Summary briefing: National Audit Office review of progress in neurology since 2012

Neurological Alliance, September 2015

This briefing summarises the National Audit Office (NAO)’s recent review\(^1\) of services for people with neurological conditions, which assessed progress against the recommendations made by the Public Accounts Committee (PAC) in 2012.

We have included a short set of headline recommendations which would begin to address the failings identified by the NAO. A full list of the PAC’s recommendations and the NAO’s progress assessments is copied at the end of this briefing.

Background

The PAC’s 2012 report\(^2\) found that neurological services delivered “poor outcomes for people with neurological conditions and poor value for money for the NHS.” Three years later, the NAO has concluded that a number of the report’s key recommendations remain unachieved, and that “considerable further work” is needed to achieve them.

As a result, services for people with neurological conditions continue to be affected by significant quality and access issues that would be unacceptable in higher-profile condition areas. This is outlined in the recent Neurological Alliance report, Invisible Patients: Revealing the state of neurology services,\(^3\) which surveyed almost 7,000 people with neurological conditions. The survey found that:

- 39.8% of respondents waited more than 12 months from when they first noticed their symptoms to see a neurological specialist
- 31.5% 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
- 58.1% of respondents have experienced problems in accessing the services or treatment that they need.

The inefficiency of neurology services places a growing burden on NHS finances, with the NHS spending £4.4 billion neurology services in 2012/13, an increase of over 200% since 2003/4.\(^4\)

Agreed recommendations identified as “poor progress”:

In this context, it is concerning that the NAO’s report shows that the key areas for improvement identified by the PAC have not been addressed:

\(^1\) https://www.nao.org.uk/report/services-for-people-with-neurological-conditions-progress-review/
\(^2\) http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/1759.pdf
\(^3\) http://bit.ly/14yBiNd
\(^4\) http://www.neural.org.uk/store/assets/files/381/original/Final_-_Neuro_Numbers_30_April_2014_.pdf
1. Neurology data

Three years after the PAC called on the government to rectify the shortage of neurology data, the NAO notes that “NHS England does not know how many people have a neurological condition because data is not centrally collated.” The government has also failed to deliver a resource for linked health and social care data or for data on emergency re-admissions relating to neurological conditions, as recommended by the PAC. As a result, neurology services operate in an information vacuum, without proper scrutiny of costs, outcomes and value for money.

Given the financial pressures within the health system, it is vital that its limited resources are used effectively and efficiently. Yet there is still no data record in place that would allow detailed analysis of patient outcomes and service effectiveness, and no substantial data resource at all for the majority of neurological conditions.

The release of the Compendium of Neurology Data by the Health and Social Care Information Centre and the formation of the Neurology Intelligence Network by Public Health England in 2014 were a significant steps forward but there is much more to be done in order to bring neurology data up to the required standard.

2. Care planning

The NAO’s review found that the objective of ensuring that everyone with a long-term neurological condition has a care plan has not been met. NHS England has not reflected this indicator in the clinical commissioning group outcomes indicator set (CCGOIS) so there is no indicator to encourage local action in this area. Only 28.5% of people with neurological conditions have been offered a care plan to help manage their condition.5

3. Improving neurology commissioning

In 2012, the PAC called on the government to use levers such as the CCGOIS and local Joint Strategic Needs Assessments (JSNAs) to improve access to neurology services across the country. However, the NAO’s review finds almost no progress in this area, with minimal representation for neurology in the CCGOIS. As the NAO suggests, the lack of indicators specific to neurological conditions may be limiting clinical commissioning groups' engagement with local neurology services.

A Freedom of Information request sent to every CCG by the Neurological Alliance in 2014 found that as few as 20% have made an assessment of the prevalence of neurological conditions locally, while only 15% are aware of the costs associated with provision of neurological services in their area.6 Similarly, data produced by the Epilepsy Society found that more than two-thirds of health and wellbeing boards do not include a section on

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neurology in JSNAs. As a result, the needs of people with neurological conditions are frequently marginalised by local commissioners.

A full list of the PAC’s recommendations and the NAO’s progress assessments is copied at the end of this briefing.

**The Alliance view of the impacts on service users**

The lack of progress on these recommendations has real consequences for neurological services and those who use them. For example, the Neurological Alliance’s survey data from just under 7,000 people with neurological conditions found that 58% have experienced difficulties accessing the services and support that they require, while almost 40% wait over a year after first symptoms to see an appropriate specialist in order to obtain a diagnosis.

The Neurological Alliance and its members have now written to the PAC, calling on it to conduct a full evidence-based review of services for people with all neurological conditions to ensure that they deliver value for money.

The PAC’s previous review led to a number of important steps forward, including the creation of a National Clinical Director post for adult neurology, and the formation of the Neurology Intelligence Network and Strategic Clinical Networks for Neurology. However, the NAO’s latest review indicates that progress has now stalled.

**In conclusion**

For too long, neurology has been treated as a low priority condition area by the health service. Inefficient and poor-quality commissioning, an absence of data, and significant under-representation in incentive and accountability architecture mean that millions of people with neurological conditions have poor and inequitable access to diagnosis and care. It is essential that neurology services are prioritised for improvement in order to address these long-standing issues.

**Neurological Alliance recommendations**

The following recommendations would help to address some of the key failings identified by the National Audit Office:

- NHS England should work with stakeholders including patient representative organisations to develop and prioritise an agreed strategy for securing improvement in neurology services.

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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, and revise the Neurosciences Service Specification to ensure clarity of commissioning responsibilities.

NHS England should work with the Neurology Intelligence Network to develop robust and measurable indicators for inclusion in key incentive and accountability mechanisms within the NHS, including the NHS Outcomes Framework, CCGOS, and Commissioning for Quality and Innovation payments (CQUINs).

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.

**List of all PAC recommendations from 2012, and the NAO’s progress assessments:**

**Recommendation 1: Appoint a national clinical lead for neurology and establish local neurological networks.**
Not agreed by the Department of Health
Progress: Good
While the Department did not agree with this recommendation, there has been progress against both aspects. NHS England has appointed a national clinical director for adult neurology and established the mental health, dementia and neurological conditions strategic clinical network.

**Recommendation 2: Develop a neurological dataset and include key indicators from the dataset in the NHS and adult social care outcomes frameworks.**
Agreed by the Department of Health
Progress: Moderate
The Health and Social Care Information Centre published a compendium of neurology data in March 2014, although it did not link health and social care data or include data on emergency readmissions as the Committee recommended. Public Health England and NHS England also jointly sponsor a new neurology intelligence network. The NHS outcomes framework includes only 1 indicator relating to neurological conditions – on epilepsy in young people under 19 years old. The adult social care outcomes framework includes no indicators relating to neurological conditions.

**Recommendation 3: Ensure all people with neurological conditions have appropriate access to services through use of the commissioning outcomes framework (now the clinical commissioning group outcomes indicator set), the joint strategic needs assessments and the health and wellbeing boards.**
Agreed by the Department of Health
Progress: Poor
The clinical commissioning group outcomes indicator set includes only 1 indicator specific to neurological conditions – on epilepsy in young people under 19 years old. Our analysis found that just over half of joint strategic needs assessments made reference to neurology or a specific neurological condition through either a specific chapter/section or one or more specific sentences. Only one fifth of joint health and wellbeing strategies referred to neurology or a specific neurological condition.

**Recommendation 4: Mandate joint health and social care commissioning of neurological services in its commissioning outcomes framework, supported by health and wellbeing boards through the joint strategic needs assessment.**
| Recommendation 5: Set out in the commissioning outcomes framework that every person with a neurological condition should be offered a personal care plan, covering both health and social care. | Not agreed by the Department of Health
Progress: Poor
The Department did not agree with this recommendation because it was not government policy to mandate specific local work. NHS England does not hold information on the extent of joint commissioning for neurological services. The Neurological Alliance told us that its members had seen only occasional examples of joint commissioning. |

| Recommendation 6: Instruct the National Institute for Health and Care Excellence (NICE) to develop a generic quality standard covering other neurological conditions. | Agreed by the Department of Health
Progress: Moderate
The Department has requested 5 quality standards relating directly to neurology. Of these, NICE has published one, one is in development and 2 are awaiting the publication of updated clinical guidelines. For the remaining standard, NICE estimates that it will publish the clinical guideline relating to generic neurological problems in January 2018. The quality standard is likely to be included in NICE’s work programme for 2017-18 when the clinical guideline is available. |