hold local commissioners to account for implementation.** There was no national baseline assessment of the cost, access to, and quality of, neurological services, when the Framework was introduced, and no national monitoring of its impact. The Framework indicated that local delivery organisations should establish a baseline of services. However, the Department does not know how local organisations have gone about this, if at all. Therefore, the Department has no way to measure the effect of the additional spending on services or patient outcomes. With the Department cancelling its mid-point review of the Framework, agreed by the previous Government, it is not clear how lessons will be learnt and integrated into the design of the Department's new long-term conditions strategy.

**11 Data limitations mean that it is difficult to assess progress in implementing the Framework. Our analysis, however, shows that since its introduction:**

- **Access to health services has improved.** Waiting times for inpatient and outpatient neurology have improved since 2007. The number of, beneficial, elective neurological operations being performed has also increased. However, the number of adults with a physical disability receiving social services has fallen since 2005-06.
- **Emergency bed days have reduced.** The Framework was to contribute to the Public Service Agreement target to reduce emergency bed days by 5 per cent by 2008. Between 2004-05 and 2007-08, emergency bed days for people with long-term neurological conditions reduced by 12 per cent.
- **Important indicators of the quality of care for people with neurological conditions have worsened.** The number of people admitted to hospital as an emergency has increased significantly. The variation of emergency admissions across Primary Care Trusts is greater than expected, after taking into account the variation due to chance. In addition, emergency readmissions following an overnight stay increased for patients with Parkinson's disease, multiple sclerosis and motor neurone disease within 7 (4.5 to 5.7 per cent of discharges) and 28 (11.2 to 14 per cent of discharges) days between 2004-05 and 2009-10.

**12 Overall, the achievement of the quality requirements within the Framework has been poor.** For example, a North East Public Health Observatory report of an audit undertaken in 2008, rated performance against the quality requirements for all Primary Care Trusts in its region as below 'the good-doing well' standard. A report by Neurological Commissioning Support of its audit of 11 sites across England found that not one had fully met a single quality requirement. However, a minority had met some of the quality requirement's individual evidence-based markers. Furthermore, the 2011 Royal College of Physicians and Multiple Sclerosis Trust audit concluded that there had been no major improvements in many aspects of service provision for people with multiple sclerosis since 2006.

Significant problems with current services remain

**13 People experienced varying quality of the diagnosis process.** While some patients we spoke to had good experiences, others had long time periods between identifying first symptoms and final diagnosis. An audit by Parkinson's UK found that only 66 per cent of people with Parkinson's disease were seen by a specialist within six weeks from referral by their GP, as per the National Institute for Health and Clinical Excellence guideline.

**14 Information and advice to patients and carers is poor.** Many patients did not receive information on their condition, local services, or available support following diagnosis. A Royal College of Physicians and Multiple Sclerosis Trust survey of people with multiple sclerosis found that 35 per cent were not given information on the condition after diagnosis.

**15 Ongoing care is fragmented and poorly coordinated.** Our focus groups mentioned having no personal care plan or single person coordinating care; a continual cycle of referral–discharge–referral; and poor coordination between health and social services. A University of Oxford survey of people with Parkinson's disease, multiple sclerosis and motor neurone disease found, for example, that only 22 per cent had a personal care plan.

**16 Access to services for people with neurological conditions and their carers varies significantly depending on where they live.** A survey of hospital trusts by Parkinson's UK found that, for a significant number of the trusts audited, access was not universal for expert Parkinson's disease services including physiotherapy, occupational therapy, and speech and language therapy. Also, our analysis highlighted the variation in the number of people with multiple sclerosis per specialist nurse across Strategic Health Authority regions.

**17 People with neurological conditions admitted to hospital as an emergency often receive care from health professionals without neurological training.**

A recent Royal College of Physicians report concluded that this increased the risk of poor patient outcomes.

**18 Previous Committee of Public Accounts and NAO reports have highlighted many of the systemic issues set out in this report.** For example, reports on dementia, autism, end of life care and rheumatoid arthritis have highlighted:

- the lack of information on prevalence and demand for services;
- poor knowledge of conditions among health professionals;
- poor information for patients about services;
- little coordination between health and social services;
- weak commissioning practices; and
- skilled workforce shortages.

**19 This report has also highlighted perverse incentives which do not support continuity of care.** We found ‘new to follow-up’ ratios, which measure the number of follow-up appointments, compared with new patients seen, put pressure on hospitals to discharge patients with the same long-term conditions leading to a cycle of referral–discharge–referral.

**20 There are examples of good practice which are delivering better services for patients, but they are often poorly supported.** For example, specialist nurses can help to improve patient care and the coordination of health and social services resulting in reduced hospital admissions. These are important initiatives that can help to promote the migration of care from hospitals to the community, supporting the Government’s aim to improve efficiency. They need to be championed, including having the information and analysis to demonstrate how such arrangements can realise actual cost savings through, for example, reductions in the number of hospital beds.

There are opportunities and risks for neurological services in the new health and social care landscape

**21** In July 2010, the White Paper, *Equity and Excellence: Liberating the NHS*, set out the plans for a fundamental reform of the NHS. The Government’s vision is to put patients at the heart of everything the NHS does; to focus on continually improving patient outcomes; and to empower and liberate clinicians to innovate, with freedom to focus on improving healthcare services. The proposed Bill aims to shift more responsibility to local bodies and ensure lines of accountability to the public, parliament and government.

**22** The Department’s current thinking on the delivery mechanisms within the bill are:

- There will be clear accountability structures. For example, the Secretary of State for Health will hold the NHS Commissioning Board to account for achieving objectives and meeting requirements set out in an annually-refreshed Mandate. The NHS Commissioning Board will in turn hold Clinical Commissioning Groups to account for delivering improvements in outcomes, including all people with long-term conditions. One intention is to ensure publicly available information on the outcomes which healthcare services commissioned by Clinical Commissioning Groups must deliver. The Commissioning Board will also issue commissioning guidance, based on Quality Standards developed by the National Institute for Health and Clinical Excellence. These may include Quality Standards for multiple sclerosis, Parkinson’s disease and motor neurone disease. The National Quality Board has commissioned the National Institute for Health and Clinical Excellence to develop quality standards covering epilepsy in children and adults.
- Clinical Commissioning Groups will be able, if they choose, to commission collaboratively across larger populations for rarer neurological conditions, whilst the NHS Commissioning Board will commission more specialised services.

- Lay representation on the Clinical Commissioning Groups is designed to ensure patient and public involvement in the commissioning process. Clinical Commissioning Groups will be able to draw on additional expertise where necessary within clinical senates and clinical networks.
- Health and Wellbeing Boards will be responsible for overseeing the health needs of the local community and for coordinating care across a local area. The Joint Strategic Needs Assessment is designed to assess all health and social care needs in the local population.

**23** Our analysis of the Framework with its devolved responsibility for implementation and for measuring services against a baseline, allowed us to identify risks to services for people with neurological conditions that the Department needs to understand and manage. In particular:

- When expanding local level decision making, national accountability structures and monitoring systems need to be put in place to reduce unintended variations in access to, and quality of, services.
- Clinical Commissioning Groups and Health and Wellbeing Boards should draw on, when required, appropriate neurological expertise to ensure that joint strategic needs assessments and joint health and well-being strategies result in the commissioning of appropriate services.
- Clinical Commissioning Groups may cover populations too small to effectively commission services for less common neurological conditions. They could choose to commission collaboratively to ensure the achievement of improved outcomes for people with neurological conditions.
- There should be appropriate mechanisms available to Health and Wellbeing Boards to ensure joint delivery of health and social care. There is currently provision for health and social services to pool budgets and jointly commission services. However, less than 5 per cent of NHS and social care budgets are spent through joint arrangements such as pooled budgets.
- When developing future outcomes-based strategies, there needs to be monitoring of inputs and outputs against outcomes. This will enable the Department, national and local commissioners and providers to be held to account for the value for money of services. For example, by setting robust empirical baselines and regularly reviewing progress.

## Conclusion on value for money

**24** The Department introduced the National Service Framework for Long-term Conditions in 2005 to address clear weaknesses in services for people with neurological conditions. Health spending on neurological services has increased significantly since the introduction of the Framework.

**25** The Department has clearly improved access by delivering against the 18-week waiting time target and reduced occupied bed days. However, although the Framework specified increased devolved decision making, it had none of the levers or incentives necessary to motivate local organisations to implement its 11 quality requirements. In addition, the Department did not put in place empirical baselines or arrangements to monitor implementation. The evidence presented in our key findings, therefore, leads us to conclude that current spending on neurological health and social services is not value for money as the Department cannot demonstrate any significant quantifiable improvements against the Framework's quality requirements.

## The Department's view on value for money

**26** It is the Department's view that there is insufficient evidence to support a conclusion that current spending on neurological health and social services is not value for money.

## Recommendations

**27** All our recommendations are to help the Department, the NHS and local commissioning bodies ensure that the new long-term conditions strategy leads to improved care for people with neurological conditions and, at the same time, to control costs.

**a** **The Framework lacked clear leadership, coordination, appropriate accountability structures and monitoring information.** In line with the new Health and Social Care Bill, the Department's new long-term conditions strategy will devolve implementation to local bodies. In order to avoid the problems identified with the Framework in this report, the Department needs to make clear who is accountable for what in delivering the new strategy. In addition, the Department, given its overall policy responsibility for health and social care, will need to show how, under these arrangements, Parliament will be able to know whether value for money has been delivered. Specifically, the Department needs to:

- define the different accountabilities between itself, the NHS Commissioning Board and local commissioners; and
- establish, as part of its wider information strategy, clear baselines and common information standards to allow robust performance management of providers by local commissioners, of local commissioners by the NHS Commissioning Board and the Commissioning Board by the Department itself. This would include the means to identify good practice in delivering joined-up services for people with long-term conditions. These standards should also take into account the requirements of the regulators – Monitor and the Care Quality Commission.



- b The Department does not know whether additional spending on neurological services has been effective.** To learn lessons for its new long-term conditions strategy, the Department needs to understand:
- why neurological spending significantly increased in real terms;
  - why emergency admissions and readmissions have increased and the extent to which the interrelationship between health and social care spending and services is the cause;
  - the causes of the variation in emergency admissions across Primary Care Trusts; and
  - the costs and benefits of different service delivery models and their impact on overall 'system' costs, with a specific emphasis on cost-benefit realisation.
- c People receive little or no information or support after diagnosis.** Local commissioners should require hospital trusts to ensure all neurologists, at the point of diagnosis, give patients information packs about their condition, including contact details for local and national services and charitable organisations.
- d Ongoing care is often fragmented and uncoordinated.** Local commissioners should:
- work with local providers to make sure that patients have a personal care plan for health and social services, with a single professional in charge of coordinating an individual's care; and
  - given the evidence about the positive impact of specialist nurses on patient care, make sure that caseloads for specialist nurses are not greater than those recommended by the National Institute for Health and Clinical Excellence.
- e People admitted to hospitals as an emergency are usually cared for by health professionals without neurological knowledge and experience.** The NHS and the National Institute for Health and Clinical Excellence should highlight to hospital trust management the importance of health professionals understanding the needs of people with neurological conditions.
- f Perverse performance incentives result in a cycle of referral–discharge–referral and undermine continuity of care.** The NHS Commissioning Board should review the 'new to follow-up' ratio performance measure so that it does not cause perverse patterns of service delivery, creating unnecessary obstacles for people with long-term conditions when accessing care.