Neurological Alliance briefing on National Clinical Director and Clinical Networks for neurology
March 2016

This briefing was developed by the Neurological Alliance, which represents over 80 organisations working on behalf of the millions of people living with a neurological condition, following NHS England's decision to cut the role of National Clinical Director (NCD) for Adult Neurology from March 2016, and to remove national funding for neurology workstreams in regional clinical networks (CNs). It explains what the NCD and CNs have achieved since the role was established in 2013, and why NHS England's decision constitutes a major setback for neurology services.

If you would like more information, please contact the Neurological Alliance at alex.massey@neural.org.uk.

Background on the NCD/CNs
In 2012, the Neurological Alliance and its members welcomed the announcements by NHS England (then the NHS Commissioning Board) that it would create the post of NCD for Adult Neurology, and would fund regional clinical networks covering neurological conditions, dementia and mental health. These steps fulfilled recommendations made by the Public Accounts Committee (PAC) in its 2012 review of neurology services.

The announcements were seen as a long-overdue signal that neurology services would begin to receive a comparable degree of focus and prioritisation as other condition areas. As the former NHS England CEO Sir David Nicholson told the PAC in 2012, neurology services (excluding dementia and stroke) have never been a priority for the NHS. Neurology is not mentioned in any key strategy documents, such as NHS England's Mandate or the Five Year Forward View. It also has minimal representation in any of the incentive and accountability mechanisms, such as the NHS Outcomes Framework or the CCG Outcomes Indicator Set. Prior to the creation of the NCD role, there was no strategic or clinical leadership for neurology services within NHS England.

As a result, neurology has largely been ignored by commissioners and has continued to lag behind other condition groups in service quality, availability and access. A 2014 Freedom of Information audit sent to every CCG found extremely high levels of disengagement from neurology: only 15% of CCGs have assessed local costs relating to the provision of neurology services, while only 20% of CCGs respectively are aware of the number of people using neurological services within their area.[i] Consequently they are in no position to improve quality and access to neurology services, and patients frequently wait months for a diagnosis or to access the right specialist care. The latest NHS England GP patient survey that patients with long-term neurological problems report both some of the worst states of pain and some of the highest levels of anxiety or depression, with the lowest health outcome scores of any long-term conditions.[ii]

In the short time since Dr David Bateman's appointment as NCD in the summer of 2013, he has begun to address these longstanding issues by spearheading national and regional improvement initiatives, and leading the development of publicly available data and intelligence sources for neurology at national level. In addition, regional clinical networks have proven to be a key source of clinical advice and expertise at the regional level, producing a range of advice and guidance for commissioners and providers, and acting as a

link between patient representatives and CCGs. The clinical networks also led the development of an ongoing NHS England project to scope out community care models for long-term neurological conditions.

Despite these achievements NHS England indicated to the Public Accounts Committee in December 2015 that the NCD role may not be continued beyond March 2016. This decision was confirmed in January 2016. In February 2016, we saw internal briefings confirming that national funding for neurology activity in clinical networks would also cease after March 2016.

To cut these roles after less than three years, just as they were beginning to lead to real progress, would be a huge step back for neurology services. Furthermore, it would reinforce and underline the perception that neurology is simply not a priority for NHS England, leading to even greater disengagement by local commissioners and other key decision-makers. The PAC's progress review of neurology services, published February 2016, recommended that the NCD role be retained.

What has the NCD achieved?

Since his appointment in 2013, Dr Bateman has worked to champion the cause of better care for the millions of people with neurological conditions in England.

- The NCD has been instrumental in the development of the first nationally available data for neurology, through the Health and Social Care Information Centre's compendium of neurology data and the analysis produced by the Public Health England's Neurology Intelligence Network (NIN), both launched in 2014.
- His expertise enabled the development of a category of neurology activity codes, which then allowed the development of the first ever national dataset for neurology services. It is now possible for the first time to compare local CCGs using key outcome and activity measures for neurology services.
- The NCD played a key role ensuring that each of NHS England's SCNs had a clear and defined neurology work programme supported with clinical neurological input.
- As Co-Chair of NHS England's Neurosciences CRG, Dr Bateman has helped develop new specialised commissioning policies and has pushed for clarification of arrangements for commissioning specialised neurology services
- He has also suggested new neurology indicators, drawn from NIN data, for potential inclusion in the NHS Outcomes Framework and the Atlas of Variation, which would help to address neurology's under-representation in NHS incentive and accountability frameworks.

What have clinical networks achieved?

CNs have supported the drive for much-needed neurological service improvement in a number of ways, including:

- Connecting commissioners, clinicians and providers to consider issues of integration and work towards the development of coordinated pathways of care
- Working with a range of stakeholders, including patient representatives, to develop new minimum service standards for neurology, in order to support commissioners and providers to secure service improvement

- Encouraging increased focus on neurological service improvement at all levels, including working with the National Clinical Director for neurological conditions at the national level and with local stakeholders including commissioners.
- The CNs developed four key national initiatives, which included:
    - developing neurology improvement programme standards to audit provision of local CCGs' care for acute neurological emergencies and scheduled care;
    - developing plans for improving management of seizures and acute headache in the local emergency departments;
    - modernising the scheduled care referral process for headache;
    - developing plans for a community care service for patients with long-term neurological conditions (supporting an NHS England project to develop a commissioning toolkit for CCGs for this purpose).

Why is it important to retain these functions beyond March 2016?

Neurology services still lag well behind other condition areas in terms of service quality, access and outcomes. Despite accounting for a large amount of hospital activity and NHS budget, neurology services are not prioritised for improvement. NHS programme budget spending on neurology services was £3 billion in 2013/14, 3.1% of the entire programme budget for England, with an additional £1.1 billion of spend on specialised neuroscience services and neurosurgery (around 8% of the specialised commissioning budget). Neurology also accounts for a significant amount of hospital activity, with 3,083,351 hospital admissions relating to neurology in 2013/14, and 827,242 emergency admissions. 5,203,889 hospital bed days were needed for people with a neurological condition in 2013/14.[iii]

There is a major postcode lottery when accessing services, with some parts of the country offering no access at all to consultant neurologists, specialist nurses, and other forms of specialist neurological support. 45 local CCG areas (22%) offer no local consultant neurology services whatsoever, meaning people who live in those areas will have to travel further away to be seen by a specialist and receive a diagnosis.[iv] As a result, access to diagnosis and treatment is often poor. A recent survey of almost 7,000 patients found that 39.8% of respondents waited more than 12 months from when they first noticed their symptoms to see a neurological specialist, while 58.1% of respondents have experienced problems in accessing the services or treatment that they need.[v]

Cutting the NCD and the CNs would endanger all the progress made in the past two and a half years and derail the improvement initiatives that the NCD and CNs have led and coordinated in that time. Moreover, it would reinforce the view of patients that NHS England is simply not willing to focus on neurology as an area requiring improvement, despite the fact that many neurology patients currently receive an unacceptably low standard of care.

---

[i] *The Invisible Patients: Revealing the state of neurology services*, Neurological Alliance 2015 http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report

[ii] Internal exploratory analysis carried out by NHS England's Analytical Services Team, using the 2013-14 GP Patient Survey. Source data not available

[iii] https://www.england.nhs.uk/resources/resources-for-ccgs/prog-budgeting/

[iv] http://www.yhpho.org.uk/default.aspx?RID=213049

[v] *The Invisible Patients: Revealing the state of neurology services*, Neurological Alliance 2015 http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report