

## Neurological Alliance briefing August 2016

### Introduction to neurology issues

#### About the Neurological Alliance

The Neurological Alliance is the only collective voice for 80 organisations working together to make life better for millions of people in England with a neurological condition. We work with our member organisations to campaign nationally and locally to ensure better services and outcomes for all those with a neurological condition. For more information, please see [www.neural.org.uk](http://www.neural.org.uk).

#### About neurological conditions

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

#### Neurology in the NHS

Neurological conditions cause a significant amount of NHS activity and spend.

- 1,358,187 people were admitted to hospital with a neurology mention in 2013/14
- 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 was £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>

#### The neurological patient experience

Patient survey data produced by the Neurological Alliance shows that people living with neurological conditions face a wide range of issues. Frequently, neurology patients experience long waits to access the specialist services and support that they require. A survey of 7,000 patients across England found that:

- 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>iv</sup>

These findings are reinforced by a poll of 1,001 GPs carried out in 2015, which found that:

- 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 their area mean that people with neurological conditions frequently do not receive a timely diagnosis.

Additional survey data collected by Sue Ryder revealed worrying levels of stigma around neurological conditions:<sup>v</sup>

- 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
- 45% of the UK public feared getting a neurological disorder the most, compared with 36% who feared getting cancer

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>vi</sup>

## Key service issues

Too often, the neurological patient experience within the NHS is characterised by:

- 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.

## 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>vii</sup>

## Commissioner disengagement

A 2014 Freedom of Information audit of clinical commissioning groups clearly shows that the majority are largely disengaged from neurology services and are in no position to deliver improved pathways of care:

- 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>viii</sup>

Specialised commissioned services for neurology have been subject to confusion arising from inconsistent statements in the current Manual for Prescribed Specialised Services and the Adult Neurosciences Service Specification. The latter in particular can be (and has been) misinterpreted by CCGs to mean that they have no neurological commissioning responsibilities. This has led to situations where neither CCGs nor NHS England are willing to take responsibility for commissioning certain services, allowing people in need of treatment and support to fall through the gaps

The lack of local commissioning engagement with neurology has led to a shortage of local services and the development of two-tier acute provision, where emergency care from a neurologist is available only to those living near specialised centres. This is reflected in the Association of British Neurologists' survey of acute neurology, which found that "the availability of a neurology review varies according to the type of hospital. There was significantly better access [to a review by a specialist neurologist] at neuroscience centres (91%) and neurology centres (80%), than at those district general hospitals with neurologists based at them (58%). In contrast, access for patients at district general hospitals with no resident neurologists was only available on 32% of days."

## 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>ix</sup> However, the National Audit Office's 2015 progress review found almost no progress in this area:<sup>x</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.

### 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

### Shortage of data to measure the effectiveness of services for people with neurological conditions

- We welcomed the development of a neurology dataset by the Health and Social Care Information Centre (HSCIC) with funding provided by NHS England (published as the *Compendium of Neurology Data, England - 2012-13*) and the creation of a Neurology Intelligence Network (NIN) by Public Health England (PHE) in 2014. However, the HSCIC's Compendium is a one-off collection of data from 2012-13, and there are currently no plans or funding in place to refresh it in future, or to introduce an ongoing, up to date compilation of neurological data.
- There is not yet a commitment from Public Health England to continue supporting the Neurology Intelligence Network in future. Such a commitment would enable the development of longer-term plans and strategies for improving access to and understanding of neurological data.
- There is still insufficient data on the incidence, mortality and survival rates, and prevalence of neurological conditions, and only 20.4% of clinical commissioning groups (CCGs) have assessed the number of people using neurological services (according to a recent [Freedom of Information audit](#) by the Neurological Alliance).
- Neurological outpatient care is in the majority of cases not coded in anywhere near the same level of detail as inpatient care. The development and roll out of routine outpatient coding in neurology is required to produce accurate data from across the whole patient pathway.
- Neurology would benefit from a regular patient experience survey supported and disseminated by Quality Health, NHS Improving Quality and NHS England (as the cancer experience survey is). There would be enormous value if these findings were incorporated into the work of PHE's NIN, Healthwatch England and the Department of Health.

## 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.

## 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.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

<sup>v</sup> <http://www.sueryder.org/media-centre/news/2016/june/public%20fear%20getting%20a%20neurological%20disorder>

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

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