



National Audit Office

**REPORT BY THE
COMPTROLLER AND
AUDITOR GENERAL**

**HC 1586
SESSION 2010–2012
16 DECEMBER 2011**

Department of Health

Services for people with
neurological conditions

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Ordered by the House of Commons
to be printed on 14 December 2011

Report by the Comptroller and Auditor General

HC 1586 Session 2010–2012
16 December 2011

London: The Stationery Office
£15.50

This report has been
prepared under Section 6
of the National Audit Act
1983 for presentation to
the House of Commons
in accordance with
Section 9 of the Act.

Amyas Morse
Comptroller and
Auditor General

National Audit Office

5 December 2011

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.

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This report can be found on the National Audit Office website at www.nao.org.uk/neurological-conditions-2011

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Key facts

2m

people in the United Kingdom with a neurological condition, excluding migraine.

£2.9bn

health spending on neurological services in 2009-10, excluding neurological pain.

38%

real-terms increase in annual health spending on neurological services between 2006-07 and 2009-10, excluding neurological pain.

- 2 million** There is no centrally collated register of the number of people with neurological conditions. It was estimated in 2003 that two million people have a neurological condition in the United Kingdom, excluding migraine.
- £2.9 billion** Department of Health's reported spending on neurological services in 2009-10, excluding neurological pain.
- 38 per cent** real-terms increase in annual health spending on neurological services between 2006-07 (£2.1 billion) and 2009-10 (£2.9 billion).
- £2.4 billion** estimate of adult social services spending on people with neurological conditions in 2009-10 based on an estimate of the proportion (25 per cent) of adults with a physical disability that have a neurological condition. Social services spending on adults with a physical disability has remained broadly flat in real terms since 2005-06.
- 31 per cent** increase in neurological inpatient admissions between 2004-05 and 2009-10, compared to 20 per cent for the NHS as a whole.
- 32 per cent** increase in emergency neurological admissions to hospital between 2004-05 and 2009-10, compared to 17 per cent for the NHS as a whole.
- 14 per cent** In 2009-10, 14 per cent of people with Parkinson's disease, multiple sclerosis and motor neurone disease that were discharged from hospital after an overnight stay were readmitted within 28 days as an emergency.
- 12 per cent** Between 2004-05 and 2007-08, emergency bed days for people with long-term neurological conditions reduced by 12 per cent. The Public Service Agreement target was to reduce emergency bed days by 5 per cent by 2008.

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.

Part One

Neurological conditions

Types of neurological condition

1.1 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 as a result of 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 stages multiple sclerosis; and
- stable: for example, post-polio syndrome or cerebral palsy in adults.

1.2 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.

1.3 This study focuses on the services for adults with neurological conditions from disease rather than an acquired condition from, for example, sudden brain or spinal cord injury.¹ We have focused mainly on three progressive conditions for our fieldwork – Parkinson's disease, multiple sclerosis and motor neurone disease (**Figure 1** overleaf). This included focus groups with people with these conditions, their carers and supporting charities.

Prevalence of neurological conditions

1.4 There is no centrally collated register of the number of people with neurological conditions. It was estimated in 2003 that two million people have a neurological condition in the United Kingdom, excluding migraine.² Estimates of prevalence, largely from academic research and the charitable sector, have significant differences (**Figure 2** overleaf).

¹ While this study focuses on adults, all health expenditure and hospital admissions data include children's neurological services. Children's services makes up a very small proportion of overall activity.

² *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, The Neurological Alliance, April 2003. Including migraine the figure is 10 million.

Figure 1

Motor neurone disease, Parkinson's disease and multiple sclerosis

Motor neurone disease: A progressive condition that attacks the upper and lower motor neurones. Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. Progression is often rapid leading to severely reduced life expectancy.

Parkinson's disease: A progressive condition mostly affecting people over the age of 50. The loss of nerve cells in the brain causes the symptoms of Parkinson's to appear. The main symptoms of Parkinson's are tremor, rigidity and slowness of movement. As well as affecting movement, people with Parkinson's can find they have other symptoms including: tiredness, pain, depression and constipation.

Multiple sclerosis: The condition results from damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body. For some people, multiple sclerosis is characterised by periods of relapse and remission while for others it has a progressive pattern. Symptoms include: difficulties with balance and dizziness; fatigue; blurred vision; bladder and bowel problems; muscle spasm; mood changes; sexual problems and difficulties with speech and swallowing.

There is currently no cure for these conditions. As they progress an increasing amount of care and support is required.

Source: Motor Neurone Disease Association, Parkinson's UK, Multiple Sclerosis Society

Figure 2

Prevalence of a selection of neurological conditions

Condition	Prevalence in UK (from the Framework)	Prevalence in UK (latest charitable sector estimates)
Essential tremor	500,000	1,000,000
Epilepsy	182,750–425,000	456,000
Parkinson's disease	120,000	120,000
Multiple sclerosis	52,000–62,000	100,000
Dystonia	38,000	70,000
Muscular dystrophy	30,000	70,000
Huntington's disease	6,000–10,000	6,400
Motor neurone disease	4,000	4,400

NOTES

- 1 For National Service Framework, figures are largely from earlier charitable sector estimates. Figures for epilepsy and multiple sclerosis are for England and Wales.
- 2 For latest charitable sector: Huntington's disease data are for England only.

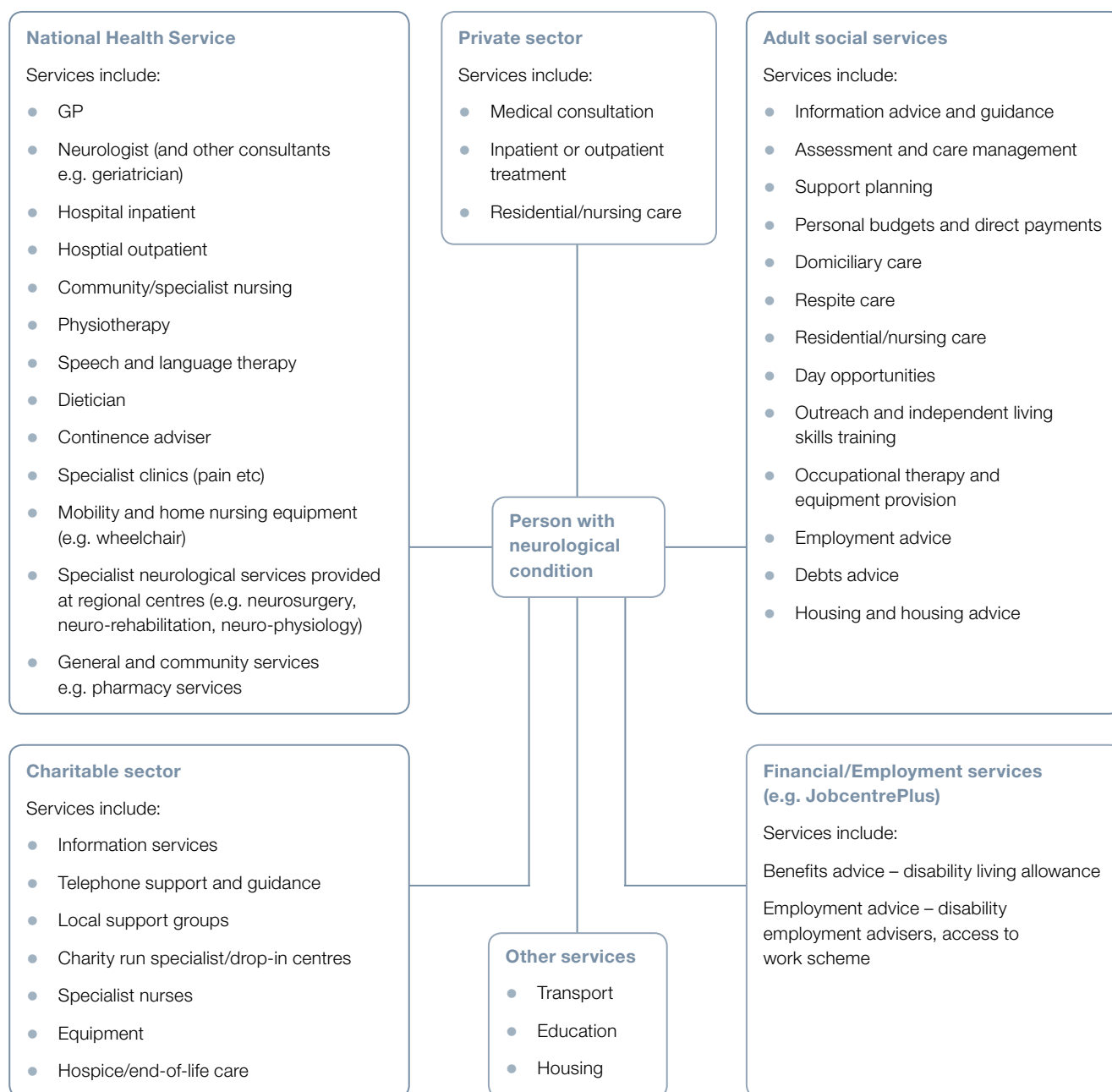
Source: National Service Framework for Long-term Conditions, Department of Health, March 2005, Charities data from charities websites apart from Huntington's – Uncovering the true prevalence of Huntington's disease, The Lancet, June 2010

Services for people with neurological conditions

1.5 Adults with neurological conditions need a wide range of services across a number of organisations (**Figure 3**). We focus on the health and social care services for adults with neurological conditions.

Figure 3

Range of services for people with neurological conditions



National Service Framework for Long-term Conditions

1.6 The Framework, introduced by the Department in March 2005, focused on people with neurological conditions. The Framework 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.

1.7 At the core of the Framework were 11 quality requirements (see **Figure 4**) 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”. These requirements were to be fully implemented by 2015. The Framework was also supposed to contribute to a range of Spending Review 2004 Public Service Agreements to:

- improve health outcomes for people with long-term conditions, by offering a personalised care plan for vulnerable people most at risk;
- reduce emergency bed days by 5 per cent by 2008 through improved care in primary and community settings for people with long-term conditions; and
- improve access to services, so that by 2008, no one waits more than 18 weeks from GP referral to hospital treatment, including all diagnostic procedures and tests.

1.8 The Framework was based on sound evidence with wide stakeholder engagement, including an external reference group, and an extensive literature review. A key theme was to move long-term care away from the acute hospital setting to primary and community care and to support people to live independent lives.

Figure 4**National Service Framework for Long-term Conditions –
11 quality requirements**

The quality requirements covered the following areas:

- 1 A person-centred service
- 2 Early recognition, prompt diagnosis and treatment
- 3 Emergency and acute management
- 4 Early and specialist rehabilitation
- 5 Community rehabilitation and support
- 6 Vocational rehabilitation
- 7 Providing equipment and accommodation
- 8 Providing personal care and support
- 9 Palliative care
- 10 Supporting family and carers
- 11 Caring for people with neurological conditions in hospital or other health and social care settings.

NOTE

- 1 A fuller description of each requirement is available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361

Source: National Service Framework for Long-term Conditions

Part Two

Impact of the National Service Framework for Long-term Conditions

Spending on services

Health services

2.1 In 2009-10, £2.9 billion was spent by the Department on neurological services, excluding neurological pain (**Figure 5**). Owing to a change in definitions, where a number of conditions were reclassified as neurological, there is a significant jump in neurological spending between 2005-06 and 2006-07. As a result, data on neurological spending cannot be viewed as a continuous time series. The trend before and after this adjustment, however, shows spending increased faster than overall NHS spending. While definitional changes compromise exact comparisons, annual spending on neurological services has increased significantly in real terms since the Framework's introduction.

2.2 Of the £2.9 billion reported spending in 2009-10, £2.7 billion was spent by Primary Care Trusts. The majority, £2 billion, was spent in secondary care, primarily outpatient and inpatient hospital admissions. An additional £670 million was spent in primary care (e.g. by GPs).

Adult social services

2.3 There are no national figures for social services spending, for people with neurological conditions, as adult social services are defined by disability and need rather than condition. The Neurological Alliance estimated in 2003 that 25 per cent of people between 16 and 64 with a chronic disability, and a third of people in residential homes, have a neurological condition.³

2.4 In 2009-10, adult social services total gross spending on people with a physical disability was £9.6 billion and this has been fairly constant, in real terms, since 2005-06 (**Figure 6**). Assuming that a quarter of total adult social services spending on people with a physical disability is for people with neurological conditions, this amounts to an estimated £2.4 billion in 2009-10.

³ *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, The Neurological Alliance, April 2003. The Neurological Alliance is a campaigning organisation representing a range of neurological charities.

Figure 5

Department of Health spending on neurological services

	2003-04	2004-05	2005-06	2006-07	2007-08	2008-09	2009-10	Average annual percentage change 2003-04 to 2005-06 (%)	Average annual percentage change 2006-07 to 2009-10 (%)
Neurological (chronic pain)				1.1	1.2	1.2	1.3		6
Neurological (other)				2.1	2.4	2.6	2.9		10
Total spending on neurological services	1.8	2.0	2.4	3.2	3.6	3.8	4.1	14	9
Total Department of Health spending	78.6	81.3	89.1	90.5	97.4	98.4	104.0	6	5
Neurological spending as percentage of total spend (%)	2.3	2.5	2.6	3.6	3.7	3.8	4.0		

↑ Break in series

NOTES

- 1 Figures are in £ billion, except where stated as percentages, and in 2009-10 prices.
- 2 There is no breakdown for neurological spending before 2006-07.
- 3 Figures do not include GP consultation costs or social care costs.
- 4 See para 2.1 for full explanation of break in series.
- 5 Figures do not sum exactly due to rounding.

Source: Department of Health Programme Budget data

Figure 6

Adult social services spending on people with a physical disability

	2005-06	2006-07	2007-08	2008-09	2009-10
Assessment and care management	1.2	1.2	1.2	1.2	1.2
Nursing and residential homes	4.4	4.3	4.2	4.1	4.1
Community care	3.9	3.9	3.9	4.1	4.3
Total gross cost	9.5	9.5	9.3	9.5	9.6
Income	1.9	1.9	1.9	1.9	1.6
Total cost net of income	7.7	7.6	7.5	7.6	8.0

NOTES

- 1 Expenditure shown in £ billion and 2009-10 prices.
- 2 Figures do not sum exactly due to rounding.

Source: National Adult Social Care Intelligence Service, NHS Information Centre

Implementing the Framework

2.5 A small dedicated policy team within the Department supported implementation of the Framework nationally which was disbanded in 2007. Policy responsibility was absorbed alongside policies for older people and dementia. Regionally, a long-term delivery support team was established with one part-time member of staff within each Strategic Health Authority.⁴ The team was disbanded in March 2011. Further support for implementation was provided through:

- the National Institute of Health and Clinical Excellence developing clinical guidance covering a range of neurological conditions;
- information and analytical support, for example, the NHS Comparators service, which allows commissioners and providers to benchmark services at a local, regional and national level for indicators including emergency admissions and length of stay; and
- the Department providing funding for initiatives including regional neurological alliances and Neurological Commissioning Support.⁵

2.6 This was a ‘new style’ framework developed at a time when accountability and delivery were being devolved to the front line rather than centrally driven. Local organisations, such as Primary Care Trusts and local authorities, were left to implement the Framework and it was for them to determine the pace of change according to local priorities. By design, it did not have the traditional levers to support implementation including specific measurable targets, regular national monitoring; ring-fenced funding; and a dedicated national clinical director to drive implementation (**Figure 7**). The Framework also relied upon Primary Care Trusts allocating additional resources for implementation, but with no obligation to do so.

2.7 While there was no ring-fenced funding to implement the Framework, overall NHS budgets were increasing, providing headroom to support new initiatives. A 2009 University of York survey of 118 Primary Care Trusts (see Figure 14 in Part Three) found that only 51 per cent of trusts had a written action plan to implement the Framework.

2.8 Although there was significant uncertainty about the Framework’s status amongst the range of stakeholders we talked to, it remains part of the Department’s approach. The Framework will be superseded by a similar generic, long-term conditions strategy. However, a mid-point review agreed by the previous Government, planned for 2010, was cancelled by Ministers after the general election. This, in conjunction with the lack of a baseline, means the Department will not understand the impact of the Framework on services and learn lessons for the new strategy.

4 Strategic Health Authorities (SHAs) were created by the Government in 2002 to develop and improve health services in their local area and ensure that national priorities are integrated into local plans. On 3 October 2011, the ten SHAs reorganised into four cluster SHAs.

5 Neurological Commissioning Support is a joint initiative led by the Motor Neurone Disease Association, Multiple Sclerosis Society and Parkinson’s UK. It works alongside Primary Care Trusts and local authorities to ensure neurological conditions are taken into consideration when commissioning services.

Figure 7

Comparison of the National Service Framework for Long-term Conditions with earlier national service frameworks

	National Service Framework for Long-term Conditions	National Service Framework for Coronary Heart Disease	National Service Framework for Cancer (The Cancer Plan)	National Service Framework for Older People (including stroke)
Implementation schedule				
Publication date	2005	2000	2000	2001
Timetable for delivery	10 years	10 years	5 years	10 years
Performance monitoring				
Clear quantitative targets	X	✓	✓	✓
Intermediate targets	X	✓	✓	✓
National monitoring	X	✓	✓	✓
Funding				
Specific additional funding to support implementation	X	✓	✓	✓
Budget impact assessment undertaken	✓	X	✓	✓
Leadership				
National Clinical Director	X	✓	✓	✓
Stakeholder involvement				
Wide stakeholder engagement in design	✓	✓	✓	✓

NOTE

1 The Framework initially had joint leadership in the form of the national director of older people's services and national director of social care who left the Department in 2008. However, there was no dedicated national clinical director of neurology.

Source: National Audit Office analysis of national service framework documentation

Impact of the Framework

2.9 It is difficult to assess the impact of the Framework. There were no intermediate targets, no central monitoring by the Department and the mid-point review agreed by the previous Government, was cancelled. Monitoring was made more difficult as there was no initial assessment of services before the introduction of the Framework, to provide a baseline for measuring progress. On the positive side, the Department did fund a research programme – The Research Initiative for Long-term Neurological Conditions – that comprised 11 research projects from a range of academic institutions.⁶ While a number of studies do provide a snapshot of services (see Figure 14 in Part Three), none could gauge progress over time, as there was a lack of baseline data. In addition, the projects did not include survey questions to set a retrospective baseline of access to, and quality of, services. The lack of data on spending and services across adult social services adds to the difficulty. However, reviewing hospital admissions data; data on adult social services for people with a physical disability; and recent literature, some conclusions can be drawn about the impact of the Framework.

Trends in hospital admissions

Neurology associated hospital admissions

2.10 Neurological hospital admissions⁷ have increased significantly in the years following the introduction of the Framework. Outpatient attendances have risen by 44 per cent, increasing from just under one million in 2005-06 to just under 1.4 million in 2009-10. This represents a larger increase than for outpatient attendances across the NHS (35 per cent over the same period).⁸

2.11 Neurological inpatient admissions (planned and emergency) rose from 387,500 in 2004-05 to 509,400 in 2009-10. This represents growth of 31 per cent over the five years compared with 20 per cent for all inpatient admissions across the NHS⁹ (**Figure 8**). After the introduction of the Framework, the growth in neurological inpatient admissions was slightly higher (6 per cent a year between 2004-05 and 2009-10) than in the years before it (5 per cent between 2001-02 and 2004-05).

2.12 Inpatient hospital admissions (planned and emergency) for Parkinson's disease, multiple sclerosis and motor neurone disease increased from just under 70,000 in 2004-05 to just under 94,000 in 2009-10, an increase of 34 per cent.¹⁰

6 See Long-term Neurological Conditions Research Initiatives website (www.ltnrc.org.uk). An overview report will be available in winter 2011.

7 All data on hospital admissions are taken from the Department of Health's Hospital Episode Statistics. For all analysis we have excluded neurological pain as this is not directly related to the treatment of specific neurological conditions.

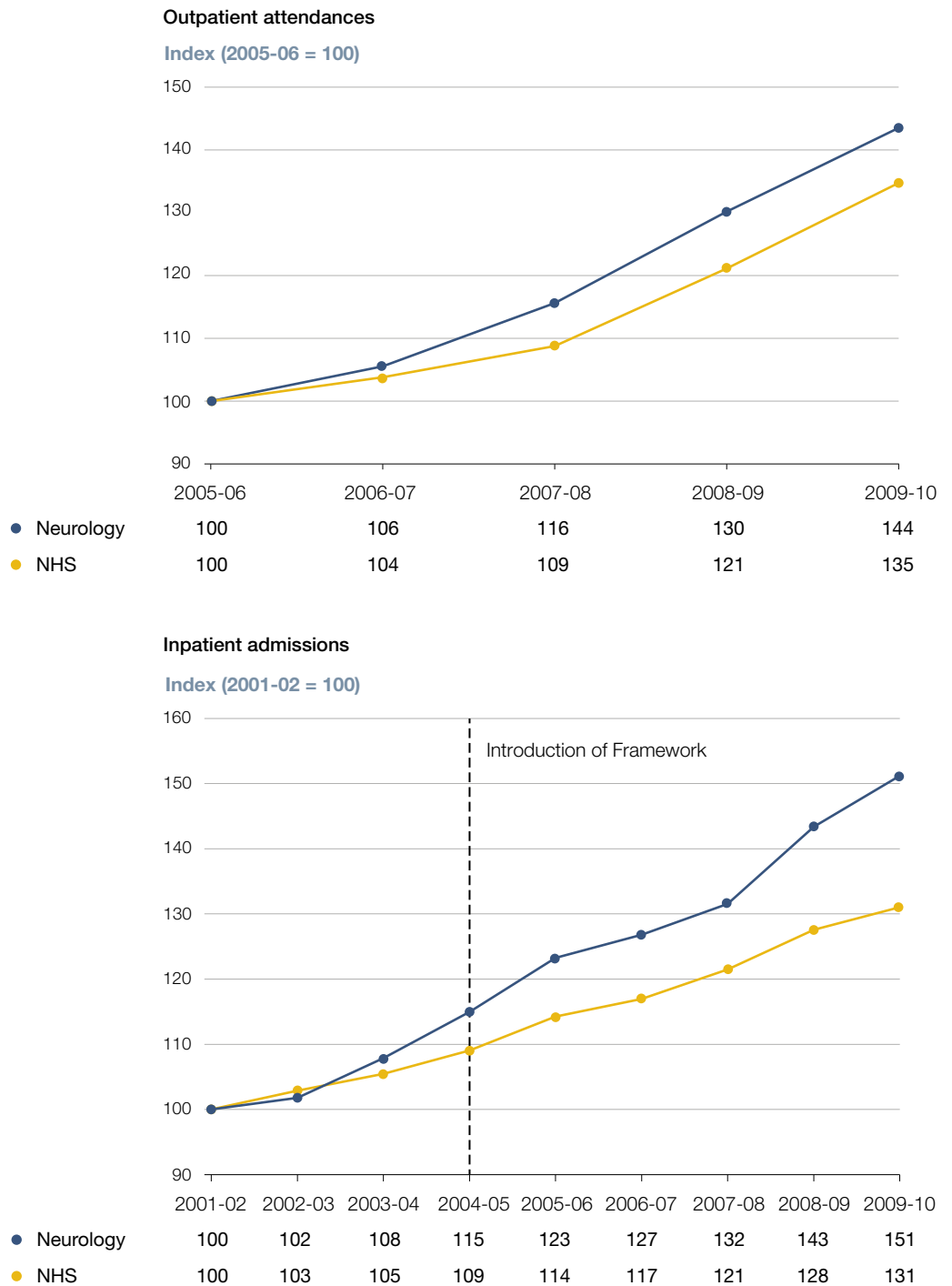
8 Outpatient attendances data before 2005-06 are described by the Department of Health as 'experimental' and are therefore not included.

9 For overall neurology inpatient admissions, including day cases, we have used primary diagnosis codes only.

10 Data for the three conditions use primary, secondary and third diagnosis codes and for readmissions analysis we used 'super spells'. Patients who have, for example, broken their arm owing to a fall may have a primary diagnosis of a broken arm. However, if the fall was owing to a neurological condition then this might be added as a secondary diagnosis. A super spell treats transfers between two hospitals as one admission rather than two separate admissions. See web-based technical appendix for further explanation.

Figure 8

Growth in neurological outpatient attendances and inpatient admissions



NOTE

1 Outpatient attendances data before 2005-06 are described by the Department of Health as 'experimental' and are therefore not included.

Source: Hospital Episode Statistics, NHS Information Centre

2.13 As discussed below, the increase in neurological admissions has been driven by positive and negative factors. On the positive side, there has been improved access to neurological services. However, there has been an increase in emergency hospital admissions and readmissions, something the Framework was specifically designed to counter.

Access to neurological services

2.14 Data from 2007 onwards show that neurology waiting times have reduced significantly, indicating an improvement in access to services. For outpatients and inpatients, neurology median waiting times (the time within which 50 per cent of people are seen) reduced significantly during 2007 (**Figure 9** on pages 25 and 26). From 2008 onwards, however, neurology outpatient median waiting times have increased while, for the NHS as a whole, waiting times have remained stable.

2.15 Alternatively, the 95th percentile measures the waiting time that 95 per cent of patients are seen within. Since 2008, this has remained relatively stable for both outpatient and inpatients. For example, in August 2011, 95 per cent of neurological outpatients were seen within 16.9 weeks.

2.16 Analysis of inpatient data shows that beneficial planned neurological admissions (e.g. admissions for an operation) have increased by 31 per cent since 2004-05. For example, the number of admissions for deep brain stimulation procedures¹¹ increased from 178 in 2004-05 to 389 in 2009-10. Recorded rehabilitation for neurological disorders increased from just over 1,000 procedures in 2006-07 to over 1,300 during 2009-10.

2.17 In the years following the introduction of the Framework, the annual rate of growth in elective admissions increased, from 2 per cent in the years between 2001-02 and 2004-05 to 6 per cent in the years between 2004-05 and 2009-10. However, it is not possible to say what impact the Framework had on this increase.

Emergency bed days

2.18 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 in both the NHS as a whole, and for people with neurological conditions, reduced by 11 and 12 per cent respectively. For our three conditions, emergency bed days were approximately 13 per cent lower by 2007-08.

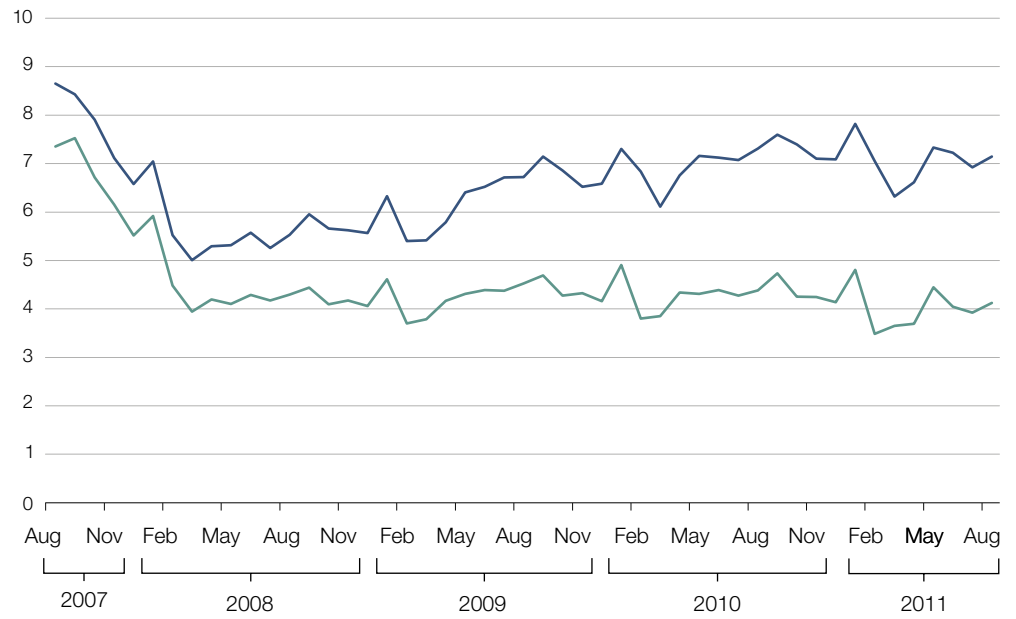
¹¹ Deep brain stimulation (DBS) is a surgical procedure used to treat a variety of disabling neurological symptoms. DBS uses a surgically implanted, battery-operated, medical device called a neurostimulator to deliver electrical stimulation to targeted areas in the brain.

Figure 9

Neurology inpatient and outpatient waiting times

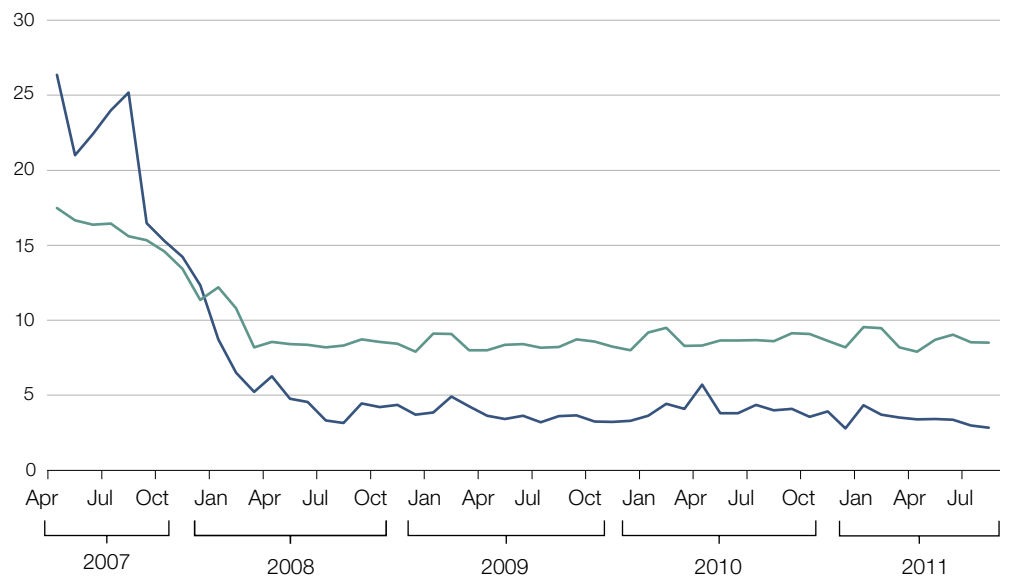
Outpatient (Median)

Median waiting time (in weeks)



Inpatient (Median)

Median waiting time (in weeks)

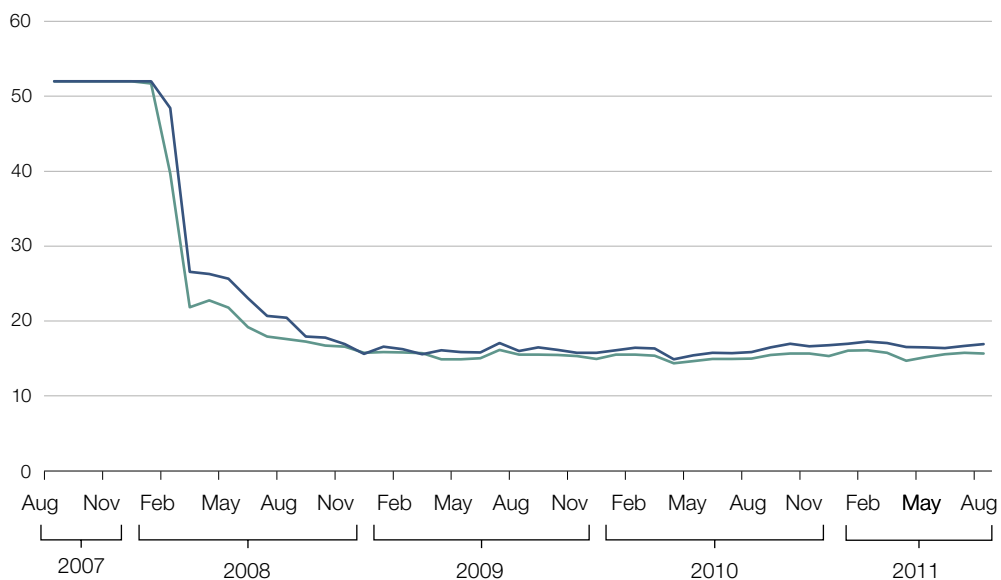


● Neurology ● Total (all specialities)

Figure 9 *continued*
Neurology inpatient and outpatient waiting times

Outpatient (95th percentile)

95th percentile waiting time (in weeks)



Inpatient (95th percentile)

95th percentile waiting time (in weeks)



● Neurology ● Total (all specialities)

NOTES

- 1 Data used are unadjusted waiting times which do not make adjustments for patients turning down offers of admissions.
- 2 Overall NHS waiting times include a basket of different medical areas including: general surgery; cardiology; ear, nose and throat (ENT); and plastic surgery.

Source: Referral to treatment statistics, Department of Health

Emergency hospital admissions and readmissions

2.19 Deteriorating services, or poorly integrated health and social services, results in increasing emergency admissions. Emergency neurological admissions to hospital increased by 32 per cent between 2004-05 and 2009-10, a larger increase than for the NHS as a whole (17 per cent). The annual average rate of growth in neurological emergency admissions remained unchanged at 6 per cent in the years just before and after the introduction of the Framework. Similarly, between 2004-05 and 2009-10, emergency admissions for the three conditions increased by 26 per cent (motor neurone disease), 19 per cent (Parkinson's disease) and 23 per cent (multiple sclerosis). A proportion of emergency admissions are made up of emergency readmission – including day case this amounts to 16 per cent in 2004-05 and 19 per cent in 2009-10 (excluding day cases the figures are 15 and 17 per cent respectively). Between this period, 35 per cent of the increase in emergency admissions for the three conditions was due to the increase in emergency readmissions (30 per cent excluding day cases).

2.20 We found a wide variation in the proportion of emergency admissions for the three conditions, across Primary Care Trusts (**Figure 10** overleaf). We would expect some variation due to chance with the expected range of variation reducing as the number of admissions increase. However, the data show that only some of the variation can be attributed to this. No research has been done to understand the remaining variation.

2.21 Another important quality-of-care indicator is emergency readmissions to hospital. Increased readmissions could be due to deteriorating hospital care, or poorly integrated health and social care, where people are readmitted because their condition has deteriorated. We reviewed two readmission measures: emergency readmission within 7 or 28 days for people with motor neurone disease, Parkinson's disease and multiple sclerosis. These measures are more likely to reflect hospital and community quality of care, respectively.

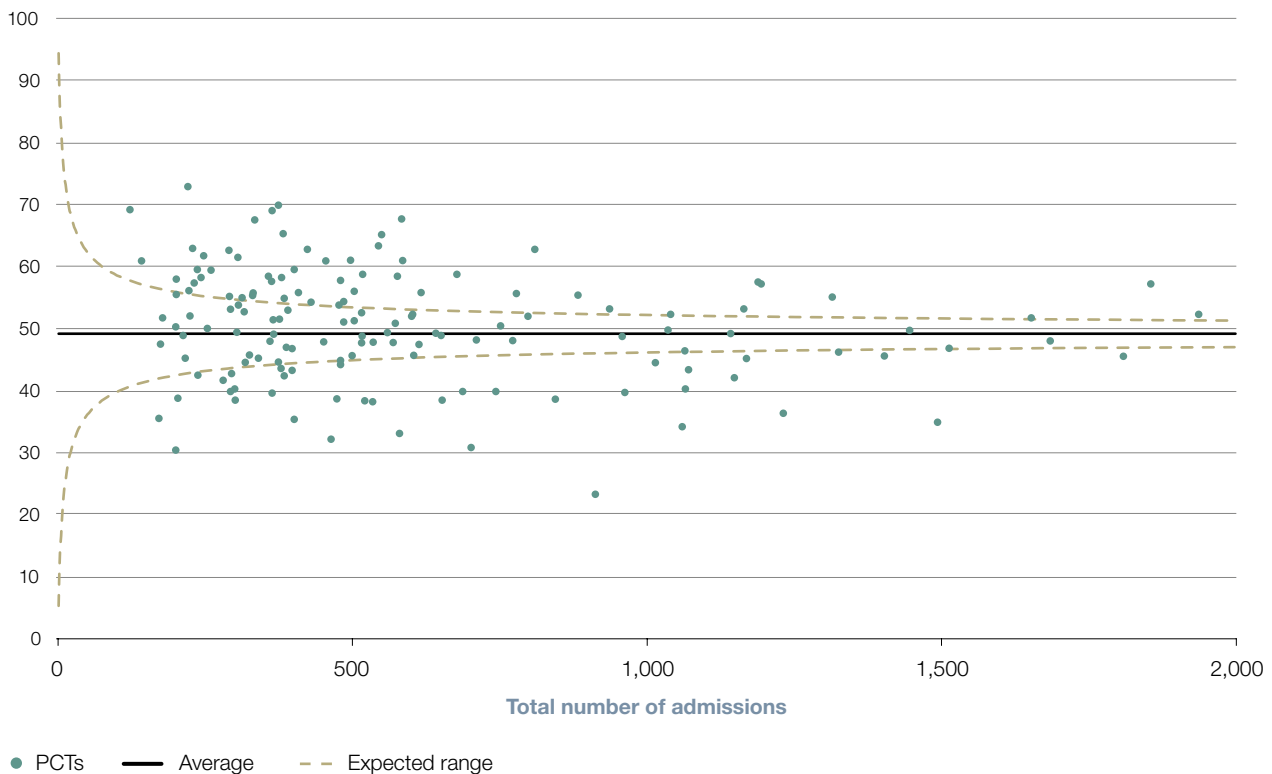
2.22 For overall inpatient admissions, including day cases, emergency readmission rates increased slightly between 2004-05 and 2009-10. However, over 90 per cent of emergency readmissions are related to overnight inpatient admissions. The proportion of patients readmitted to hospital within seven days of discharge following an overnight stay increased from 4.5 per cent of discharges in 2004-05 to 5.7 per cent in 2009-10. The percentage of patients readmitted to hospital within 28 days after being discharged following an overnight stay increased from 11.2 per cent of discharges in 2004-05 to 14 per cent in 2009-10.

2.23 There is a wide variation in emergency readmissions, as a percentage of the number of patients discharged across Primary Care Trusts. As **Figure 11** on page 29 shows, after standardising for differences in patient characteristics (age, gender, deprivation and ethnicity), there was little variation outside that expected by the number of discharges across trusts.

Figure 10

Emergency admissions as a percentage of total admissions (for motor neurone disease, Parkinson's disease and multiple sclerosis), by Primary Care Trust

Percentage of emergency admissions



NOTES

1 The dotted lines represent the upper and lower range of the proportion of emergency admissions expected for each Primary Care Trust based on the number of their total admissions including day cases. Standard assumptions are made about the distribution of the percentage of emergency admission, with the overall mean equal to the average for all trusts. All else being equal, there is a 95 per cent probability that the proportion of emergency admissions should lie within this range.

2 Data for 2009-10.

Source: National Audit Office analysis of PCT level summary data from Hospital Episode Statistics provided by Dr Foster Intelligence

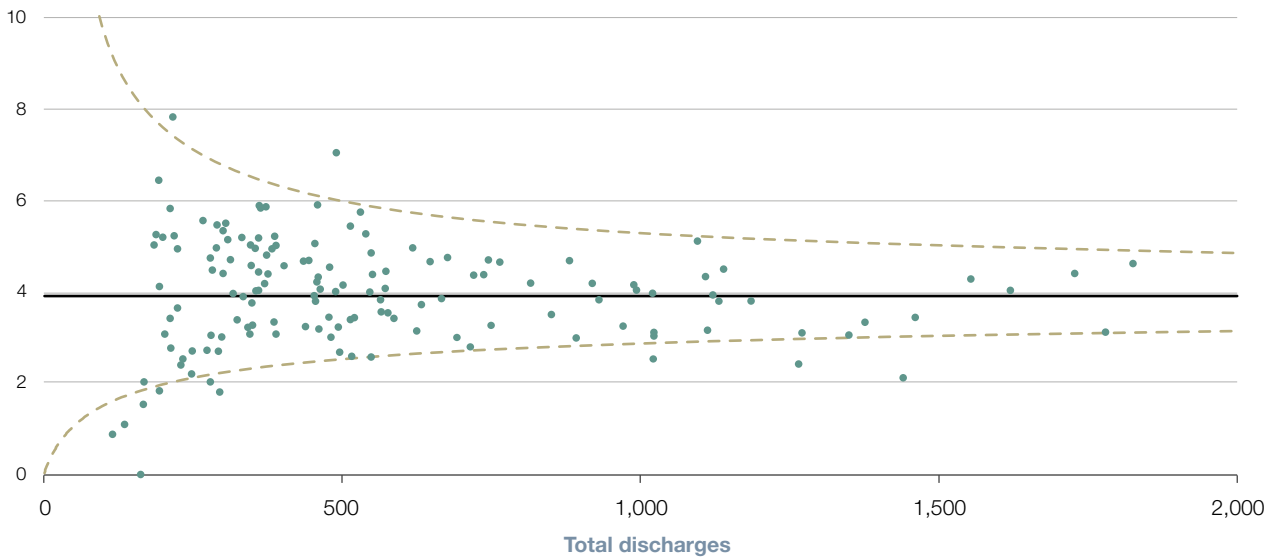
2.24 The Department recognises the importance of driving down emergency admissions and readmissions. In 2011-12, for example, Primary Care Trusts will not pay for an emergency readmission within 30 days following an elective admission due to changes in the Payment by Results tariffs (with some exceptions).¹² For emergency readmissions following an emergency admission the aim is to deliver at least a 25 per cent reduction in the readmission rate over the previous year. In addition, the Department's Quality, Innovation, Productivity and Prevention Programme (QIPP), has a long-term conditions work-stream which also aims to contribute to a reduction in emergency admissions.

¹² See technical appendix (NAO website) for a further description of changes to the tariff.

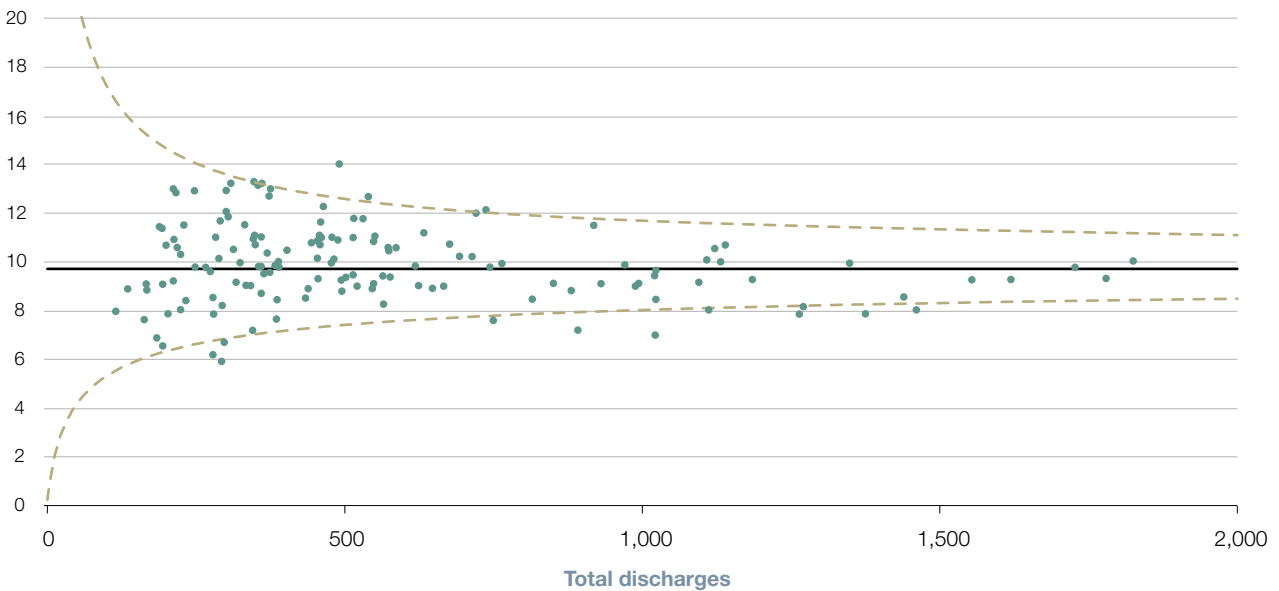
Figure 11

Variation in standardised emergency readmissions as a percentage of discharges (for motor neurone disease, Parkinson’s disease and multiple sclerosis), by Primary Care Trust

Percentage of readmissions within 7 days



Percentage of readmissions within 28 days



● PCTs — Average - - - Expected range

NOTES

1 Percentage of readmissions have been standardised to account for differences in patient profiles including age, gender, ethnicity and deprivation in order to make readmission rates comparable across PCTs. Data includes day cases. See technical appendix on NAO website for full explanation.

2 Data for 2009-10.

Source: National Audit Office analysis of PCT level summary data from Hospital Episode Statistics provided by Dr Foster Intelligence

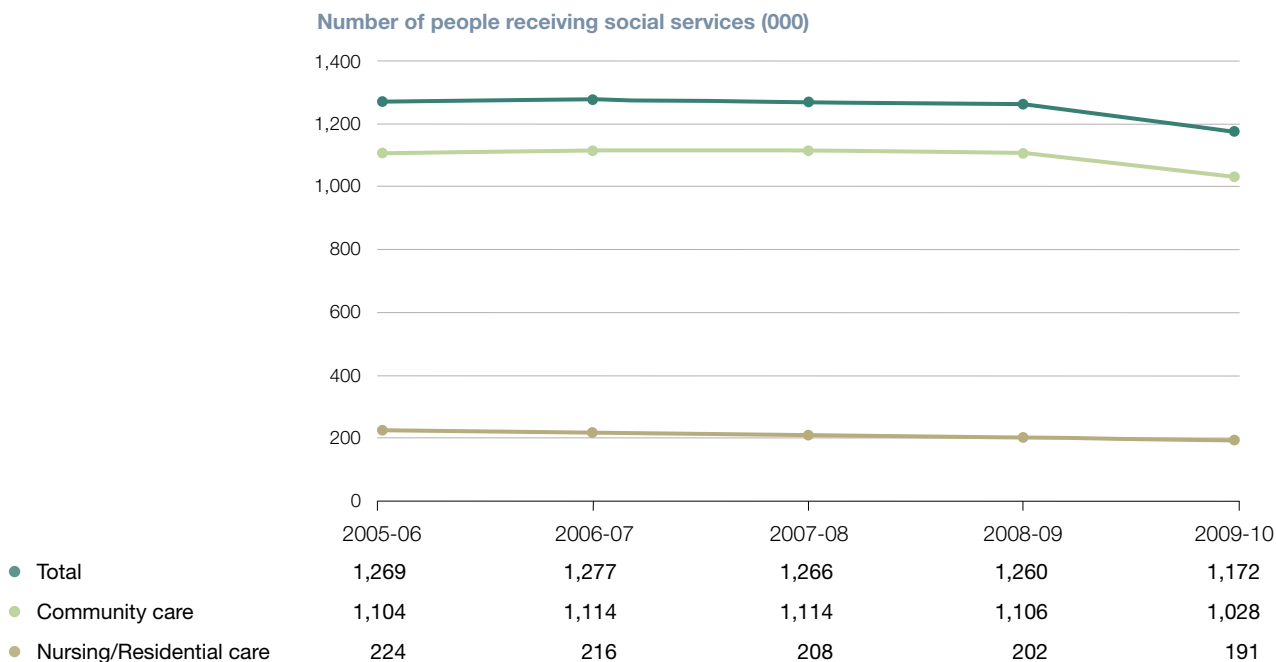
Trends in social services for adults with a physical disability

2.25 A significant proportion of adults with physical disabilities are likely to have a neurological condition. Between 2005-06 and 2009-10 the number of adults with a physical disability receiving social care has fallen by approximately 8 per cent (just under 100,000 people). While the number of adults receiving nursing and residential care has fallen steadily over the period, adults receiving community care (e.g. home help) remained stable until 2008-09, before falling sharply between 2008-09 and 2009-10. Local authorities have tightened their eligibility criteria for social services in recent years (**Figure 12**).

2.26 Other data show the number of adults receiving more than ten hours of home care a week has increased since 2005-06 while the number receiving two hours or less has fallen (**Figure 13**). The trends outlined in Figures 12 and 13 may indicate that adults with a physical disability have moved from nursing and residential care into community care. They also indicate that adults with more moderate community care needs are receiving less care from social services.

Figure 12

Number of adults with physical disability receiving social services

**NOTE**

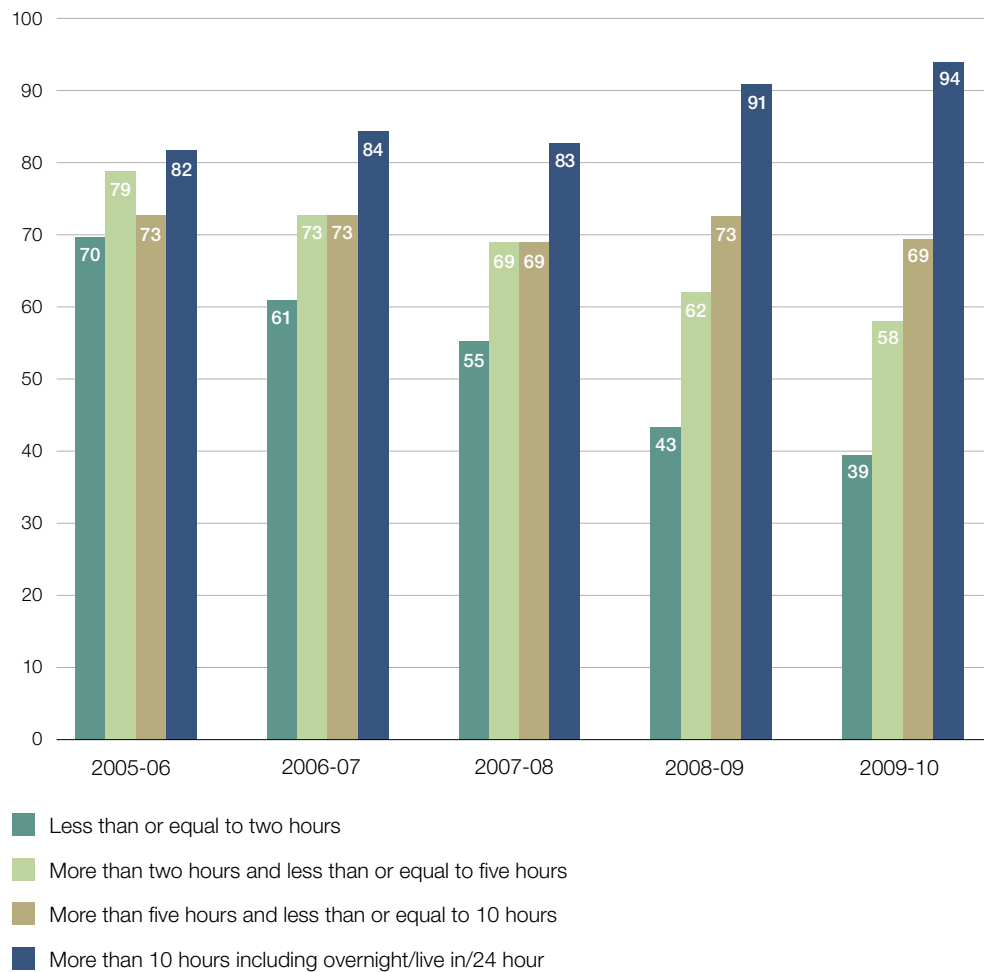
1 When added together, the numbers for nursing, residential care and community care exceed the total as some people receive both types of care in a given year.

Source: National Adult Social Care Intelligence Service, NHS Information Centre

Figure 13

Distribution of home care hours (per week) for service users with a physical disability

Number of people (000)



Source: National Adult Social Care Intelligence Service, NHS Information Centre

2.27 It is not possible to determine the links between hospital admissions and changes in access to social services as integrated health and social services data are not available. However, having fewer people receiving social care runs the risk of increasing emergency admissions to hospital. This is counter to the aim of the Framework to move long-term care away from the acute hospital setting to primary and community care and to reduce emergency admissions.

Evidence from recent literature

2.28 A number of studies have undertaken a 'snapshot' assessment of services against the Framework's 11 quality requirements, although none were able to measure progress against a baseline. Reports by Neurological Commissioning Support and the North East Public Health Observatory found that Primary Care Trusts' compliance with the quality requirements was poor.¹³ The 2011 Royal College of Physicians and Multiple Sclerosis Trust audit (see Figure 14) concluded that there had been no major improvements in many aspects of service provision since 2006 and that, for the seven quality requirements in the Framework most relevant for people with multiple sclerosis, all showed a low level of attainment.

¹³ *Half way through are we half way there?*, Neurological Commissioning Support, 2010. *Health needs assessment for long-term neurological conditions in North East England*, North East Public Health Observatory, June 2009.

Part Three

Issues with current services

3.1 This section reviews four key aspects of current services: diagnosis; patient information; ongoing care; and inpatient hospital visits. Our literature review and four quantitative studies provided a patient, carer and NHS organisational (**Figure 14**) understanding of the key related issues. We also drew on our focus groups and interviews with people with Parkinson's disease, motor neurone disease and multiple sclerosis and their carers. Overall, our findings highlight variation in the quality and access to services for people with neurological conditions. This is consistent with the Department's forthcoming overview report of their Research Initiative for Long-term Neurological Conditions.

Figure 14
Key quantitative studies

Organisation	Date survey carried out	Number of respondents	Comments
University of Oxford	October 2008 to January 2009	1,157 people with multiple sclerosis, 901 people with Parkinson's disease, 505 people with motor neurone disease and 1,910 carers	Both form part of the Department of Health funded Research Initiative for Long-term Neurological Conditions
University of York, Social Policy Research Unit	July 2009 to September 2009	118 Primary Care Trusts	
Parkinson's UK	July 2010 to November 2010	1,880 people with Parkinson's disease and 37 hospital trusts	Patient audit data were submitted by 53 hospital trusts for newly diagnosed people with Parkinson's disease based on their first clinical visit. Organisational data were received from 37 trusts
Royal College of Physicians and Multiple Sclerosis Trust	January 2011 to April 2011	England and Wales: 704 people with multiple sclerosis, 51 Primary Care Trusts, 105 hospital trusts	This is the third in a series of audits conducted in 2006, 2008, and 2011

NOTES

- 1 The National Audit Office reviewed the reports and consider them to be good quality.
- 2 For all results shown we have excluded 'Don't know' responses.

Source: National audit of services for people with multiple sclerosis 2011, Royal College of Physicians and Multiple Sclerosis Trust, 2011. Fitzpatrick, R., Peters, M., Doll, H., Harris, R., Jenkinson, C., Playford, D. and Ziebland, S. *The Needs And Experiences of services by individuals with long-term progressive neurological conditions and their carers. A benchmarking study*, University of Oxford, 2010. Bernard, S., Aspinall, F., Gridley, K. and Parker, G. *Integrated services for people with long-term neurological conditions: evaluations of the impact of the National Service Framework*, Social Policy research Unit – University of York, 2010. Parkinson's Audit 2010, Parkinson's UK, 2011.

Diagnosis

3.2 Quality requirement two of the Framework highlights the importance of prompt diagnosis. As stated in the Framework, people with neurological conditions have improved health outcomes and better quality of life with prompt diagnosis and initiation of treatment.

3.3 Our evidence highlighted difficulties in diagnosing neurological conditions. While final diagnosis is usually by a neurologist, GPs have a key role in identifying early symptoms and referring patients to the right consultant. Early symptoms are often similar to those of many other illnesses with diagnosis relying on patients' medical history and multiple examinations. Interviews with GPs highlighted that GP's often have limited experience of neurological conditions. For some rarer conditions, such as motor neurone disease, a GP may only come across one case in their career. It is, therefore, unfeasible for GPs to have a comprehensive knowledge of rare conditions.

3.4 Our interviews and focus groups highlighted a range of experiences of diagnosis. While some people said they had experienced a quick and straightforward diagnosis others experienced a range of difficulties such as long time periods between identifying first symptoms and final diagnosis.

3.5 The National Institute for Health and Clinical Excellence guidelines¹⁴ state that people with suspected Parkinson's should see a specialist within six weeks of referral from their GP. The Parkinson's UK audit found, however, that only 66 per cent of patients were seen within this six-week timeframe with a wide variation across Primary Care Trusts.

Patient information

3.6 Good information and advice to patients on their neurological condition and services available to them, particularly after diagnosis, is highlighted by the Framework (quality requirements one, two and three).

3.7 Lack of information was a recurring theme across our interviews, focus groups and literature review. Many people, for example, were given no information on the condition or local services after diagnosis. The Royal College of Physicians and Multiple Sclerosis Trust survey, and the Parkinson's UK audit – found, respectively, that 35 per cent and 37 per cent of people were not given information on their condition during or after diagnosis. A smaller number were not given contact details for a specialist nurse – 30 per cent of people with multiple sclerosis and 18 per cent of people with Parkinson's disease.¹⁵

¹⁴ *Parkinson's disease: diagnosis and management in primary and secondary care*, NICE clinical guideline 35 – National Institute for Health and Clinical Excellence, June 2006.

¹⁵ For Parkinson's disease, for 6 per cent of respondents there was no service locally available.

Ongoing care

3.8 The Framework's quality requirement one highlights the need for integrated care planning and delivery across health and social services. Access to rehabilitation and lifelong support and care for people with neurological conditions is covered in quality requirements four, five, seven and eight.¹⁶ A key Framework objective is to increase the number of vulnerable people with a personalised care plan.

3.9 Our interviews and focus groups showed a variation in service levels with most agreeing that quality and access depended on where people live and that people had to continually fight to get the services they required. Further difficulties with ongoing care included:

- a lack of personal care plans and care coordination;
- poorly integrated health and social care services;
- geographical variations in access to specialist nurses and other services;
- continual cycle of GP referral for consultation or treatment, being discharged after short treatments, then being re-referred for further treatment; and
- long lead times for home and mobility equipment, which is often not fit for purpose.

3.10 Our literature review highlighted poorly coordinated services, poorly integrated health and social care, and variable access to services:

- **Coordination of services.** The University of Oxford survey of people with Parkinson's disease, multiple sclerosis and motor neurone disease found that only 22 per cent of respondents had a formal personal care plan. While 24 per cent of respondents were not sure, of those who did know, 53 per cent said they did not have a single health or social care professional coordinating their care.
- **Integration between health and social care.** The Royal College of Physicians and Multiple Sclerosis Trust survey found 53 per cent of acute hospital trusts did not have health and social service coordinated care pathways; with only 14 per cent having pathways specifically for multiple sclerosis (both have deteriorated since the 2008 audit).¹⁷ Less than 5 per cent of NHS and social care budgets are spent through joint arrangements such as pooled budgets.¹⁸

¹⁶ Quality requirements six (vocational rehabilitation) and nine (palliative care) were outside the scope of this report.

¹⁷ These percentages exclude the 9 per cent of trusts that did not know.

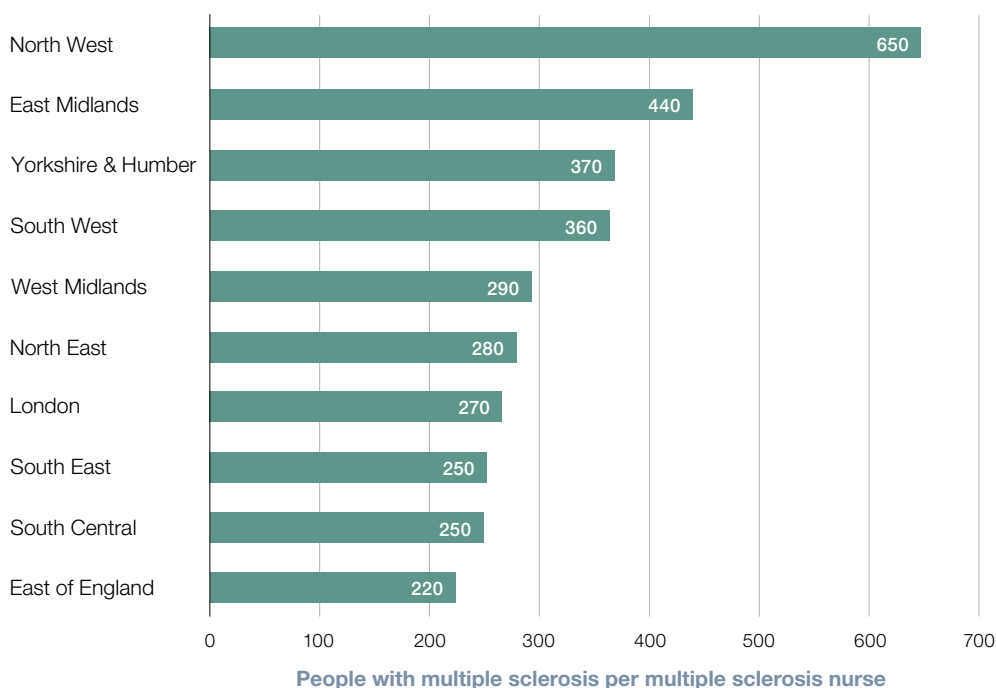
¹⁸ Humpries, R. *Social care funding and the NHS. An impending crisis*, King's Fund, 2011.

- Access to services.** The Parkinson's UK audit found that, while 97 per cent of hospital trusts audited reported Parkinson's disease nurses in their area, only 76 per cent said access was universal. In the same survey, 84 per cent of trusts provided expert¹⁹ physiotherapy, 68 per cent occupational therapy and 81 per cent speech and language therapy. Fewer trusts, however, reported universal access to physiotherapy (52 per cent), occupational therapy (41 per cent), and speech and language therapy (49 per cent). Similarly, the University of York survey found, for example, 78 per cent of Primary Care Trusts had occupational therapy services with expertise in neurology covering their full geographic area. This data does not show variations in caseloads. For example, **Figure 15** shows that the average number of people with multiple sclerosis per multiple sclerosis nurse varies significantly by Strategic Health Authority region.

Figure 15

Estimated number of people with multiple sclerosis per multiple sclerosis nurse, by Strategic Health Authority region

Strategic Health Authority region



NOTES

1 Figures derived using estimated number of people with multiple sclerosis in each region (based on national estimated prevalence of 144 per 100,000) divided by the number of multiple sclerosis specialist nurses in each region.

2 There are no comparable data for Parkinson's nurses or motor neurone disease nurses.

Source: Data on number of nurses for October 2011 – MS Society. Prevalence of multiple sclerosis – Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition, The Neurological Alliance, April 2003

19 The survey defines 'expert' as therapists with specialist knowledge and expertise in Parkinson's disease management.

3.11 A recurring frustration for patients, carers and health professionals was the continual cycle of referral–discharge–referral. Patients felt that this affected continuity of care, but was also inefficient with many unnecessary GP visits. This cycle was confirmed at our focus group with neurologists who reported pressure from Primary Care Trusts and hospital managers to discharge patients. They thought this was driven by outpatient ‘new to follow-up’ ratio performance measures. These measure the number of follow-up appointments, compared with new patients seen, with Primary Care Trusts trying to reduce follow-up appointments to lower costs.

3.12 There was only limited evidence about access to equipment. The University of Oxford survey found that only a small number of people reported problems getting equipment. A study of neurological services for people with motor neurone disease in Lancashire and South Cumbria found that the provision of equipment and home adaptations was not always timely.²⁰ Timely access to equipment is vital for people with motor neurone disease as the condition often deteriorates rapidly.

3.13 The Framework’s quality requirement 10 focuses on support for families and carers. Our carer’s focus group noted a variation in services depending on where people lived, and the significant financial and health impact on carers. The University of Oxford survey of carers found a mixed picture. For example, of carers who said they wanted a carer’s assessment, 52 per cent had not had one. Also, 64 per cent of carers did not want any training but, of those who did, 62 per cent had not received any.

Inpatient hospital visits

3.14 Quality requirements 3 and 11 highlight the importance of meeting the specific needs of people with neurological conditions when admitted to hospital. The Framework states that they should be treated by people with experience of neurological conditions.

3.15 The Royal College of Physicians’ report highlighted shortcomings in neurology services at district general hospitals that increased the risk of poor patient outcomes.²¹ People having a neurological or related emergency (for example, as a result of a fall) are usually admitted to the local district general hospital. While more complex cases can be transferred to a regional centre where most neurologists are based, there are often delays due to, for example, bed shortages. Subsequently, emergency neurology care is mainly delivered by district general hospital doctors with patients cared for in general wards by non-specialist nurses or junior staff.

20 National Institute for Health Research, *Optimisation of services for the care of people with Motor Neurone Disease (MND), based on an understanding of personal experience of MND in Lancashire and South Cumbria*, NIHR Research for Patient Benefit Programme – Final report, 2010.

21 Royal College of Physicians. *Local adult neurology services for the next decade*. Report of a working party – Royal College of Physicians, 2011.

3.16 Our evidence shows that hospital staff without knowledge of neurological conditions affected patient care. People with Parkinson's disease must, for example, receive medication at specific, personalised times. Not doing so can result in uncontrolled symptoms, and severe avoidable illness. Hospitals often have medication rounds at fixed times that do not cater for the needs of people with Parkinson's disease. Bromley District General hospital audited emergency admissions of people with Parkinson's over a two-month period in 2007. Of the 35 patients admitted, 26 had their medication stopped, omitted or prescribed inappropriately.²²

Potential to improve services and reduce costs

3.17 It is clear from our analysis that there are significant inefficiencies in the care of people with neurological conditions. **Figure 16** illustrates that good practice can reduce hospital admissions; neurologist outpatient appointments; and shift care away from residential to home care. By freeing up capacity there is potential to improve services, for example by allowing neurologists to focus on emergency inpatient admissions.

3.18 The impact on costs is more difficult to determine. As the examples show, there is potential to reduce admissions freeing up resources for other services. However, if resources are redirected to other activities rather than reduced, then overall costs may increase. In Parts One and Two, our analysis shows that hospital admissions and costs have increased significantly in real terms since the introduction of the Framework. Social care costs for adults with a physical disability have remained flat in real terms. At the same time important quality-of-care indicators (emergency admissions and readmissions) have worsened. This indicates that more work needs to be done to understand the 'whole system' costs of services for people with neurological conditions.

Services for other neurological conditions

3.19 While we have focused on three neurological conditions, other literature highlights similar issues for people with other neurological conditions:

- **The All Party Parliamentary Group for Muscular Dystrophy**²³ found that, outside the specialist centres, there was considerable variation in neuromuscular services. Many patients in poorer-served regions faced delays in accessing clinicians and poor community-based services. This compromised patient survival and well-being.
- **The All Party Parliamentary Group on Epilepsy**²⁴ found high rates of misdiagnosis; long waiting times for diagnostic tests; lack of availability of surgery and significant workforce shortages, for example, of specialist epilepsy nurses.

²² *Parkinson's ('Get it on time') hospital medicines management audit guidelines*, Parkinson's UK, 2010.

²³ *Access to Specialist Neuromuscular Care: The Walton Report*. All Party Parliamentary Group for Muscular Dystrophy, 2009.

²⁴ *The human and economic cost of epilepsy in England: Wasted money, wasted lives*, All Party Parliamentary Group on Epilepsy, 2007.

Figure 16

Good practice examples

Parkinson's nurse

Across our patient focus groups the impact of having access to a specialist nurse was clear. Care was significantly improved and better coordinated with the specialist nurse being the key contact point; and providing clinical leadership, case management, and education to patients, carers and hospital staff.

Parkinson's UK research to assess the impact of Parkinson's nurses has found reductions in emergency admissions to hospital; length of hospital stays; and visits to neurologists. For example:

- **Western Cheshire Primary Care Trust.** Over a 12-month period 504 patients were seen at a nurse-led clinic rather than by a consultant.
- **Harlow Hospital.** Admissions for people with Parkinson's disease reduced from 55 in 2004 to 18 in 2005 after introducing a Parkinson's nurse.
- **Penine Acute Trust.** There were 294 fewer bed days between 2008-09 and 2009-10 after appointing a Parkinson's nurse.

Integrated health and social care – Torbay Care Trust

While this example is not specifically related to neurological conditions it shows how integrating health and social care can improve patient outcomes and reduce costs.

After a period of gradual integration and piloting, Torbay Care Trust was established in 2005 to provide health and social care services in the area and includes a single budget covering health and social care; a single commissioning team; an integrated management structure; and health and social care coordinators. While establishing cause and effect is difficult, there is strong circumstantial evidence that integrating has had a significant impact on services:

Health

- The daily average number of occupied beds fell from 750 in 1998-99 to 502 in 2009-10.
- Emergency bed day use in the population aged 65 and over is the lowest in the region, with emergency bed day use for people aged 75 and over falling by 24 per cent between 2003 and 2008.
- Delayed transfers of care from hospital have been reduced to a negligible number.

Social care

- Since 2007-08, Torbay Care Trust has been financially responsible for 144 fewer people aged over 65 in residential and nursing homes.
- There has been a corresponding increase in the use of home-care services, some of which are now being targeted on preventative low-level support.

Source: Parkinson's nurse – affordable, local, accessible and expert care, Parkinson's UK, 2011. Thistlethwaite P., Integrating health and social care in Torbay, King's Fund, March 2011

Barriers to improving services

3.20 In summary, our report notes a range of systemic issues limiting service improvements for people with neurological conditions including:

- poor data on prevalence of neurological conditions;
- poor information for patients and carers about services;
- poor knowledge of neurological conditions among health professionals;
- performance measures that create cycles of referral–discharge–referral;
- little integration between health and social services; and
- skilled workforce shortages.

3.21 In addition, while our report has not focused on commissioning arrangements, our literature review noted significant weaknesses. For example, the University of York survey (Figure 14) found that 36 per cent of Primary Care Trusts had not completed a needs assessment for people with neurological conditions.

3.22 Many of these systemic issues have been highlighted in previous Committee of Public Accounts and NAO reports (**Figure 17**).

Figure 17

Systemic issues highlighted in a selection of previous Committee of Public Accounts and NAO reports

Systemic issue	Subject area of report			
	Rheumatoid arthritis	End of life care	Dementia	Autism
Poor data on prevalence and demand for services	✓	✓	✓	✓
Poor information for patients and carers about services	✓	X	X	✓
Poor knowledge of conditions among health professionals	✓	✓	✓	✓
Performance measures that create cycles of referral–discharge–referral	X	X	X	X
Weak commissioning practices	✓	✓	X	✓
Little integration between health and social services	✓	✓	✓	✓
Skilled workforce shortages	X	✓	✓	X

Source: Comptroller and Auditor General, *Improving dementia services in England – an interim report*, Session 2009-10, HC 82, National Audit Office, January 2010. Comptroller and Auditor General, *Services for people with rheumatoid arthritis*, Session 2008-09, HC 823, National Audit Office, July 2009. Comptroller and Auditor General, *Supporting people with autism through adulthood*, Session 2008-09, HC 125, National Audit Office, June 2009. Comptroller and Auditor General, *End of life care*, Session 2007-08, HC 1043, National Audit Office, November 2008. Committee of Public Accounts, *Improving dementia services in England*, Session 2009-10, HC 321, House of Commons, March 2010. Committee of Public Accounts, *Services for people with rheumatoid arthritis*, Session 2009-10, HC 46, House of Commons, February 2010. Committee of Public Accounts, *Supporting people with autism through adulthood*, Session 2008-09, HC 697, House of Commons, July 2009. Committee of Public Accounts, *End of life care*, Session 2008-09, HC 99, House of Commons, March 2009.

Appendix One

Methodology

Method

Data analysis

Hospital Episode Statistics data and National Adult Social Care Information System data and data from the representative charities.

Semi-structured interviews with

Department of Health officials; GPs; Strategic Health Authority long-term condition leads; and people with motor neurone disease.

Eight focus groups with

- people with Parkinson's disease and multiple sclerosis;
- carers;
- charities (Parkinson's UK, MS Society, MND Association, Dystonia Society; Multiple System Atrophy Trust; Sue Ryder Care; Transverse Myelitis Society; Trigeminal Neuralgia Association; Action for ME; Neurological Alliance);
- neurologists;
- specialist nurses; and
- Primary Care Trust officials.

Literature review

We commissioned PricewaterhouseCoopers to systematically review 146 documents (see detailed methodology on NAO website for bibliography).

Purpose

To identify trends in neurology-related hospital admissions and social services for people with a physical disability.

To understand:

- the design and implementation of the Framework;
- current service for people with neurological conditions; and
- opportunities and risks to services under the new health and social care landscape.



Design and Production by
NAO Communications
DP Ref: 009744-001

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