



National Audit Office

Department of Health

Services for people with
neurological conditions

Methodology

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Methodology

1 This appendix outlines the research methods used in the course of our examination.

Study scope

2 Our report examines the services provided for people with neurological conditions. We examined: the trends in health and social care spending on people with neurological conditions; progress in implementing the National Service Framework for Long-term Conditions (the Framework); and access to, and quality of, current services.

3 We focused on health and social care services for adults with a neurological condition as a result of disease rather than from accident or injury. While we focus on adult services, all health expenditure and hospital admissions data include children's neurological services. Children's services make up a very small proportion of overall activity. Our fieldwork took place between March 2011 and July 2011.

Methodology

4 We used a literature review to help us understand the scope of the work and interpret our analysis. Quantitative evidence from the Department of Health (the Department) and the representative charities was used as the basis of our findings. The focus groups and interviews were subsequently used to highlight the issues raised in our analysis.

5 The main methods used during the course of this study were:

- analysis of existing datasets;
- literature review of key policy documents, major reports and academic literature;
- semi-structured interviews with the Department and key stakeholders; and
- focus groups with stakeholder groups.

Analysis of existing datasets

6 We obtained and evaluated a range of published and unpublished datasets from the Department, NHS Information Centre (NHS IC), charities and Dr Foster intelligence. Our purpose was to understand: expenditure by the NHS on neurological conditions; trends in hospital admissions nationally and variations across Primary Care Trusts; trends in referral to treatment waiting times for neurology; and access to social services by adults with a physical disability (as a proxy for people disabled by neurological conditions).

7 Key datasets obtained and evaluated included:

- Programme Budgeting data on neurological conditions (2003-04 to 2009-10), published by the Department;
- summary inpatient and outpatient Hospital Episode Statistics (HES)¹ (2001-02 to 2009-10), published by the NHS IC;
- personal social service expenditure returns from the National Adult Social Care Intelligence Service (NASIS) (2005-06 to 2009-10), published by the NHS Information Centre; and
- referral to treatment waiting time data for neurology specialities (April 2007 to August 2011), published by the Department.

8 For all health expenditure and hospital admissions data we excluded neurological pain as many of the categories under neurological pain (e.g. back pain) are not directly related to the management of neurological conditions.

Data analysis on NHS neurological expenditure

9 We reviewed the Department's Programme Budgeting data on neurological expenditure. Total spending at national level for neurological conditions was split into expenditure on chronic neurological pain and neurological conditions. The report shows total neurological spending and the split between chronic pain and conditions. The headline figures quoted in the report are, however, for neurological conditions only for the reason explained above. We also analysed Primary Care Trust expenditure on neurological conditions split by primary care (provided by GPs or in community settings) and secondary care (primarily hospital inpatient and outpatient appointments) from Primary Care Trust Programme Budgeting submissions. All data were adjusted to 2009-10 prices using the GDP deflator published by the Treasury.

¹ Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions to NHS hospitals in England. It includes: private patients treated in NHS hospitals; patients who were resident outside of England; and care delivered by treatment centres (including those in the independent sector) funded by the NHS. HES also contains details of all NHS outpatient appointments in England.

10 The Programme Budgeting data are only indicative to demonstrate the trend in changes in NHS expenditure for different disease areas. Continual refinements have been made to the Programme Budgeting data collection methodology since the first collection in 2003-04. The underlying data that supports Programme Budgeting data are subject to yearly changes. Previous NAO and King's Fund reports have also highlighted issues with the Programme Budgeting data in terms of poor data validation, lack of consistency over the years and across Primary Care Trusts. Another issue with Programme Budgeting data is that it systematically underestimates the cost for specific disease areas, as they exclude capital expenditure, social care, GP consultations and any other public health interventions such as screening or vaccination from disease specific expenditures.

Trends in neurological outpatient and inpatient admissions

11 To understand the trends in activity by neurological conditions and by neurology specialties, we analysed summary level HES data for inpatient admissions (2001-02 to 2009-10) and outpatient attendances (2005-06 to 2009-10). For inpatient admissions, we included only those conditions classified as 'neurological conditions' (e.g. Parkinson's disease, epilepsy and motor neurone disease) in the Department's revised Programme Budgeting definitions.² For outpatients, we included the following specialties: Neurology; Neurosurgery; Clinical Neuro-physiology; Paediatric Neurology; Paediatric Neuro-disability; Paediatric Neurosurgery. For the analysis in the trends in inpatient and outpatient admissions for neurological conditions as a whole (Figure 8 in the main report), we have included day cases in the total number of admissions.

Trends in emergency admissions and emergency readmissions

12 To understand the trends in emergency admissions, as important indicators of the quality of hospital and community care, we carried out data analysis with patient level inpatient HES data for three conditions: motor neurone disease (ICD G122), Parkinson's disease (ICD G20X) and multiple sclerosis (ICD G35X). This was done in collaboration with Dr Foster Intelligence. We defined an admission as the entire period from a patient being admitted to their final discharge from hospital. Where a patient was transferred to another hospital, this was not counted as a separate admission. Emergency admissions are defined as any admission with an admission method of one of the following in HES: 21: Emergency – via A&E; 22: Emergency – via GP; 23: Emergency – via Bed Bureau; 24: Emergency – via Out-patient clinic; 28: Emergency - via other means.

13 Emergency readmission is defined as a patient being readmitted through one of the routes defined in paragraph 12 above, either within 7 days or 28 days of the discharge date of a previous spell which could be either an elective or an emergency admission. Those admissions with a recorded discharge destination of death in HES were excluded. We analysed emergency readmissions under two scenarios: including day cases and excluding day cases (in the report, this is referred to as "emergency readmissions following an overnight stay"). If a patient is admitted from A&E but with a recorded zero-length of stay, it will be included in the scenario excluding day cases.

² Department of Health, Programme Budgeting Mappings available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_general/@dh/@en/documents/digitalasset/dh_118575.xls

14 For emergency readmissions as a percentage of the number of discharge spells, the denominator is defined as the discharge spells excluding those with a discharge destination as 'death'; either including or excluding day cases depending on the numerator. NHS IC quality indicators' approach to its calculation of percentage of emergency readmissions is to exclude day cases;³ in Paragraph 2.22 in the main report we have taken this approach. For Figure 11 showing the variations in the percentage of emergency readmissions across Primary Care Trusts in the main report, we have used the scenario with day cases to reflect the variations in patient's profile across Primary Care Trusts.

15 We have included anyone with a diagnosis for the three conditions in the first three diagnostic fields in HES for the analysis of emergency admissions. This approach is informed by a study carried out by the National Cancer Services Analysis Team (NatCanSat). NatCanSat investigated patients recorded with an emergency admission, and concluded that in order to get a real picture of emergency admission patterns for a specific condition, it is inappropriate to include only those patients with the diagnosis in the primary diagnostic field. A large proportion of emergency admissions are for the apparent symptoms rather than the underlying conditions which are often recorded in the secondary or tertiary diagnostic fields. They have suggested, as a rule of thumb, to use the first three diagnostic fields for cancer patients.

16 While it is arbitrary to include only patients defined using the top three diagnostic fields, this approach would have captured most patients with a certain diagnosis. This would also limit the bias by including too many diagnostic fields in the analysis, as the further away a diagnosis is from the primary diagnosis, the more unlikely that diagnosis will be the underlying condition for the admission. Although the analysis by NatCanSat is focused on cancer patients, it is reasonable to assume that this pattern also applies to a wider range of conditions including neurology. For both cancer patients and neurology patients, the majority of inpatient admissions, and in particular for emergency admissions, are admitted to a wide range of specialties rather than oncology or neurology specialties.^{4,5} In addition, most acute neurological emergencies are not routinely seen by a neurologist on admission.⁶ To mitigate the impact of any inherent bias in this approach to data analysis, we have applied the same method to data for all financial years under examination (Para 2.19 to 2.23 in the main report).

3 NHS IC, Indicators for quality improvement: Emergency readmissions to hospital within 28 days of discharge, Available at: <https://mqi.ic.nhs.uk/Search.aspx?query=emergency%25readmission&ref=1.01.17>

4 Gail Pittam, Damian Haywood (2010) *Health Needs Assessment for Long Term Neurological Conditions – A report for Oxfordshire PCT*.

5 Chapman F.A. et al. (2009) *Acute neurological problems: frequency, consultation patterns and the uses of a rapid access neurology clinic*. J R Coll Physicians Edinb 2009; 39: 296-300.

6 David Bateman (2011) *The future of neurology services in the UK*. Practice Neurology 2011; 11: 134-135.

17 For Primary Care Trust level analysis, we aggregated patient level data to Primary Care Trust area for all inpatient admissions, emergency admissions, and emergency readmissions within 7 and 28 days of previous discharge. Primary Care Trust data were presented using a funnel plot, to demonstrate the extent of the variation which is not expected statistically given the national average and the underlying patients profile each Primary Care Trust faces where data are available. The methodology is in line with that developed by the Association of Public Health Observatories.⁷ For the report, we used funnel plots to look at the variation in admission and readmission measures across Primary Care Trusts. For example, in Figure 10 of the report, the funnel plot is a scatter plot of the rate of emergency admissions against the total number of admissions including day cases. You would expect some variation in rates of emergency admissions simply due to chance which has an inverse relationship to the size of their population. The funnel plot shows this expected range of variation; we used a 95 per cent confidence interval for the funnel plot, which narrows as the number of admissions in a Primary Care Trust increases – the resulting ‘funnel’ shape is a general characteristic of such plots. In this way, we can distinguish the variation across Primary Care Trusts that you would expect due to chance based on known data (points lying within the funnel). Where there is variation that is not explained by these random effects (i.e. many points lying outside the funnel) including the effect of their size on rates calculated, this may be due to underlying differences in their service provision or because other factors (e.g. the area or patient profile) are influencing the measure. It says nothing about whether or not any given trust falling within the funnel is operating efficiently or inefficiently given dispersion is conditional on the national, or mean for all trusts; as the national mean changes (up or down), so does the ‘funnel’.

18 Our initial examination of emergency readmission data showed wide variation across Primary Care Trusts, but we suspected that this was partly due to differences in the area and patient profiles of each trust. We controlled for such factors which are generally outside the control of Primary Care Trusts to gain a better understanding of the variations in emergency readmissions. To do this, we carried out logistic regression with patient level data. For each patient discharged, we used the regression model to calculate an expected level of emergency readmissions based on factors such as the patient’s age, gender, deprivation and ethnicity. These were then aggregated to Primary Care Trust level, to obtain an expected number of readmissions for each trust. For each Primary Care Trust, we calculated the standardised rate of emergency readmission by first dividing the total actual number of readmissions by the total expected number of readmissions; the resultant ratio is then multiplied by the national average rate of readmissions to obtain an adjusted rate of readmissions for a trust. This standardised rate of readmission (including day cases) is then used for the funnel plot in Figure 11 of the report. By contrast, for Figure 10, we have not been able to standardise the data due to a lack of robust information on prevalence and patient profiles.

7 Analytical tools for public health: Funnel plot for proportions and percentages available at: <http://www.apho.org.uk/resource/item.aspx?RID=47241>

19 We examined the trend in emergency admissions and readmissions nationally between 2004-05 and 2009-10 for the three conditions. Some of the emergency admissions are emergency readmissions. For those readmissions following an overnight stay (i.e. not following a day case discharge) in 2004-05, emergency readmissions (28 days) represented 15 per cent of total emergency admissions. By 2009-10, this has risen to 17 per cent. Total emergency admissions increased by 7,590 between 2004-05 and 2009-10, of which emergency readmissions rose by 2,256, accounting for 30 per cent of the increase in total emergency admissions over that period. For this trend analysis, we have assumed a constant patient profile over the five years nationally and the figures quoted in the main report (Paragraph 2.19, and 2.22) are not standardised in the same way as the analysis for variations across Primary Care Trusts in Figure 11.

20 The Department recognises the importance of driving down emergency admissions and readmissions (overall emergency readmissions increased by 50 per cent between 1998-99 to 2007-08). 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). 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. Some emergency readmissions are excluded from this tariff penalty, including: cancer patients, chemotherapy and radiotherapy, children under the age of four, mental health and maternity admissions.

21 It is estimated that total penalties associated with 30-day emergency readmissions could potentially cost NHS trusts £584 million in lost income (an average of £4 million per trust) and 3 per cent of the total Payment by Result tariff.⁸

Adult social services for people with a physical disability

22 We obtained data on adult social services from the National Adult Social Care Intelligence Service (NASIS). The data were extracted separately for adults aged 18 to 64 and aged 65 and above.

23 The expenditure for those aged 18 to 64 are the reported expenditure for people with a physical disability. For people age 65 and above, the expenditure is proportioned based on the number of service users with a physical disability out of the total number of service users for the age group. All expenditure was adjusted to 2009-10 prices using the GDP deflator published by the Treasury.

Literature review

24 We commissioned PricewaterhouseCoopers (PWC) to undertake a literature review of key documents. The review covered relevant literature since January 2006 including: medical/social policy journals; Department of Health published literature; and charitable sector published literature. It also included 'grey' literature from the Department of Health and the charitable sector which was sourced by the NAO. In total 146 documents were reviewed (see annex for full bibliography).

⁸ Sg2 Service Kit (2011) Reducing emergency readmissions. Available at: http://www.hsj.co.uk/Journals/2/Files/2011/6/15/Sg2_Service%20Kit_Reducing%2030-Day%20Readmissions.pdf

25 The study questions provided a basis for identifying relevant categories and key words which were used to carry out searches to help identify all relevant literature. The key words were used to carry out general online searches, including relevant websites, such as the Department of Health and charities. In addition, PWC undertook keyword searches for academic articles using the following online libraries:

- UK Pub Med Central at: <http://ukpmc.ac.uk/>
- NHS Evidence – neurological conditions at: <http://www.library.nhs.uk/neurological>
- NHS Evidence at: <http://www.library.nhs.uk>
- NHS Research programme at: www.ltn.org.uk

26 The literature was categorised according to publication type (e.g. author and organisation) and its relevance to the key study questions. **Figure 1** provides a breakdown of the documents by document type and by publishing organisation. To ensure that more robust literature was given more weight, the document's quality was assessed using the following criteria with 82 per cent rated as either excellent or good:

- Are the aims of the document clearly understood?
- Is the methodology robust?
- Are the findings evidence based?
- Is there a clear link between aims, methods and findings?

27 An evidence matrix, covering the study questions, was used to organise the evidence from the review. This was used in conjunction with our evidence from the data analysis, interviews and focus groups, which was also entered into the evidence matrix, to answer the study questions. Some specific reports were selected, due to their significant quantitative content, to support specific areas of the report (see Figure 14 in the main report).

Figure 1
Types of documents reviewed

Type of document	(%)	Published by	(%)
Policy	18	Government / Public sector	50
Research	37	Charitable sector	12
Review	21	Academic	21
Best practice	12	Other independent	27
Other	21	Other	2

NOTE

1 Some documents fell into more than one category so percentages do not add to 100.

Semi-structured interviews with the Department of Health and key stakeholders

28 We conducted semi-structured interviews with the Department and key stakeholders to gain an in-depth understanding of: the implementation of the National Service Framework for Long-term Conditions; the range, quality and access to current services; and risks to services under the new health and social care landscape. The key stakeholders we interviewed included: people with motor neurone disease; long-term condition leads at Strategic Health Authorities; representatives from a number of adult social services departments; GPs; representatives from charitable organisations; and neurologists. Key information from our interviews was entered into our evidence matrix.

Focus groups with stakeholder groups

29 We held eight focus groups with different stakeholder groups. We were assisted in the recruitment by a number of organisations in **Figure 2**. Topic guides were developed covering the key study questions and sent to participants in advance. Groups lasted for around two hours. Each focus group and most interviews were recorded and transcribed prior to analysis with the consent of the participants.

30 Using the transcriptions, each focus group was summarised and these summaries were used to enter information into the evidence matrix. In this way, the focus groups were used alongside evidence from our interviews and literature to answer the study questions. Specific information from the focus groups on patient's experience of current services was used to highlight the key issues set out in Part Three of the final report.

Figure 2
Overview of focus groups

Stakeholder group	Number of participants	Assistance with recruitment
People with Parkinson's disease	7	Parkinson's UK
People with multiple sclerosis	8	Multiple Sclerosis Society
Carers of people with Parkinson's disease, multiple sclerosis and motor neurone disease	5	Parkinson's UK, Multiple Sclerosis Society and Motor Neurone Disease Association
Specialist neurological nurses	6	Neurological Commissioning Support
Neurologists	9	Association of British Neurologists
Representatives from Primary Care Trusts	3	NHS Confederation
Representatives from Parkinson's UK, Multiple Sclerosis Society and Motor Neurone Disease Association	9	Parkinson's UK, Multiple Sclerosis Society and Motor Neurone Disease Association
Representatives from other charities	7	Neurological Alliance

Literature review bibliography

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