



National Audit Office

Report

by the Comptroller
and Auditor General

Department of Health and NHS England

Services for people with neurological conditions: progress review

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National Audit Office

Department of Health and NHS England

Services for people with neurological conditions: progress review

Report by the Comptroller and Auditor General

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Sir Amyas Morse KCB
Comptroller and Auditor General
National Audit Office

7 July 2015

This report sets out the findings of our review of progress against the recommendations that the Committee of Public Accounts made in its 2012 report on services for people with neurological conditions.

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Key facts

4.7m

estimated number of neurological cases in England (excluding migraine, headache, dementia and stroke)

£3.3bn

estimated NHS spending on neurological services in 2012-13 (excluding chronic pain)

3.5%

percentage of total NHS spending accounted for by neurological services in 2012-13

£8.2 billion spending by local authorities on social care services for adults with a physical disability in 2013-14 (an estimated quarter of whom have a neurological condition)

65% proportion of people with a long-term neurological problem who said they definitely, or to some extent, had enough support from local services, reported in January 2015

3.6% growth in neurological inpatient admissions between 2010-11 and 2013-14

17.4% growth in neurological outpatient appointments between 2010-11 and 2013-14

11% proportion of people with a long-term neurological problem who had a written care plan, reported in January 2015

1 new National Institute for Health and Care Excellence (NICE) quality standard relating to neurological conditions

Summary

1 We reported on services for people with neurological conditions in December 2011.¹ The subsequent report by the Committee of Public Accounts (the Committee), published in March 2012, made 6 recommendations aimed at improving services and achieving better outcomes for people with neurological conditions.² The Committee's report also asked us to follow up on progress against these recommendations. This report sets out the findings of our review of progress. We set out our audit approach in Appendix One.

2 Neurological conditions result from damage to the brain, spinal column or peripheral nerves. Some neurological conditions are life-threatening with many severely affecting quality of life and causing lifelong disability. The most recent estimate indicates that there are 4.7 million neurological cases in England.

3 Health spending on neurological services has increased faster than overall NHS spending. In 2012-13, £3.3 billion was spent on neurological services. This represented 3.5% of total NHS programme budget spending – up from 3.1% in 2010-11. Hospital activity involving patients with neurological conditions has continued to increase since we reported in 2011. However, growth in both inpatient admissions and outpatient appointments has slowed.

4 There are no data on spending on social care for people with neurological conditions. In 2013-14 local authorities spent £8.2 billion on social care services for adults with a physical disability (around one quarter of whom have a neurological condition according to estimates from the Neurological Alliance). This was a reduction of 16% in real terms since 2009-10. The number of adults with a physical disability receiving social services has fallen significantly from just under 1.2 million people in 2009-10 to 840,000 in 2013-14.

5 Part One of this report sets out a range of data on the quality of neurological services since we reported in 2011, including waiting times and emergency admissions. In the most recent GP Patient Survey, published in January 2015, 65% of people with a neurological problem said they definitely, or to some extent, had enough support from local services, while 21% of people felt they did not. The results for people with neurological problems were less positive than for people with long-term conditions more broadly. Overall satisfaction with social care services for people with a physical disability has increased slightly in recent years, with 63% of people stating they were either extremely or very satisfied with their care and support in 2013-14.

¹ Comptroller and Auditor General, *Services for people with neurological conditions*, Session 2010–2012, HC 1586, National Audit Office, December 2011.

² HC Committee of Public Accounts, *Services for people with neurological conditions*, Seventy-second Report of Session 2010–2012, HC 1759, March 2012.

Conclusion on progress against the Committee's recommendations

6 Overall, progress against the Committee's 6 recommendations has been mixed. Of the 4 recommendations that the Department of Health (the Department) accepted, we assess that progress has been moderate against 2 and poor against 2 (**Figure 1**). There has been good progress in relation to 1 of the recommendations that the Department did not initially accept with poor progress against the other. Considerable further work is therefore needed to implement the recommendations in full and achieve the better services and outcomes that the Committee was seeking.

Figure 1

Assessment of progress against the Committee's recommendations

	Department's response	Our assessment of progress	Commentary
Recommendation 1 Appoint a national clinical lead for neurology and establish local neurological networks.	Not agreed	Good	While the Department did not agree with this recommendation, there has been progress against both aspects. NHS England has appointed a national clinical director for adult neurology and established the mental health, dementia and neurological conditions strategic clinical network.
Recommendation 2 Develop a neurological dataset and include key indicators from the dataset in the NHS and adult social care outcomes frameworks.	Agreed	Moderate	The Health and Social Care Information Centre published a compendium of neurology data in March 2014, although it did not link health and social care data or include data on emergency readmissions as the Committee recommended. Public Health England and NHS England also jointly sponsor a new neurology intelligence network. The NHS outcomes framework includes only 1 indicator relating to neurological conditions – on epilepsy in young people under 19 years old. The adult social care outcomes framework includes no indicators relating to neurological conditions.
Recommendation 3 Ensure all people with neurological conditions have appropriate access to services through use of the commissioning outcomes framework (now the clinical commissioning group outcomes indicator set), the joint strategic needs assessments and the health and wellbeing boards.	Agreed	Poor	The clinical commissioning group outcomes indicator set includes only 1 indicator specific to neurological conditions – on epilepsy in young people under 19 years old. Our analysis found that just over half of joint strategic needs assessments made reference to neurology or a specific neurological condition through either a specific chapter/section or one or more specific sentences. Only one fifth of joint health and wellbeing strategies referred to neurology or a specific neurological condition.
Recommendation 4 Mandate joint health and social care commissioning of neurological services in its commissioning outcomes framework, supported by health and wellbeing boards through the joint strategic needs assessment.	Not agreed	Poor	The Department did not agree with this recommendation because it was not government policy to mandate specific local work. NHS England does not hold information on the extent of joint commissioning for neurological services. The Neurological Alliance told us that its members had seen only occasional examples of joint commissioning.

Figure 1 *continued*

Assessment of progress against the Committee's recommendations

	Department's response	Our assessment of progress	Commentary
<p>Recommendation 5</p> <p>Set out in the commissioning outcomes framework that every person with a neurological condition should be offered a personal care plan, covering both health and social care.</p>	Agreed	Poor	The Department's mandate to NHS England includes an objective for everyone with a long-term condition, including a neurological condition, to be offered a personalised care plan by 2015. However, NHS England has not reflected this indicator in the clinical commissioning group outcomes indicator set so there is no indicator to encourage local action in this area. Recent survey evidence indicates that only a small proportion of people with a long-term neurological problem have a written care plan or have been offered one.
<p>Recommendation 6</p> <p>Instruct the National Institute for Health and Care Excellence (NICE) to develop a generic quality standard covering other neurological conditions.</p>	Agreed	Moderate	The Department has requested 5 quality standards relating directly to neurology. Of these, NICE has published one, one is in development and 2 are awaiting the publication of updated clinical guidelines. For the remaining standard, NICE estimates that it will publish the clinical guideline relating to generic neurological problems in January 2018. The quality standard is likely to be included in NICE's work programme for 2017-18 when the clinical guideline is available.

Source: National Audit Office

Part One

Overview of services for people with neurological conditions

1.1 This part of the report sets out background information on services for people with neurological conditions and data on service quality.

Neurological conditions

1.2 Neurological conditions result from damage to the brain, spinal column or peripheral nerves. They fit broadly into four types of condition: sudden onset; intermittent and unpredictable; progressive; and stable. Some neurological conditions are life-threatening with many severely affecting people's quality of life and causing lifelong disability.

1.3 NHS England does not know how many people have a neurological condition because it does not collate data centrally. In 2014 the Neurological Alliance estimated that there are 4.7 million neurological cases in England based on extrapolating prevalence data from research studies (**Figure 2**).³ This figure excludes migraine and headache, as these were outside the scope of our 2011 report. It also excludes dementia and stroke as these are managed mainly by old age psychiatry and stroke services.

1.4 The estimate of 4.7 million represented a significant increase on the Alliance's 2003 estimate of 1.8 to 1.9 million people with a neurological condition for the United Kingdom as a whole.⁴ However, the two estimates are not comparable because in 2014 the Alliance included a number of additional conditions that affect significant numbers of people.

Delivery of neurological services

1.5 People with neurological conditions may draw on a wide range of public services including health, social care, employment support and housing. Our 2011 report and that of the Committee of Public Accounts, in 2012, focused on health and social care services.⁵

³ Neurological Alliance, *Neuro numbers*, April 2014.

⁴ Neurological Alliance, *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, April 2003. The total excludes headache, migraine, dementia and stroke.

⁵ Comptroller and Auditor General, *Services for people with neurological conditions*, Session 2010–2012, HC 1586, National Audit Office, December 2011; HC Committee of Public Accounts, *Services for people with neurological conditions*, Seventy-second Report of Session 2010–2012, HC 1759, March 2012.

Figure 2

Estimated number of neurological cases in England, 2014

Type of condition	Estimated number of cases (millions)
Progressive (eg motor neurone disease and Parkinson's disease)	1.9 (excluding dementia)
Stable (eg acquired brain injury)	2.2
Intermittent and unpredictable (eg epilepsy)	0.6 (excluding migraine and headache)
Sudden onset (eg spinal cord injury often as a result of an accident)	0.03 (excluding stroke)
Total	4.7

Notes

- 1 The prevalence numbers relate to the number of cases rather than number of people. There may be people with more than one neurological condition who would be counted more than once in the figures above.
- 2 The total excludes migraine and headache as this was outside the scope of our 2011 report. We have also excluded dementia and stroke as these are managed mainly by old age psychiatry and stroke services.
- 3 The estimated number of people suffering from migraine and headache is 6.8 million, from dementia is 670,000 and from stroke is 300,000.

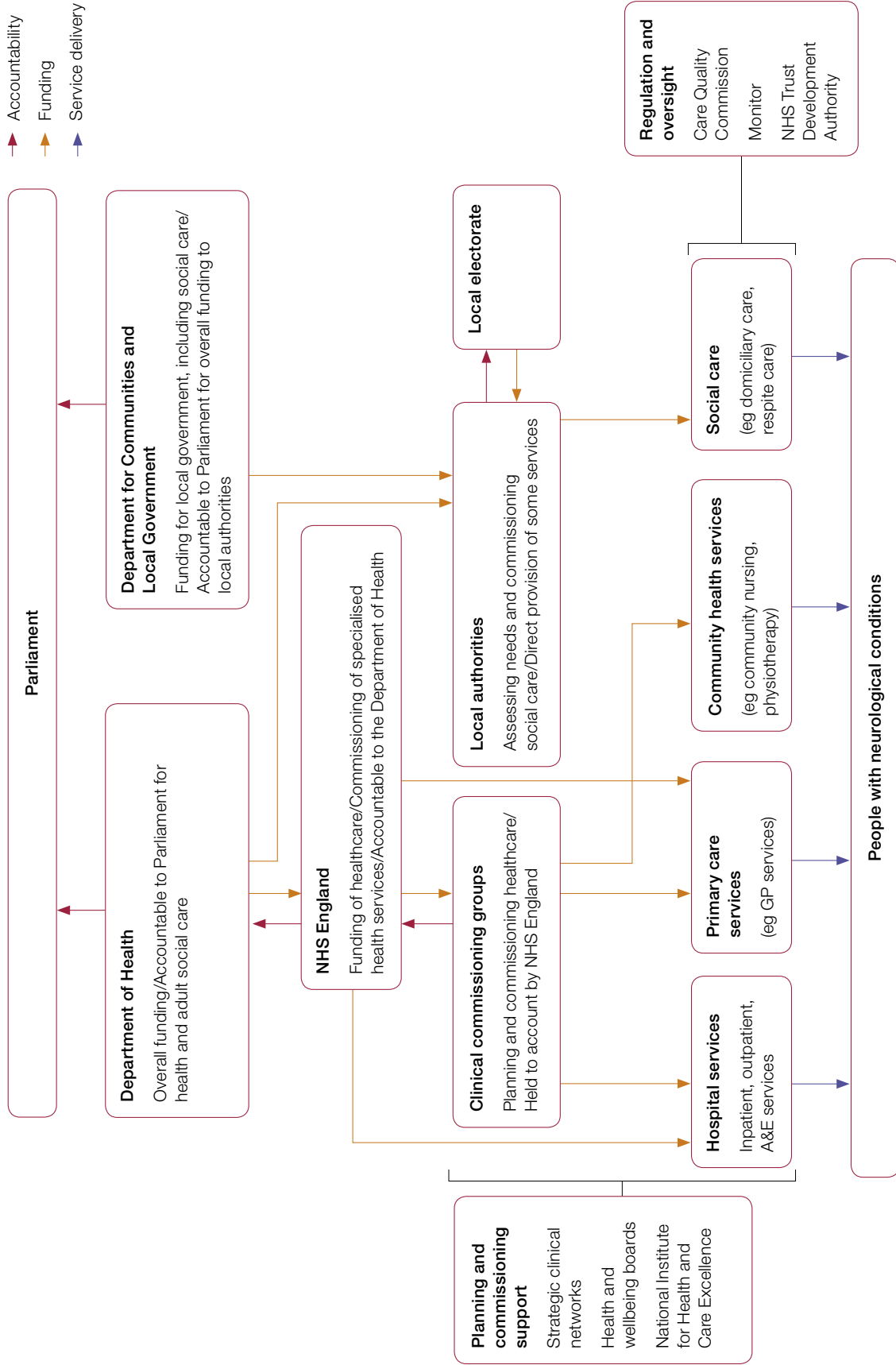
Source: Neurological Alliance, *Neuro Numbers*, April 2014

1.6 The Department of Health (the Department) is ultimately responsible for securing value for money from spending on healthcare, including neurological services. Following the reforms to the health system in 2013, the Department is the steward of the system as a whole. It relies on a system of assurance around the commissioning, provision and regulation of healthcare (**Figure 3** overleaf).

1.7 The arrangements for commissioning health services, including neurological services, have changed since we last reported on this topic in 2011. The reforms to the health system created new structures for commissioning healthcare:

- Clinical commissioning groups commission most health services from providers of hospital, community and mental health services.
- NHS England commissions specialised health services, including some neurological services such as diagnostic services for rare neuromuscular disorders. Specialised services are provided in relatively few hospitals and accessed by comparatively small numbers of patients.
- Clinical commissioning groups and NHS England now share responsibility for commissioning GP services. From April 2015, more than 70% of clinical commissioning groups took on greater responsibility for commissioning GP services. These services are the first and most regular point of contact with the NHS for most patients.

Figure 3
Accountability and funding structures for neurological services



1.8 Although they have been in place for two years, the new arrangements for commissioning healthcare are still bedding in. The Association of British Neurologists and the Neurological Alliance both highlighted to us what they saw as continued confusion over which neurological services should be commissioned by NHS England and which by clinical commissioning groups.

1.9 When we reported on this topic in 2011, the policy framework for services for people with neurological conditions was set out in the Department's *National Service Framework for Long-term Conditions*, which was introduced in March 2005. NHS England now aims to improve the quality of life for all people with long-term conditions. This includes supporting the development of a system-wide approach that is able to deal with the increasing numbers of people with multiple long-term conditions.

1.10 The Department holds NHS England to account. It sets objectives for NHS England through an annual mandate and measures progress against these objectives through indicators in the NHS outcomes framework. In turn, NHS England supports and holds to account, through an assurance process, the 209 clinical commissioning groups for delivering their statutory functions, including improving outcomes for their populations.

1.11 The 152 local authorities with adult social care responsibilities (county councils, London boroughs, metropolitan borough councils and unitary authorities) commission most social care from a range of providers. These include social enterprises and commercial organisations. Local authorities are accountable to their local electorate. They also have a statutory responsibility to provide certain services, for example adult social care to those who are eligible. The Department for Communities and Local Government is accountable to Parliament for the proper stewardship of the resources allocated to it, most of which it distributes to local authorities. The Department of Health is responsible for adult social care policy and provides some funding for adult social care.

Spending and activity

Healthcare

1.12 Spending on neurological services has increased at a faster rate than overall NHS spending, although up-to-date data are not available. The most recent data indicate that, in 2012-13, £3.3 billion was spent on neurological services (**Figure 4** overleaf). The way total spending is calculated was changed in 2010-11. This means that the figures for 2009-10 and before cannot be meaningfully compared with those for 2010-11 and after. However, both before and after the change, spending on neurological services made up an increasing percentage of overall NHS programme budget spending. In 2012-13, neurological services accounted for 3.5% of overall spending – up from 3.1% in 2010-11.

Figure 4

Department of Health spending on neurological services, 2007-08 to 2012-13

	2007-08	2008-09	2009-10		2010-11	2011-12	2012-13
Spending on neurological services (£bn)	2.3	2.5	2.8	Break in series	2.9	3.1	3.3
Total programme budget spending (£bn)	82.3	85.5	92.9		94.8	93.9	94.8
Neurological spending as percentage of total programme budget spending (%)	2.8	2.9	3.0		3.1	3.3	3.5

Notes

- 1 Figures are in 2012-13 prices.
- 2 Data on spending on neurological services are taken from the programme budget data. We have excluded neurological chronic pain as the revised definition of adult neurological conditions published by Public Health England almost entirely excludes the conditions listed under neurological conditions chronic pain.
- 3 Public Health England's revised definition of adult neurological conditions also includes more than 100 conditions not included in the programme budget definition. Therefore, there is a significant disconnect between programme budget data on spending on neurological services and the activity data presented in this report.
- 4 The data on spending exclude headache, dementia and most spending on stroke (some related complications are included, for example brain stem stroke syndrome). Migraine is included as it is not possible to exclude this spending.
- 5 There is a break in the series between 2009-10 and 2010-11. Figures for years 2006-07 to 2009-10 are calculated using provider costs as a basis. Figures for 2010-11 to 2012-13 are calculated using price paid for specific activities and services purchased from healthcare providers.

Source: Department of Health programme budget data

1.13 Hospital activity involving patients with neurological conditions has continued to increase since we reported in 2011 (**Figure 5**). The growth in outpatient appointments for people with neurological conditions has slowed, with growth broadly in line with the NHS as a whole (covering all conditions):⁶

- Between 2010-11 and 2013-14, neurological outpatient appointments increased by 17.4% (from 1,462,497 to 1,716,628), compared with 30.3% over the previous 3 years (2007-08 to 2010-11).
- Between 2010-11 and 2013-14, outpatient appointments for the NHS overall increased by 16.8%.

1.14 Growth in neurological inpatient admissions has slowed to just below the rate for the NHS as a whole (covering all conditions):

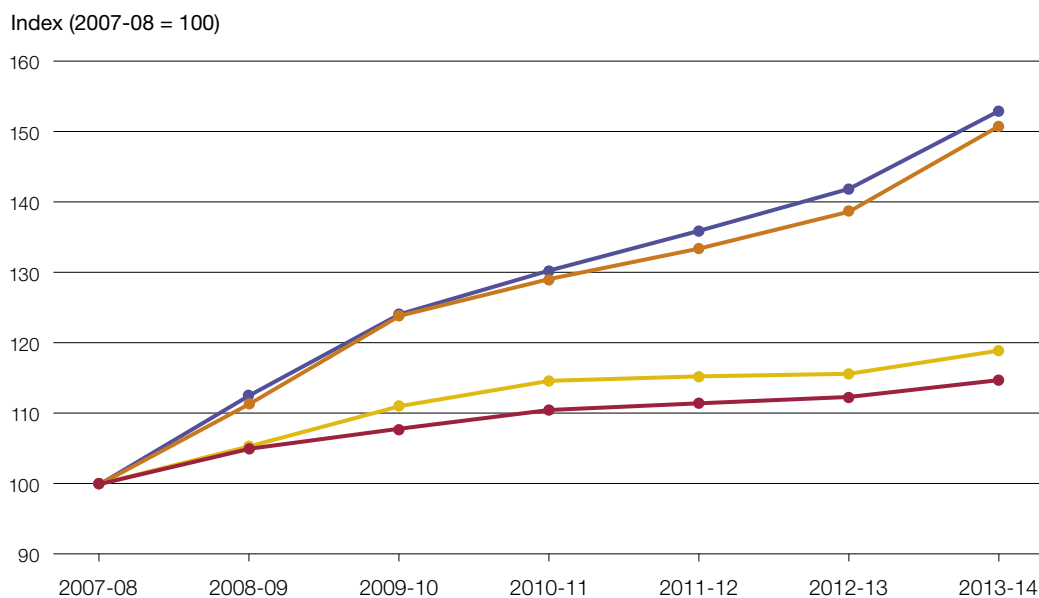
- Between 2010-11 and 2013-14, neurological inpatient admissions increased by 3.6% (from 447,276 to 463,510), compared with 14.6% over the previous 3 years (2007-08 to 2010-11).
- Between 2010-11 and 2013-14, inpatient admissions for the NHS overall increased by 3.8%.

⁶ All growth rates are over the three-year period described, not per year. They also represent absolute growth in admissions, not per person.

Figure 5

Growth in hospital inpatient admissions and outpatient appointments: neurology compared with the NHS as a whole, 2007-08 to 2013-14

The growth in both inpatient admissions and outpatient appointments between 2010-11 and 2013-14 slowed compared with between 2007-08 and 2010-11



● Inpatient – NHS	100	105	108	110	111	112	115
● Inpatient – Neurology	100	105	111	115	115	116	119
● Outpatient – NHS	100	111	124	129	133	139	151
● Outpatient – Neurology	100	113	124	130	136	142	153

Notes

- 1 Inpatient activity is based on Public Health England's definition of adult neurological conditions – Public Health England, *Defining adult neurological conditions: National Neurology Intelligence Network technical briefing*, March 2015.
- 2 Public Health England's definition of neurological conditions does not include dementia and stroke. In addition, for inpatient activity we have excluded headache and migraine.
- 3 Inpatient activity is based on neurology featuring in one of the top three diagnostic codes. Outpatient activity is based on the treatment specialty the patient was treated under.

Source: National Audit Office analysis of hospital episode statistics

Social care

1.15 There are no data on spending on social care for people with neurological conditions, as adult social services are defined by disability and need rather than condition. People with neurological conditions generally fall within the category of 'people with a physical disability'. While there are no data on the number of people within this category that have a neurological condition, the Neurological Alliance estimated in 2003 that 25% of people between 16 and 64 with a chronic disability had a neurological condition.

1.16 Since we reported in 2011, central government has significantly reduced the funding it gives to local authorities. Social care spending on adults with a physical disability has fallen in real terms. Between 2009-10 and 2013-14, spending fell by £1.6 billion (16%) in real terms, from £9.8 billion in 2009-10 to £8.2 billion in 2013-14.⁷

1.17 The number of adults with a physical disability receiving social care services has fallen significantly since our last report, from 1.2 million in 2009-10 to 0.8 million in 2013-14 (**Figure 6**). The reduction is partly due to the fact that, to help manage cost and demand, some local authorities have raised the thresholds for eligibility for care.⁸

Quality of neurological services

Patient experience

1.18 NHS England collects information every 6 months, through the GP Patient Survey, on the experiences of patients, including people with long-term neurological problems. In the most recent survey, published in January 2015, 65% of people with a neurological problem said they definitely, or to some extent, had enough support from local services (**Figure 7** on page 16). However, the results for people with neurological problems were less positive than for people with long-term conditions more broadly and for people with epilepsy specifically: 21% of people with a neurological problem said they did not think they had enough support compared with 12% for the broader group of people with long-term conditions and 14% for epilepsy. These proportions have remained stable since June 2012 when the data were first collected.

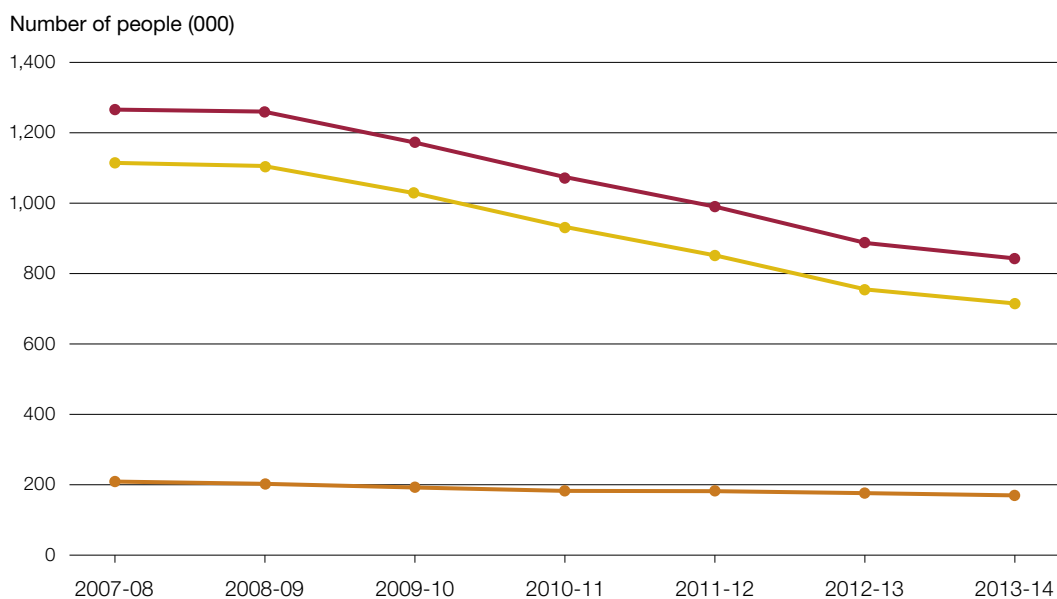
7 Health and Social Care Information Centre, *Personal Social Services: Expenditure and Unit Costs Return*, 2013-14 final release, December 2014.

8 Local Government Association/Association of Directors of Adult Social Services, *Adult social care funding: 2014 state of the nation report*, October 2014.

Figure 6

Number of adults with a physical disability receiving social care services, 2007-08 to 2013-14

The number of adults with a physical disability receiving social care services has fallen significantly since 2007-08



● Total	1,266	1,260	1,172	1,074	990	886	842
● Community	1,114	1,106	1,028	932	851	754	714
● Nursing/Residential care	208	202	191	182	181	175	169

Note

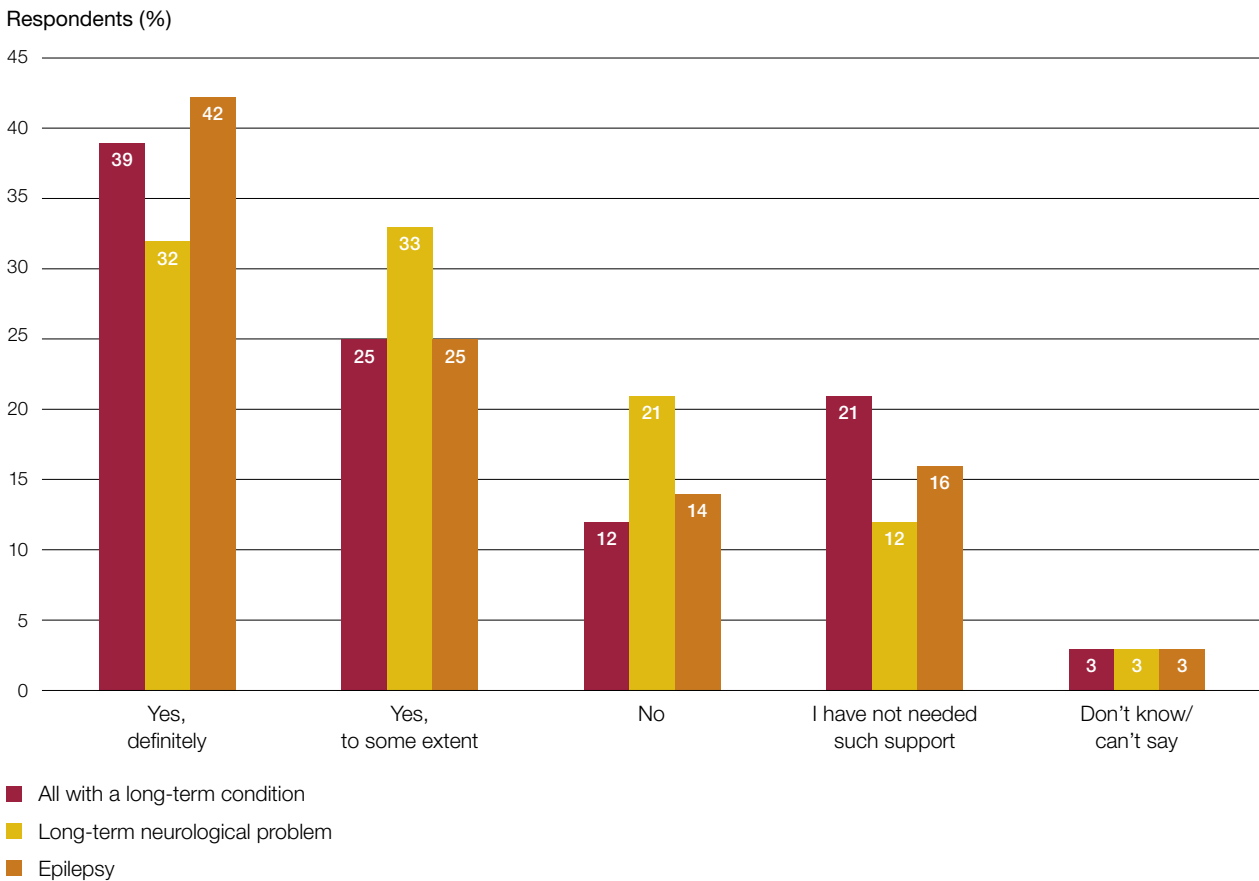
1 When added together, the numbers for nursing, residential and community care exceed the total as some people receive more than one type of care in a given year.

Source: Health and Social Care Information Centre, *Community Care Statistics, Social Services Activity, England – 2013-14, Final release*, December 2014

Figure 7

Patient experience of support from local services, data published in January 2015

In the last 6 months, have you had enough support from local services/organisations to help you to manage your long-term health condition(s)?



Notes

- 1 Total respondents: all long-term conditions, 415,443; long-term neurological problems, 15,338; epilepsy, 9,278.
- 2 The data for the January 2015 publication were collected during January–March 2014 and July–September 2014.
- 3 The questionnaire makes clear that respondents should think about all services and organisations, not just health services.

Source: GP Patient Survey, January 2015

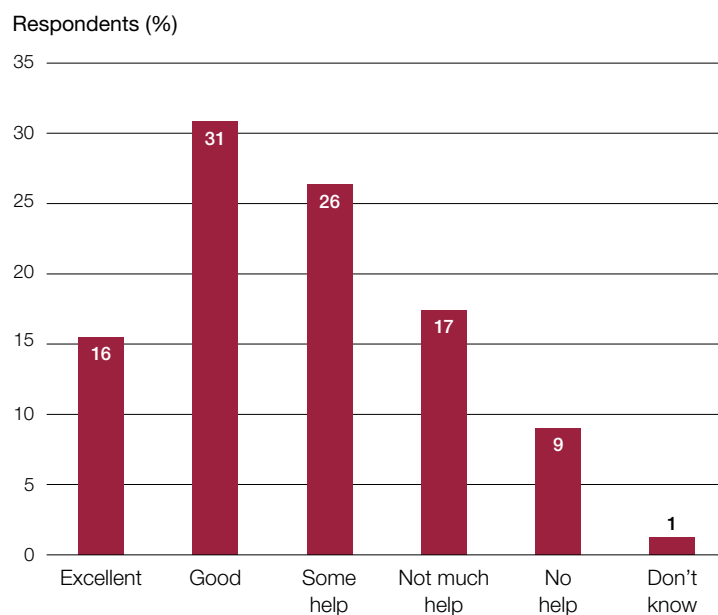
1.19 The Neurological Alliance also collects information on the experience of patients. In January 2015, it published a survey that showed a mixed picture of patients' experience of their ongoing care and treatment. The survey found that:

- 46% of respondents rated their care and treatment as either excellent or good, while 26% rated it as either not much help or no help (**Figure 8**);
- 58% of respondents said they had experienced problems or delays in accessing treatment; and
- 43% of respondents said the different people treating them worked well together all or most of the time, but 42% said this was the case only some of the time or never.⁹

Figure 8

Patient experience of care and treatment, data published in January 2015

Overall, how do you rate the care and treatment you have received for your neurological condition?



Notes

- 1 Number of respondents for this question: 5,852.
- 2 Due to rounding, the numbers in the chart do not exactly match those in the text.

Source: Neurological Alliance, *The Invisible Patients – Revealing the state of neurological services*, January 2015

⁹ Neurological Alliance, *The Invisible Patients – Revealing the state of neurological services*, January 2015. For the questions mentioned the number of respondents was 5,852 for each question.

Waiting times for treatment

1.20 Data show that inpatient neurology waiting times (from first referral – usually by a GP – to admission to hospital) have been relatively stable since 2011.¹⁰ They remain much shorter than for the NHS as a whole. In March 2015, the median waiting time for neurological services (the time within which 50% of people were admitted) was 3.2 weeks. This compared with 2.8 weeks in August 2011 (the latest data in our 2011 report). The median waiting time across the NHS for all inpatient admissions was 9.2 weeks in March 2015.

1.21 For neurology outpatient appointments (from first referral to starting consultant-led care), waiting times remain longer than for the NHS as a whole. In March 2015, the median waiting time was 7.9 weeks, compared with 7.1 weeks in August 2011. The median waiting time across the NHS for all outpatient appointments was 5.0 weeks in March 2015.

Access to acute neurological services

1.22 The Association of British Neurologists published a survey in December 2014 indicating significant variation in access to acute neurology services.¹¹ The survey tested performance against a number of the quality standards developed by the Association. For example:

- **Adults admitted to acute medical units with an acute neurological problem should have access to daily consultation by neurology specialists (if necessary by telemedicine)**

The survey found that, in the top quarter of sites, neurological reviews were available on 89% of days on average. In the bottom quarter of sites they were available on only 17% of days on average.

- **Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (computerised tomography (CT) and magnetic resonance imaging (MRI)) where indicated**

The survey found that almost every site met the CT standard, but less than one third of sites had MRI services available 24 hours a day, 7 days a week.

¹⁰ NHS England, *Consultant-led referral to treatment waiting times data*, to March 2015.

¹¹ Association of British Neurologists, *ABN Acute Neurology services survey 2014*, December 2014. The survey covered 195 sites: neuroscience centre (16%); neurology centre (10%); district general hospital with neurologist based there (35%); and district general hospital with no neurologist based there (39%).

Emergency admissions and readmissions

1.23 The rate of emergency admissions and readmissions for an existing long-term neurological condition, where patients require unplanned hospital treatment, is an indicator of poor quality health or social care services, or both, or poorly integrated health and social care. The growth in neurological emergency admissions has slowed significantly since we last reported in 2011. For example:¹²

- Between 2010-11 and 2013-14, neurological emergency admissions increased by 2.8% (from 318,893 to 327,788). This was similar to the growth rate for emergency admissions for the NHS as a whole, which covers all conditions (2.4%).
- In the previous 3 years (2007-08 to 2010-11) neurological emergency admissions grew much more quickly (by 18.3%), compared with 11.2% for the NHS as a whole.

1.24 The position on neurological emergency readmissions has remained stable since 2011. For the NHS as a whole (which covers all conditions), the rate of emergency readmissions increased slightly. In 2013-14, the percentage of neurological patients readmitted as an emergency within 30 days of discharge was 10.1% compared with 10.2% in 2010-11. For the NHS as a whole, the emergency readmission rate was 12.0% in 2013-14 compared with 11.5% in 2010-11.¹³

Social care services for people with a physical disability

1.25 While there are no measures of the quality of social care services for people with a neurological condition, satisfaction with social care for people with a physical disability has increased slightly. The Personal Social Services Adult Social Care Survey, first run in 2010-11, asks a range of questions about how effectively services are helping users, and the impact of services on their quality of life. In 2013-14, the survey found that 63% of people with a physical disability were either extremely or very satisfied with their care and support, compared with 61% in 2010-11.

¹² The analysis is based on Public Health England's definition of neurological conditions, which does not include dementia and stroke. In addition, we excluded headache and migraine. The analysis is based on patients with a diagnosis of a neurological condition in the first 3 diagnostic fields in hospital episode statistics. All growth rates are over the three-year period described, not per year. They also represent absolute growth in admissions, not per person.

¹³ The analysis for emergency admissions and readmissions is based on the Public Health England definition of neurology, which excludes dementia and stroke (see Figure 5). We also excluded headache and migraine from the analysis.

Part Two

Progress against the Committee's recommendations

2.1 This part of the report sets out progress against the recommendations made by the Committee of Public Accounts (the Committee) in its report *Services for people with neurological conditions*, published in March 2012. The government set out its response to the Committee's report in April 2012.¹⁴

Recommendation 1

Committee's recommendation

Implementation of the Framework lacked leadership at both national and local level, which led to a lack of impetus, focus and direction. The Department accepts that leaving implementation solely to local bodies has not delivered. Unlike other treatment areas, such as stroke and cancer, neurology does not have a dedicated National Clinical Director or local networks to coordinate services. **The proposed NHS Commissioning Board should appoint a dedicated National Clinical Lead for neurology to provide leadership on the commissioning and design of neurological services. It should also establish local neurological networks, coordinated by the NHS, with clearly responsible and accountable local leadership.**

Progress against the recommendation

2.2 While the Department of Health (the Department) did not agree with the Committee's recommendation, there has been progress against both aspects.

National clinical director

2.3 NHS England appointed a national clinical director for adult neurology in June 2013, reporting to its medical director for long-term conditions. The national clinical director is a practising neurologist.

¹⁴ HM Treasury, *Treasury Minutes: Government responses on the Sixty-Eighth, the Seventieth, the Seventy-Second and the Seventy-Fourth Reports from the Committee of Public Accounts: Session 2010–2012*, Cm 8347, April 2012.

2.4 Like his counterparts for other conditions, the national clinical director for neurology is part-time, in his case, working two days a week in this role. What is less clear is how many NHS England staff are dedicated to supporting the national clinical director for neurology and how that compares with other conditions. The national clinical director can draw on expertise from NHS England's different directorates as needed and NHS England does not hold information on the support provided to each national clinical director. It confirmed that the resources available to support the national clinical directors are weighted towards areas of particular priority such as cancer, dementia and mental health. NHS England told us that, as part of a recent restructuring, further dedicated staff time had been made available to support a range of national clinical directors, including neurology.

2.5 The Association of British Neurologists and the Neurological Alliance agreed that the appointment of a national clinical director had provided a focus for coordinating the development of neurological services. The national clinical director has undertaken a range of activities including: playing a leading role in improving the available data on neurology; co-chairing the clinical reference group for neurosciences; and working with NHS England to scope a 'commissioning toolkit' for community care of neurological conditions. However, the Association of British Neurologists and the Neurological Alliance also highlighted that, in their view, the national clinical director's effectiveness was constrained by the part-time nature of the role and limited administrative support.

Strategic clinical networks

2.6 NHS England established four strategic clinical networks in April 2013, including a network for mental health, dementia and neurological conditions. Strategic clinical networks aim to improve services so that patients experience better outcomes and quality of care. They support local commissioners' decision-making and strategic planning by bringing together commissioners, providers and voluntary organisations within 12 regions.

2.7 NHS England allocates programme funding to each network region and the region decides how to distribute it between the four clinical networks and clinical senates.¹⁵ NHS England does not hold information centrally on how much funding is available for strategic clinical network activity for neurological conditions specifically. Overall funding for the four strategic clinical networks and clinical senates was £42 million in 2013-14 and 2014-15 (£32 million of programme funding, £10 million for running costs). NHS England has reduced the funding for 2015-16. Programme funding has fallen to £24 million with the amount for running costs reduced to £7 million.

¹⁵ Clinical senates have been established to provide independent strategic advice and guidance to commissioners and other stakeholders to help them in making decisions about healthcare for the populations they represent.

2.8 While NHS England’s guidance for strategic clinical networks set out proposed staffing structures, each region is responsible for deciding how to staff its networks.¹⁶ NHS England does not hold information on how many staff support the different networks. However, it did highlight to us that an ongoing review of the role and purpose of strategic clinical networks has affected staff retention and that the networks had a number of vacancies. The Neurological Alliance told us that some of its members had reported a significant fall in network activity recently with less focus on neurology. It had linked this to the reductions in funding and the staff vacancies.

2.9 Nevertheless, the Association of British Neurologists and the Neurological Alliance are positive about the role of the strategic clinical network in coordinating stakeholders and developing integrated care pathways. Strategic clinical networks carry out work relating to national priorities agreed across the 12 regions. The work streams of the network for mental health, dementia and neurological conditions include: acute seizure care in emergency departments; headache outpatient referrals; and neurological rehabilitation. The strategic clinical networks also identify local priorities (for example, the London network has set up local clinical commissioning group data profiles). The Association of British Neurologists told us that, in its view, a lack of central coordination had led to some duplication in pilot projects across England. NHS England confirmed that regions may have similar local priorities and this could help to support rapid spreading and adoption of best practice.

Recommendation 2

Committee’s recommendation

The Department lacks the data to measure the effectiveness of services for people with neurological conditions. The Framework lacked an empirical baseline from which progress could be measured nationally or locally for health and social care, and the Department has no way of assessing what resources and activities result in the best outcomes. **The Department should develop a neurological data set covering resources, services and outcomes, which should include linking existing health and social care data using the patient’s NHS number. Key indicators from the data set, including emergency admissions and readmissions for neurological conditions, should be included in the NHS and Adult Social Care Outcomes Frameworks with appropriate targets for reduction.**

Progress against the recommendation

Neurological dataset

2.10 In March 2014, the Health and Social Care Information Centre published the *Compendium of Neurology Data, England – 2012-13*.¹⁷ This brought together extracts from existing national datasets relevant to neurology. Extracts included: hospital episode statistics; data on inpatient admissions and outpatient appointments; inpatient and outpatient waiting times; workforce statistics; and prescribing data.

¹⁶ NHS Commissioning Board (now NHS England), *Strategic Clinical Networks – Single Operating Framework*, November 2012.

¹⁷ Health and Social Care Information Centre, *Compendium of Neurology Data, England - 2012-13*, March 2014.

2.11 The publication of the compendium did not fully meet the Committee's recommendation, which also specified that it should link health and social care data and include data on emergency readmissions. The compendium could also have been strengthened by including data on trends, which are available for all of the indicators.

2.12 In addition to the compendium, the neurology intelligence network was launched in June 2014. The intelligence network is hosted by Public Health England and jointly sponsored with NHS England. It aims to provide intelligence for commissioners, policy-makers, clinicians and health professionals to help them improve services and outcomes. NHS England told us that, rather than commissioning another compendium of neurology data, it intended to support Public Health England in developing the intelligence network to provide more timely and usable data on an ongoing basis.

2.13 The work of the neurology intelligence network has initially focused on:

- developing neurology profiles around an epilepsy care pathway; and
- emergency hospital admissions for a further 11 neurological conditions, such as Parkinson's disease and motor neurone disease.

2.14 The profiles give clinical commissioning group-level data, which has highlighted significant variation in performance across England. For example, both the Association of British Neurologists and the Neurological Alliance highlighted to us performance against an important indicator under the epilepsy care pathway – the proportion of adults receiving treatment for epilepsy who have remained seizure-free for 12 months. In 2013-14, performance ranged from 87% in South-West Lincolnshire to 46% in North Manchester.

2.15 The Association of British Neurologists and the Neurological Alliance consider that the development of the compendium has been a significant step forward for neurology data. They highlighted a number of outputs that the compendium has helped to produce. These include the profiles produced by the neurology intelligence network. However, the Neurological Alliance raised concerns about the limited analytical resources that NHS England and Public Health England have made available to the neurology intelligence network to exploit the existing data. It also mentioned the lack of primary and social care data, which limits coverage of the compendium to only a small part of the neurology patient pathway.

Outcomes frameworks

2.16 There is limited specific coverage of neurological conditions in the NHS outcomes framework. The framework contains a range of indicators that the Department uses to hold NHS England to account for NHS outcomes. There were no specific indicators in the 2014-15 NHS outcomes framework covering neurological conditions apart from epilepsy in young people under 19 years old.¹⁸ One wider indicator – ‘potential years of life lost from causes considered amenable to healthcare’ – included a category labelled ‘people with neurological problems’ on the Health and Social Care Information Centre indicator portal website. However, the data in fact covered only people with epilepsy.

2.17 People with neurological conditions are represented within a number of broader indicators in the NHS outcomes framework, but their outcomes are not monitored separately. NHS England highlighted that the part of the framework relating to ‘enhancing quality of life for people with long-term conditions’ covers people with neurological conditions. Similarly, the indicators on ‘emergency admissions for acute conditions that should not usually require hospital admission’ and ‘emergency readmissions within 30 days of discharge from hospital’ will pick up people with neurological conditions, but they are not specific to these conditions as the Committee recommended. For some of these indicators, it would be possible to identify performance for people with neurological conditions, as the source data from both the GP Patient Survey and hospital episode statistics could be disaggregated. However, disaggregated data are not available on the Health and Social Care Information Centre’s indicator portal website.

2.18 The adult social care outcomes framework does not contain any indicators relating to neurological conditions.

2.19 Before 2014-15 the GP quality and outcomes framework included 3 indicators relating to neurological conditions, specifically to epilepsy. Following changes across a range of conditions, 2 of these epilepsy indicators were taken out of the framework from 2014-15 onwards. The Association of British Neurologists and the Neurological Alliance raised concerns about the removal of 1 of the indicators on – ‘adults with epilepsy remaining seizure-free for 12 months’ – especially given the significant variation in performance (paragraph 2.14).¹⁹

18 The NHS outcomes framework includes indicators relating to dementia and stroke; however, NHS England does not regard these as neurological indicators because these conditions are managed mainly by old age psychiatry and stroke services.

19 The quality and outcomes framework is the annual reward and incentive programme detailing GP practice achievement results.

Recommendation 3

Committee's recommendation

The quality of services for people with neurological conditions varies around the country, with some areas having insufficient expertise both in hospitals and in the community. The compliance of individual Primary Care Trusts with the Framework's quality requirements has been poor and so the support and treatment available to people continue to depend on where they live. **The Department should set out in its reply to us how it will ensure all people with neurological conditions have appropriate access to services. We would expect this to include how the Department will drive improvements through the quality section of the NHS Standard Contract, the Commissioning Outcomes Framework, the Joint Strategic Needs Assessments and the Health and Wellbeing Boards.**

Progress against the recommendation

2.20 In its response to the Committee's report, the Department outlined the new structures established by the Health and Social Care Act 2012 and how it expected these to improve access and provide more local accountability for services. This section covers progress against two key elements of the Committee's recommendation.

These are the extent to which neurological conditions feature in:

- the clinical commissioning group outcomes indicator set; and
- local joint strategic needs assessments and joint health and wellbeing strategies.

Clinical commissioning group outcomes indicator set

2.21 Reviewing progress against the clinical commissioning group outcomes indicator set forms part of the NHS England's assurance of clinical commissioning groups. As with the NHS outcomes framework, the clinical commissioning group outcomes indicator set for 2014-15 included no specific indicators relating to neurological conditions apart from epilepsy in young people under 19 years old. Therefore, the majority of neurological conditions were not covered by a specific indicator. NHS England expects to publish new indicators for 2015-16 in summer 2015. It confirmed there would be no extra indicators dedicated to neurological conditions.

2.22 The Neurological Alliance suggested to us that the lack of indicators specific to neurological conditions may be limiting clinical commissioning groups' engagement with local neurology services. During 2014, the Alliance asked for information from all clinical commissioning groups to understand their level of engagement.²⁰ Of the 191 clinical commissioning groups that responded, 78% confirmed that they commissioned services for people with neurological conditions. However, 54% and 57% respectively said that they had not assessed the prevalence of neurological conditions or the number of people using neurological services in their local area.

Joint strategic needs assessments and joint health and wellbeing strategies

2.23 Health and wellbeing boards, together with local authorities and clinical commissioning groups, have a legal duty to produce joint strategic needs assessments and joint health and wellbeing strategies for their area. These aim to improve the health and wellbeing of their local community and reduce inequality. The Department issued guidance in 2012 stating that joint strategic needs assessments should assess current and future health and social care needs within the health and wellbeing board area and should cover the whole population.²¹

2.24 The Department and NHS England do not hold data on the content of joint strategic needs assessments or joint health and wellbeing strategies as they consider these documents should be determined and used locally. We reviewed 151 joint strategic needs assessments and 150 joint health and wellbeing strategies to find out how far these documents explicitly cover the needs of people with neurological conditions. We found that just over half of joint strategic needs assessments made references to neurology or a neurological condition through either a specific chapter/section or one or more specific sentences. The other joint strategic needs assessments either did not mention neurology or a specific neurological condition or only included it within a list of conditions or within a data table. We also found that only one fifth of joint health and wellbeing strategies referred to neurology or a specific neurological condition, with 25 of these 30 doing so only within a list of conditions or data table.²²

Recommendation 4

Committee's recommendation

Despite people with neurological conditions requiring a wide range of services, health and social services are poorly integrated. Poorly integrated services can result in, for example, increased emergency readmissions to hospital. Less than 5% of overall NHS and social care budgets are spent through joint arrangements such as pooled budgets. **In its Commissioning Outcomes Framework, the Department should mandate joint health and social care commissioning of neurological services, supported by Health and Wellbeing Boards through the Joint Strategic Needs Assessment.**

20 Neurological Alliance, *The Invisible Patient – Revealing the state of neurology services*, January 2015.

21 Department of Health, *Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies*, April 2012.

22 Our review included searching for the term 'neuro' as well as for four specific conditions: epilepsy; motor neurone disease; multiple sclerosis; and Parkinson's disease. Joint strategic needs assessments come in a range of formats. Some are single documents while others are webpages containing a range of documents. In the latter case, we searched documents that we considered might be relevant to people with neurological conditions.

Progress against the recommendation

2.25 In its response to the Committee's report, the Department said it did not agree with the recommendation on mandating joint health and social care commissioning of neurological services. This was because it was not government policy to mandate specific local work. It highlighted that, under the Health and Social Care Act 2012, every clinical commissioning group would have a statutory duty to exercise its functions with a view to ensuring that health services were provided in an integrated way.

2.26 NHS England does not hold information on the extent of joint commissioning of neurological services. It told us that local Better Care Fund plans may include examples of services for people with complex needs being commissioned jointly, but that neurological services were unlikely to feature explicitly in the plans.²³ The Neurological Alliance told us that its members had seen only occasional examples of joint commissioning and that these examples were too few and too recent to draw conclusions about their impact on services. NHS England also told us that some localities are testing new payment and commissioning arrangements to support the integration of health and social care services for people with complex care needs.

Recommendation 5

Committee's recommendation

Individual care is often poorly coordinated, with only 22% of people with Parkinson's disease, multiple sclerosis and motor neurone disease having a personal care plan. Specialist nurses can play an important role in helping people navigate their way through the range of support they need. While the Department cited a figure of 80% of people with all long-term conditions having care plans, this related to a wider range of conditions and only serves to further underline the disparity between the support available to people with neurological conditions and that available to people with other long-term conditions. **The Department should set out in its Commissioning Outcomes Framework that every person with a neurological condition should be offered a personal care plan, covering both health and social care. The evidence suggests that this is best done by a single professional, for example a specialist nurse or care coordinator.**

Progress against the recommendation

2.27 Through its mandate to NHS England, the Department has set an objective for everyone with a long-term condition, including a neurological condition, to be offered a personalised care plan by 2015. NHS England has not, however, reflected this objective in the clinical commissioning group outcomes indicator set. Therefore there is no indicator to encourage local action in this area. NHS England told us that personalised care and support planning is an important area of its work. However, it acknowledged that, while not everyone with a long-term condition would benefit from a personalised care plan or want one, progress in this area has been slow.

²³ The 2013 Spending Review announced the creation of the Better Care Fund. This aims to integrate health and social care more closely to, for example, reduce emergency hospital admissions. In 2015-16, the Fund will comprise at least £3.8 billion of pooled local budgets shared between the NHS and local authorities.

2.28 NHS England does not collect information to assess progress against its objective that everyone with a long-term condition should be offered a care plan and does not have a target date for meeting this objective. The evidence available indicates that there is a significant way to go to meet this objective:

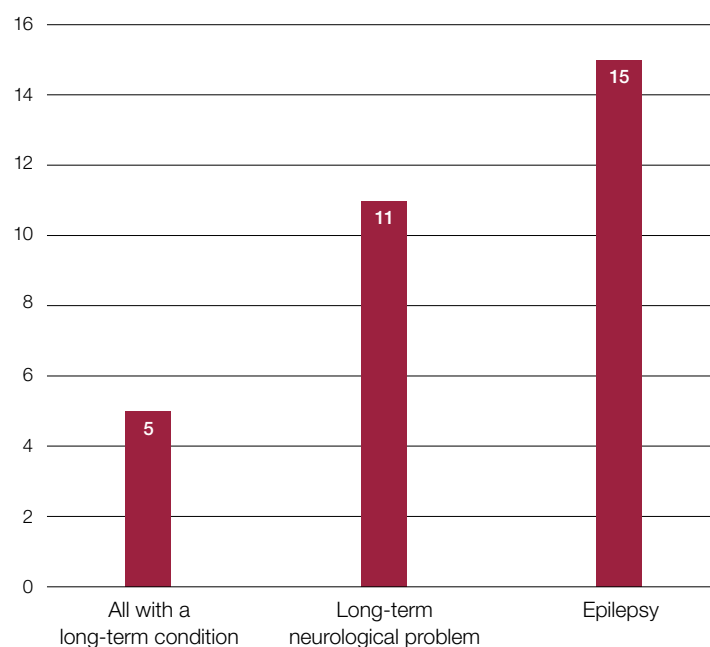
- The GP Patient Survey published in January 2015 found that just 11% of people with a long-term neurological problem reported that they had a written care plan (**Figure 9**). This was, however, a higher proportion than that for the broader group of people with any long-term condition. The proportion had not changed from the GP Patient Survey published in July 2014 when the question about care plans was first included.
- A survey by the Neurological Alliance, published in January 2015, did collect data on the specific question of whether people were offered a care plan. This found that, of the 6,438 respondents with a neurological condition, 20% had been offered a care plan.²⁴ Of the people who had been offered a care plan, 6% refused one.

Figure 9

Use of written care plans, data published in January 2015

Do you have a written care plan?

Percentage of respondents with a written care plan



Notes

- 1 Total number of responses: all with a long-term condition, 449,331; long-term neurological problem, 15,337; epilepsy, 9,284.
- 2 The data for the January 2015 publication were collected during January–March 2014 and July–September 2014.

Source: GP Patient Survey, January 2015

24 Neurological Alliance, *The Invisible Patient – Revealing the state of neurological services*, January 2015.

2.29 Most people who do have a care plan are positive about how it is being used. The GP Patient Survey, reported in January 2015, found that 71% of people with a long-term neurological problem who had a written care plan said it was being used to help manage their health day-to-day.

2.30 In its response to the Committee's report, the Department also noted the valuable contribution made by nurse specialists and highlighted the guidance it had published on *Long Term Neurological Conditions: A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse*. The Department and NHS England do not hold information on the number of specialist neurological nurses and whether this is increasing.

Recommendation 6

Committee's recommendation

The Quality Standards planned by the National Institute for Health and Clinical Excellence (NICE) will not cover all neurological conditions. We welcome the announcement at our hearing that NICE will be developing Quality Standards for Parkinson's disease, multiple sclerosis and motor neurone disease. However, these will not cover other neurological conditions. **In addition to the three Quality Standards announced, the Department should instruct NICE to develop a generic Quality Standard covering other neurological conditions.**

Progress against the recommendation

2.31 In its response to the Committee's report, the Department said it would not be possible to cover every neurological condition with a quality standard. The quality standards are produced by the National Institute of Health and Care Excellence (NICE). They are statements designed to encourage measurable improvements in quality within a particular area of health or social care. The quality standards are derived from evidence such as NICE's own clinical guidelines and other accredited evidence sources. This means clinical guidelines are usually published before quality standards.

2.32 NICE announced in March 2012 that the Department had referred 123 new quality standards to it, of which 5 related directly to neurology. **Figure 10** overleaf sets out progress in publishing both clinical guidelines and quality standards in these 5 areas. NICE has published quality standards for one of the areas and one is in development. A further 2 areas are awaiting publication of updated clinical guidelines. For the remaining quality standard, NICE has recently scheduled the clinical guideline most closely linked to the Committee's recommendation (generic neurological problems) with an estimated publication date of January 2018. NICE told us that the quality standard is likely to be included in its work programme for 2017-18 when the clinical guideline is available.

Figure 10

Progress in publishing quality standards relating to neurological conditions

Topic	Progress on clinical guideline	Progress on quality standard	Comments
Management of transient loss of consciousness in adults	Published in August 2010.	Published in October 2014.	
Motor neurone disease	Published in July 2010. Update in development, due to be published in February 2016.	Scheduled to begin in November 2015, due to be published in summer 2016.	The start of work on this quality standard has been scheduled to overlap with work on the updated clinical guideline currently being developed.
Multiple sclerosis	Published in October 2014.	In development, due to be published in January 2016.	
Neurological problems (relatively uncommon neurological problems, eg muscular dystrophy)	Scheduled with estimated publication date of January 2018.	Not yet scheduled.	Quality standard likely to be included in NICE's work programme for 2017-18 when the clinical guideline is available.
Parkinson's disease	Published in June 2006. Update in development, due to be published in April 2017.	Not yet scheduled.	Quality standard likely to be included in NICE's work programme for 2017-18 when the updated clinical guideline is available.

Note

- 1 The Department's Treasury Minute response noted that the Department had referred 7 neurological-related conditions to NICE for quality standards. NHS England does not consider that delirium and faecal incontinence are neurological conditions and we have therefore reported progress only on the remaining 5 areas.

Source: National Institute of Health and Care Excellence

Appendix One

Our audit approach

Scope

1 In December 2011, we published our report *Services for people with neurological conditions*.²⁵ This was followed by the Committee of Public Accounts hearing and publication of its report in March 2012.²⁶ The Committee's report made 6 recommendations aimed at improving services for people with neurological conditions. The report also requested that we follow up on progress against the recommendations.

2 This review was a short, focused piece of work looking specifically at progress against the recommendations rather than a value-for-money examination. We carried out the review between February and May 2015.

Methods

3 In examining the progress made against the Committee's recommendations we used the following methods:

- Self-assessment questionnaire – for each recommendation we compiled a series of questions to collect evidence on the progress made. We asked the Department of Health and NHS England to complete the questionnaire jointly. We also requested supporting evidence where relevant.
- Interviews – with officials at the Department of Health, NHS England (including the national clinical director for adult neurology) and Public Health England.
- Stakeholder consultation – we sought written responses to a short series of questions from the Association of British Neurologists and the Neurological Alliance. We also interviewed the Association of Directors of Adult Social Services.

25 Comptroller and Auditor General, *Services for people with neurological conditions*, Session 2010–2012, HC 1586, National Audit Office, December 2011.

26 HC Committee of Public Accounts, *Services for people with neurological conditions*, Seventy-second Report of Session 2010–2012, HC 1759, March 2012.

- Document review and analysis – we assessed the:
 - inclusion of neurological conditions in the NHS and adult social care outcomes frameworks;
 - compendium of neurology data; and
 - coverage of neurological conditions in the joint strategic needs assessments and joint health and wellbeing strategies.
- Data analysis – we:
 - replicated some of the analysis from our original report adding additional years to the time series – spending data/inpatient and outpatient attendances/ waiting times/emergency admissions and emergency readmissions;
 - analysed responses from the GP Patient Survey and ran a range of cross-tabulations against the subset of respondents with long-term neurological problems; and
 - analysed surveys/data collections by charities, for example Neurological Alliance, *The Invisible Patients*, January 2015.

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