

Subject

Briefing note for the debate asking "Her Majesty's Government what progress they have made in improving neurological services in England".

- Debate date: 31 January 2017
- Date of briefing note: 26 January 2017
- **About the Neurological Alliance:** 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

Issue

There have been significant changes within the NHS structure for adult neurological care in England. More specifically, there was serious concern last year when the National Clinical Director position was cut. A new leadership structure, the National Neurological Advisory Group - or NNAG - is now in place ([see below](#) for more information). This is a very welcome development but with neurology barely visible within NHS priorities, an undertaking of support for the NNAG and for front-line and specialist healthcare professionals supporting those with neurological conditions is urgently needed.

Background and introduction to neurology issues

- **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 of these conditions are still not well understood.

There are a large number of neurological conditions, some very common - dementia, stroke, epilepsy, migraine - and 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 Clinical Commissioning Group.¹

- **Neurology in the NHS**

Neurological conditions cause a significant and concerning amount of NHS activity and spend. Among the headline figures:

- 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
- Social care expenditure on care services for people with a neurological condition amounted to approximately £2.4 billion in 2013 - nearly 14% of adult social care spendⁱⁱ

- **The neurological patient experience**

Patient survey data collected by the Neurological Alliance in 2016 (due for publication in March 2017) shows that people living with neurological conditions face a wide range of issues. The survey data, with more than 7,000 responses, has three headlines:

- Significant delays in diagnosis
- A lack of patient involvement in care planning and decision making

- High prevalence of mental health issues among patients with neurological conditions coupled with poor patient experience of accessing mental health support

To illustrate the diagnosis delay issue:

- Over 42% of patients saw their GP five times or more before seeing a neurological specialist (compares to 31.5% in 2014)
- Almost 20% of patients waited more than 12 months to see a neurological specialist after first seeing a GP
- After seeing a specialist, 22% waited more than 6 months for a diagnosis

- **What patients want**

These are the four key outcomes identified as priorities by people living with a neurological condition or disability, drawn from survey data from 2014ⁱⁱⁱ and meetings with patient organisations and health care professionals:

- "I received a timely and accurate diagnosis and was given the support I needed throughout the process"
- "I feel informed about my treatment and care which is simple to arrange and enables me to live life as I choose"
- "My treatment and care is excellent"
- "I see scientific innovations benefitting me and my family"

Considerations

- **Commissioner disengagement**

A 2016 Freedom of Information audit of Clinical Commissioning Groups (CCGs) clearly shows that the majority are largely disengaged from neurology services and in no position to deliver improved pathways of care. It must also be noted that the situation has deteriorated since the same data was collected in 2014^v:

- Only 13.9% of CCGs have assessed local costs relating to the provision of neurology services
- Only 19.1% have assessed the prevalence of neurological conditions within their area
- Only 20.1% of CCGs have made an assessment of the number of people using neurology services locally

Specialised commissioned services for neurology have been subject to unacceptable confusion arising from inconsistent statements in the current Manual for Prescribed Specialised Services and the Adult Neurosciences Service Specification. The latter in particular has been misinterpreted by CCGs to mean that they have no neurological commissioning responsibilities, leading to situations where neither CCGs nor NHS England are willing to take responsibility for commissioning certain services, allowing people in need to go without treatment and support.

NHS England has now committed to up-dating the Adult Neurosciences Service Specification. It is critical that this happens, and the opportunity to ensure people no longer fall through the gaps is seized.

- **Clinical leadership and advice**

- NHS England ended the role of National Clinical Director for adult neurology from April 2016 and ended national funding for neurology clinical networks. The positions of NCD for spinal disorders and trauma were also discontinued. This reflects the low priority given to neurology by NHS England in the past.

- The Neurological Alliance worked with NHS England to put forward an alternative leadership structure, which is now in place as the National Neurological Advisory Group (NNAG) for NHS England.
- The NNAG brings together a range of stakeholders including the Neurological Alliance, the Association of British Neurologists, the Society of British Neurosurgeons, Professor Adrian Williams (chair of the Neurosciences Clinical Reference Group) and a secretariat provided by NHS England.
- **It is essential that this new group is listened to** and that its expertise feeds into key decisions affecting people with neurological conditions.

- **Data**

The Neurological Alliance has worked hard to improve the understanding of neurological patients' services and outcomes, by working with Public Health England's Neurology Intelligence Network, by recently working with RightCare, and through its own data gathering exercises.

For example, the Alliance is planning, with the Neurology Intelligence Network, to examine the prevalence of neurological conditions to provide - for the first time - definitive data to commissioners, patient groups and other stakeholders. The Neurological Alliance is also working with Public Health England to analyse the 2016 patient survey results at a local level, breaking them down to local CCG areas.

With the right data and intelligence, the NHS has the opportunity to significantly improve outcomes for people with neurological conditions. Developing comprehensive data capture and analysis across the spectrum of these conditions will not be a short term project; it will need multi-agency commitment and hard work. But this is the only option; the NHS cannot afford the consequences of anything less than this and the Neurological Alliance cannot accept anything less on behalf of the millions of people living with neurological conditions.

It is critical that this work is supported and allowed to continue over the longer-term to provide an evidence base and enable the neurological community to measure improvement and highlight variations.

Recommendations

- The establishment of the National Neurological Advisory Group (NNAG) is welcome but NHS England must support and draw advice from the leadership now available for neurology at the national level.
- The Alliance would like to see the NNAG lead a national plan for neurology as part of its remit.
- NHS England must reconfirm their commitment to the urgent revision of the Neurosciences Service Specification to ensure clarity of commissioning responsibilities. This has been planned for 2017 and must be a priority.
- NHS England should actively engage with CCGs to ensure that they understand their commissioning responsibilities relating to neurological conditions.
- 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. In doing so, this would support a long-term commitment to the NIN and the valuable data it generates.

- The National Audit Office should undertake a progress review within three years of the Public Accounts Committee's review to monitor progress in improving the quality and efficiency of neurology services.

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

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

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

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