

## **Issues affecting neurology services**

### **Neurological Alliance briefing April 2016**

#### **Background**

Neurological conditions are disorders of the brain, spinal cord or nerves. They can have a range of causes including genetic factors, traumatic injury, and infection. The causes of some neurological conditions are still not well understood.

There is a large number of diverse neurological conditions. Some are very common, such as dementia, stroke, epilepsy, and migraine, while some are comparatively rare such as multiple system atrophy and progressive supranuclear palsy. In between is a wide range of conditions such as Parkinson's disease, multiple sclerosis, and traumatic brain injury. The total number of neurological cases in England has now reached 12.5 million, or 59,000 cases per CCG.<sup>i</sup>

#### **General stats**

- The number of neurological cases in England reached approximately 12.5 million in 2013-4.
- 1,358,187 people were admitted to hospital with a neurology mention in 2013/14 hospital admissions were recorded for people with a neurological diagnosis in 2012/13 – representing an increase of more than 500,000 over a six year period.
- There were 1,466,583 emergency hospital admissions with a mention of neurology in 2013-14.
- NHS expenditure on neurological conditions alone amounted to £4.4 billion in 2012/13, which represents an expenditure increase of 200% since 2003.
- The total programme budget spend for 2013-14 is £3.0bn although this does not include specialised services.<sup>ii</sup>
- In addition, social care expenditure on care services for people with a neurological condition amounted to approximately £2.4 billion in 2013, or just under 14% of adult social care spend.<sup>iii</sup>

#### **Public perceptions**

A recent survey report by Sue Ryder found that:<sup>iv</sup>

- 45% of the UK public feared getting a neurological disorder the most, compared with 36% who feared getting cancer
- 62% felt that the general public can be scared or embarrassed to talk to people with neurological problems in public
- 1 in 13 people have witnessed people with neurological conditions being teased or bullied in public
- 26% of the public thought that 'nothing much can be done' for people with neurological disorders

#### **Key messages**

Neurology has never been a priority for the NHS (as Sir David Nicholson told the Public Accounts Committee (PAC) in 2012).<sup>v</sup> This may be due to its perceived rarity although there are over 12 million cases of neurological conditions including headache. We can see the impact of this lack of focus in:

- Poor patient experience and outcomes.
- Highly variable service availability.
- Shortage of specialist medical staff.
- Disengagement of local commissioners.
- Lack of incentives or strategic objectives within NHS systems.
- Need to keep key developments of last few years.

Most of all, we need NHS England to recognise that neurology is a problem area and formally prioritise it for improvement.

## **Key issues**

### **What patients want**

- Equitable access to appropriate specialist expertise.
- Timely access to a diagnosis and appropriate treatment, support and information.
- An agreed care plan led by the patient and a named care coordinator.
- A coordinated pathway of care across all services and settings.
- Multidisciplinary, integrated approach addressing the totality of the individual's needs.
- Ongoing research into improved understanding and new treatments and therapies.

### **Patient experience is poor**

- 58% of respondents have experienced problems in accessing the services or treatment that they need.
- 40% of respondents waited more than 12 months from when they first noticed their symptoms to see a neurological specialist.
- 31% of respondents had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist.
- Only 29% have been offered a care plan.<sup>vi</sup>

From a survey of 1,001 GPs taken in November:

- 86 per cent of GPs are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to seeing a consultant neurologist.
- 61 per cent feel that the local services and systems in place mean that people with neurological conditions frequently do not receive a timely diagnosis.
- 85 per cent feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.<sup>vii</sup>

In addition, the 2013-14 NHS England survey of patients of GP practices found that people with long-term neurological conditions have the lowest health-related quality of life (based on EQ5D scores) of any long-term condition.<sup>viii</sup>

### **Postcode lottery in service access**

- There are clear regional disparities in the availability of local appointments, which are relatively well provided in the South, East, and West Midlands regions of England, but are almost entirely unavailable across the East Midlands and North West regions.
- Local rates of new consultant adult neurology outpatient appointments vary hugely by CCG area, from 2,531 per 100,000 resident population in Camden to as low as 165 per 100,000 population in Doncaster.
- In total, there are 89 CCGs (42%) in which the number of new consultant adult neurology outpatient appointments is 'significantly below' the national average of 913 per 100,000 population.
- 45 CCGs (22%) offer no local consultant neurology services whatsoever.
- The likelihood of a patient with a neurological problem being seen by a neurologist varies dramatically depending on where they are admitted. Hospitals in the top quartile provide daily review on 89% of days, while in the bottom quartile this service is only available on 17% of days.<sup>ix</sup>

### **Shortage of specialist medical staff**

- By 2006 the number of UK neurology consultants had risen from one full-time equivalent (FTE) per 200,000 population in 1996 to one per 115,000. However, this still remains less than a third of the European average.<sup>x</sup>
- Specialist nurses are often working with unrealistically high and unsustainable caseloads. A recent MS Trust report identified a sustainable caseload of 358 people with MS per WTE nurse and found there is a shortfall of 62 MS nurse specialists, and an inequitable pattern of provision across the UK. They estimate conservatively that each MS nurse saves the NHS £77,400 per year in emergency admissions.<sup>xi</sup>

### **Commissioners are disengaged from neurology services**

- Only 14.7% of CCGs have assessed local costs relating to the provision of neurology services.
- Only 26.2% have assessed the prevalence of neurological conditions within their area.
- Only 20.4% of CCGs have made an assessment of the number of people using neurology services locally.<sup>xii</sup>
- Compounded by ongoing confusion over the division of responsibility between specialised and non-specialised commissioners, which NHS England has still not addressed.

### **Very few incentives and levers relating to neurology**

- In 2012, the PAC called on the government to use levers such as the CCG Outcomes Indicator Set (CCGOIS) and local Joint Strategic Needs Assessments to improve access to neurology services across the country.<sup>xiii</sup> However, the National Audit Office's progress review found almost no progress in this area:<sup>xiv</sup>
  - Only three neurological conditions are referred to in the 2015-16 NHS Outcomes Framework, by which the Department of Health holds NHS England to account (these are stroke, dementia, and epilepsy in under-19s).
  - Only three neurological conditions are referred to within the CCGOIS stroke, dementia, and epilepsy in under-19s).
  - Only one neurological condition is mentioned in the Adult Social Care Outcomes Framework in a placeholder indicator (dementia).

- In addition, there is no national strategy for neurology, nor is it mentioned at all in NHS England's Mandate.

### **Transition to new commissioning environment**

- Lack of clear division of responsibilities between CCGs and specialised commissioners
- Lack of focus and prioritisation within NHS England.
- Neurology wrapped up in the long-term conditions agenda which means it is competing for attention with the biggest spend areas and most prevalent conditions such as diabetes.
- Ongoing clinical reference group restructuring has created further uncertainty in this area.

### **Reduction in clinical leadership and advice**

- NHS England has ended the role of National Clinical Director (NCD) for adult neurology from April 2016, and ended national funding for neurology clinical networks. The positions of NCD for spinal disorders and trauma have also been discontinued.
- This leaves a clear gap around clinical leadership and advice. Future arrangements to provide clinical expertise is still unclear
- Indicative of low prioritisation within NHS England
- Clear commitments needed to assure clear source of clinical leadership and advice in future

### **Recommendations**

- NHS England must retain and develop clinical leadership for neurology at the national and regional level.
- NHS England should work with stakeholders including patient representative organisations to develop and implement an agreed strategy for securing improvement in neurology services.
- The Secretary of State for Health should ask the Care Quality Commission to carry out a themed review of neurology services.
- NHS England should urgently revise the Neurosciences Service Specification to ensure clarity of commissioning responsibilities.
- NHS England should actively engage with CCGs to ensure that they understand their commissioning responsibilities relating to neurological conditions and hold them to account on this basis.
- NHS England and the Department of Health should work with the Neurology Intelligence Network (NIN) and the voluntary sector to develop robust and measurable indicators for inclusion in key incentive and accountability mechanisms within the NHS such as the NHS Outcomes Framework and CCGOIS.
- The Department of Health and Public Health England should jointly commit to funding a regularly updated central data resource for neurology services, including linked health and social care data and data on emergency readmissions, with analytical capacity provided through the NIN.
- The National Audit Office should undertake a progress review within three years of the PAC's review to monitor progress in improving the quality and efficiency of neurology services.

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<sup>i</sup> <http://www.neural.org.uk/store/assets/files/381/original/Final - Neuro Numbers 30 April 2014 .pdf>

<sup>ii</sup> 2013-14 NHS programme budget data

<sup>iii</sup> <http://www.neural.org.uk/store/assets/files/381/original/Final - Neuro Numbers 30 April 2014 .pdf>

<sup>iv</sup> <http://www.sueryder.org/media->

[centre/news/2016/june/public%20fear%20getting%20a%20neurological%20disorder](http://www.sueryder.org/media-centre/news/2016/june/public%20fear%20getting%20a%20neurological%20disorder)

<sup>v</sup> <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/services-to-people-with-neurological-conditions-progress-review-15-16/>

<sup>vi</sup> <http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

<sup>vii</sup> Forthcoming Neurological Alliance survey data

<sup>viii</sup> Internal exploratory analysis carried out by NHS England's Analytical Services Team, using the 2013-14 GP Patient Survey. Source data not available

<sup>ix</sup> <http://www.neural.org.uk/updates/253-First->

[ever%20data%20on%20neurology%20appointments%20shows%20significant%20variation%20in%20access%20to%20services](http://www.neural.org.uk/updates/253-First-ever%20data%20on%20neurology%20appointments%20shows%20significant%20variation%20in%20access%20to%20services)

<sup>x</sup>

<https://www.mstrust.org.uk/sites/default/files/files/Local%20adult%20neurology%20services%20for%20the%20next%20decade.pdf>

<sup>xi</sup> <https://www.mstrust.org.uk/news/views-and-comments/putting-ms-specialists-heart-ms-care>

<sup>xii</sup> <http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

<sup>xiii</sup> <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/services-to-people-with-neurological-conditions-progress-review-15-16/>

<sup>xiv</sup> <https://www.nao.org.uk/report/services-for-people-with-neurological-conditions-progress-review/>