

Neurological Alliance comments on the Department of Health's response to the Public Accounts Committee (PAC) report, Services for people with neurological conditions: progress review (the twenty fourth report of session 2015-16).

This document sets out the Neurological Alliance's comments on the Department of Health's response to the Public Accounts Committee report, [Services for people with neurological conditions: progress review](#) (the twenty fourth report of session 2015-16). The Department's response is contained in the [April 2016 Treasury Minute](#).

The Neurological Alliance is a charity providing a collective voice for over 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. Please see www.neural.org.uk for more information.

Summary

Overall, the Department of Health's response is a very disappointing reflection of the low level of priority given to neurology within the NHS. The PAC's report made it clear that services for people with neurological conditions "are not consistently good enough", and this conclusion is further supported by the Government's failure to accept key PAC recommendations.

Neurological conditions affect 12 million people in England and are a significant spending area for the NHS. The National Audit Office assessed NHS spending as £3.3 billion on neurological conditions in 2012-13,¹ although this may underestimate the total spending (programme budget data lists NHS spending on neurological conditions as £4.4 billion in 2012-13). In this context, the decision to remove national clinical leadership for neurology, with no clear plan in place to replace the functions of the National Clinical Director, is inexplicable.

As a result, neurology services will continue to lag behind other service areas in service standards and patient outcomes. There is considerable evidence that neurology services suffer from a number of serious issues, including enormous [regional variation in access](#) to services and [widespread disengagement by local commissioners](#). A [survey of almost 7,000 people](#) with neurological conditions found that 58% of patients have experienced problems in accessing the services or treatment they need.²

Neurology requires a clear strategy for improvement, supported by national and regional/local leadership, reliable and accurate data, and active engagement with clinical commissioners and other key decision makers, as outlined in the 2005 National Service Framework, the 2012 PAC review of neurology, and the latest PAC review. The Department of Health should reconsider rejected PAC recommendations as well as producing a plan and timetable for implementing accepted recommendations.

¹ <https://www.nao.org.uk/report/services-for-people-with-neurological-conditions-progress-review/>

² <http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

We will work closely with NHS England, the Department of Health and Public Health England to implement the currently accepted recommendations and develop supporting plans. We welcome the PAC's intention to return to this topic in the current parliament.

Rejected recommendations:

Recommendation: *The Department should confirm how it is measuring performance against the objective that everyone with a long-term condition should be offered a personalised care plan. NHS England should set out a timetable for meeting the objective and the Department should hold NHS England to account for achieving this timetable.*

Neurological Alliance response: It is disappointing that the Government no longer includes within the NHS England Mandate a commitment to delivering a personalised care and support plan to everyone living with a long-term condition. For those living with long-term health conditions, care planning is central to delivering personalised, coordinated care. Studies such as The Cochrane Review on personalised care planning³ found that personalised care planning plus appropriate follow-up support leads to improvements in physical and psychological health status, and people's capability to self-manage their condition. NHS England lists the benefits of personalised care and support planning to individuals and their carers include:

- Understanding their condition(s) or disability better.
- Feeling more confident and able to manage their own health and care.
- Playing a more active role in managing their condition and getting recognition and support from professionals in this role.
- Preventing deterioration in their condition or symptoms.
- Tailored support to increase confidence and skills in self-management.⁴

As NHS England itself has concluded, "personalised care and support planning is an essential gateway to better supporting people living with long term physical and mental health conditions, and carers, helping them to develop the knowledge, skills and confidence to manage their own health, care and wellbeing."

NHS England's lack of progress on this objective so far should not be a justification for abandoning an important target. The Neurological Alliance's survey of just under 7,000 neurological patients in 2014 found that fewer than 29% had been offered a care plan, despite the existent of the Mandate commitment to deliver them.⁵ We are very concerned that progress towards delivering personalised care plans will be slowed even further by NHS England's decision to discontinue this objective.

³ Coulter A, Entwistle V A, Eccles A, Ryan S, Shepperd S, Perera R. (2014) *Personalised care planning for adults with chronic or long-term health conditions*, Cochrane Database of Systematic Reviews 2014

⁴ England, *Personalised care and support planning handbook: The journey to person-centred care*, March 2016 <https://www.england.nhs.uk/wp-content/uploads/2016/04/exec-summary-care-support-planning.pdf>

⁵ Neurological Alliance, *The Invisible Patients: Revealing the state of neurology services*, January 2015, <http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

In its response, the Government notes that “the support provided to patients with long-term conditions will continue to be measured locally and nationally through the GP survey and via indicators in the new CCG Improvement and assessment framework and the NHS Outcomes Framework.” However, neurology is almost entirely unrepresented in these frameworks, with no specific neurology measures in the CCG Improvement and assessment framework and only two in the NHS Outcomes Framework, covering dementia and epilepsy only. In addition, NHS England does not break down the published GP survey data so that the responses of people with neurological conditions can be separately analysed. Therefore, these frameworks will not enable close scrutiny of neurology services without the addition of specific measures.

Recommendation: *NHS England should retain the role of national clinical director for adult neurology.*

Neurological Alliance response: It is extremely disappointing that the Government has rejected the clear recommendation of the Public Accounts Committee to retain the role of national clinical director (NCD) for adult neurology. In the short time since Dr David Bateman’s appointment in the summer of 2013, he has spearheaded national and regional improvement initiatives, and lead the development of publicly available data and intelligence sources for neurology at the national level. He has played a vital role in the development of the first national compendium of neurology data, as well as providing leadership to Public Health England’s Neurology Intelligence Network and the Right Care programme, NHS England’s Neurosciences Clinical Reference Group and the Strategic Clinical Networks for neurology. He was pivotal in initiating and developing NHS England’s current project on community neurology services. He has been a key source of clinical expertise and advice for a wide range of initiatives, and an important point of contact for patient representative organisations in the field of neurology.

It is clear that NHS England took the decision to discontinue the post without having a clear plan to obtain clinical leadership and advice on neurology services in the future. In responses to parliamentary questions tabled in February and March, NHS England stated that new arrangements would be put in place by April 2016, and cited ‘NHS England-funded neurology clinical networks’ as a future alternative source of advice. (See for example the answers to parliamentary questions [29133](#), [27966](#), [27532](#), [27534](#), [HL6082](#), [26275](#), and [25394](#)).

However, by April 2016 no alternative arrangements had even been proposed, while all national funding for neurology clinical networks, which had been an important source of clinical expertise and advice at the regional level, was withdrawn.

To cut the NCD role after less than three years, just as it was beginning to lead to real progress, is a huge step back for neurology services. Furthermore, it reinforces 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. In conjunction with the loss of neurology clinical networks and NHS England’s failure to put any alternative arrangements in place, this decision will have major negative consequences for the future development of neurology services. People living with neurological conditions will ultimately suffer the consequences of NHS England’s ongoing refusal to give neurology comparable priority to other condition areas.

Recommendation: *The Department should report back to us by April 2016 setting out how it plans to link health and social care data, including a clear timetable for when it expects care data to be fully implemented across the NHS.*

Neurological Alliance response: Given the longstanding issues affecting the availability of data on neurological conditions and services, it is disappointing that the Government has rejected this recommendation. Some progress has been made on the development of neurology data in the last two years following the establishment of Public Health England's [Neurology Intelligence Network](#), which has produced a range of data and analysis on health services and outcomes for certain neurological conditions, and the Rightcare programme's production of neurology focus packs in April 2016. However, these outputs are strongly focused on medical care (especially hospital care). The long-term future of these data sources remains unclear and it is disappointing that the Department made no mention of them in their response. There is currently no data on the social care services received by people with long-term neurological conditions specifically, nor their experiences and outcomes.

Both the Department and NHS England agreed in their evidence to the Committee that the linking of data across different care settings was vital for planning and improving the quality of services, but said that a generic solution had to be found. Una O'Brien, permanent secretary at the Department of Health, said that "we have to solve (the issue of linked data) for all people with all conditions", and referred to the national care.data programme as a potential solution.⁶ Given that the national care.data programme is not expected to working by 2020, it is disappointing that no linked data resource will be available until then. As noted by Dr David Bateman in his evidence to the Committee, it is essential that any generic data solution is supported by sufficient neurological expertise to allow for informed interpretation and analysis of the data.

Accepted recommendations:

Recommendation 1: *NHS England should set out by April 2016: how it will use the new commissioning for value data packs to help clinical commissioning groups improve neurological services and reduce the variation in services and outcomes; and how it will then hold clinical commissioning groups to account for their performance in this regard.*

Neurological Alliance response: The development of locally-tailored commissioning for value packs is a positive development which we hope will support stronger CCG engagement with neurology services. We are particularly pleased to see the neurology-specific focus packs sent to CCGs in April 2016,⁷ and we hope that this focus will be maintained in future years. However, it is essential that NHS England presses CCGs to make the best possible use of this data in order to give neurology appropriate level of focus and attention, and identify paths to improvement. It is not yet clear how NHS England intends to hold CCGs to account for improving their performance against the measures contained in the neurology focus

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http://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/50207.htm#_idTextAnchor013

⁷ <https://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

packs. NHS England must explain how this will be monitored and managed, so that the information provided in the packs translates to real change in commissioning practice, service standards, and patient outcomes.

Recommendation: *NHS England should report back to us by April 2017 on what it has done to make best use of the available neurologists and reduce the variations in access, including through re-designing services and making more use of other clinical staff, particularly specialist nurses.*

Neurological Alliance response: It is positive that the Government recognises the need to reduce variation in access to neurologists. 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. 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.⁸

However, we were disappointed that NHS England in its evidence to the Committee rejected the possibility of increasing the rate of growth in neurologist numbers over the next five years. The Association of British Neurologists advocates a 50% increase in the current number of consultant neurologists, bringing the total to around 1,000 full-time equivalents.⁹ While there is clearly potential to use existing resources more effectively by re-designing services and care pathways, we are sceptical that this approach on its own will be sufficient to address the problem fully, particularly without any specific focus on solving the capacity problem in neurology specifically. NHS England should provide a clear plan for how it will address the unacceptable level of variation in access to neurologists across the country.

Recommendation: *NHS England should set out clearly by April 2016 which neurological services are specialised services to be commissioned by NHS England and which services should be commissioned locally by clinical commissioning groups.*

Neurological Alliance response: It is positive that the Government has accepted this recommendation and acknowledges the need for clarity on commissioning responsibilities for neurology.

However, NHS England has been aware of this issue for at least three years, but has not yet clarified the situation. As a result, the distinction between specialised and non-specialised neurology services remains unclear, which leads to services 'falling through the gaps' with no commissioner taking responsibility. The impact of this problem falls on the patients who are unable to access the services that they require.

⁸ <http://www.yhpho.org.uk/default.aspx?RID=213049>

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http://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/50206.htm#_idTextAnchor010

Ongoing confusion on the future direction of specialised commissioning has prevented the Adult Neurosciences Clinical Reference Group from revising the relevant service specification to clarify this issue. Given the ongoing restructure of CRGs and the proposed merger of the Neurosciences and Neurosurgery CRGs, NHS England must ensure that this clarification is delivered as rapidly as possible. This will require consistent messaging from NHS England on the future of specialised commissioning as a whole, including issues such as the introduction of collaborative commissioning. NHS England must urgently work with the restructured Neurosciences and Neurosurgery CRG to ensure that these issues are resolved.

We are also concerned that the proposed restructuring of CRGs may impede work on defining commissioning responsibilities. In April NHS England announced the merging of the Neurosciences and Neurosurgery CRGs, which was not included as a proposal in the preceding consultation document. It has presented no rationale or explanation for this decision and will not allow any consultation. Historically, neurosurgeons have little to no involvement in wider neurological services, and we are concerned that a combined CRG membership of four neurologists and four neurosurgeons (as is proposed) will not be able to access easily the required expertise on the full range of neurological conditions and services.

In addition, the CRG chair will be remunerated for only four hours a week, which will necessarily limit their ability to lead the work. This issue is exacerbated by the fact that, following the loss of the National Clinical Director for neurology, the CRG chair is likely to be asked to take on a clinical advice role for neurology on behalf of NHS England. It is difficult to see how any candidate will be able to drive forward the work of the CRG, as well as provide general clinical advice to NHS England, in only four hours per week.