



Meg Hillier MP  
House of Commons  
London SW1A 0AA

August 4<sup>th</sup> 2015

Dear Meg,

Congratulations on your recent election as Chair of the Public Accounts Committee (PAC). We write to you in connection with the recommendations made by the PAC in 2012 relating to services for people with neurological conditions.

The National Audit Office (NAO)'s [recent review](#) of services for people with neurological conditions, which assessed progress against the PAC's recommendations of 2012, shows a disappointing lack of improvements. The PAC's [2012 report](#) found that neurological services deliver "poor outcomes for people with neurological conditions and poor value for money for the NHS." Three years later, the report's key recommendations remain unachieved, and the NAO finds 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](#). Furthermore, much of the estimated [£4.4 billion](#) NHS spending on neurology services remains wasteful and poorly targeted, with expenditure [growing by over 200%](#) between 2003/4 and 2012/13.

The NAO's report shows that the key areas for improvement identified by the PAC have not been addressed, for example:

### **Neurology data**

Three years after the call 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" (clause 1.3). The Government has also failed to deliver a resource for linked health and social care data, despite [major weaknesses in social care planning](#), 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.

### **Improving neurology commissioning**

The PAC also called on the government to use levers such as the clinical commissioning group outcomes indicator set (CCGOIS) and local Joint Strategic Needs Assessments 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 (2.22). 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. As a result, the needs of people with neurological conditions are frequently marginalised by local commissioners.

### **Full review of neurology services**

The lack of progress on these recommendations has real consequences for neurological services and those who use them. [Our recent survey](#) of 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 for a diagnosis.

We ask that the PAC 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. However, the NAO's latest review indicates that progress has now stalled.

For far 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. We hope that the PAC will bring its influence and powers of scrutiny to bear on this issue as soon as possible. We would be happy to meet with you to discuss these issues in more detail. We have copied this letter to all members of the Committee.

Yours sincerely,

Arlene Wilkie, Chief Executive, Neurological Alliance

Alice Doyle, Chief Executive, Brain and Spine Foundation

Amanda Swain, Trustee and Executive Board Member, UK Acquired Brain Injury Forum



Angela Greer, Chief Executive, Epilepsy Society

Annette Scivier, Trustee, Hampshire Neurological Alliance

Bryan Rowley, Chair, British Polio Fellowship

Caroline Morrice, Director, GAIN

David Wray, Chairman, Swindon and Wiltshire Neurological Alliance

Dawn Cranswick, Chairman, Northern Neurological Alliance

Fergus Logan, Chief Executive, PSP Association

Glenys Marriott, Chairman, Cumbria Neurological Alliance

Guy Parckar, Chief Executive, The Dystonia Society

Hilary Boone, Treasurer, Polio Survivors Network

Hilary Evans, Chief Executive, Alzheimer's Research UK

Irene Waters, Chairman, West Berkshire Neurological Alliance

Jamie Miller, Chief Executive, Headway Oxfordshire

Jane Hanna OBE, Chief Executive, SUDEP Action

Jean Waters, Gloucestershire Neurological Alliance

Jillie Abbott, Chairman, Trigeminal Neuralgia Association UK

John Morgan, Chair, Staffordshire Neurological Alliance

Karen Walker, Interim Chief Executive, MSA Trust

Natalie Beswetherick, Director, Practice & Development, Chartered Society of Physiotherapists

Nick Rijke, Executive Director for Policy and Research. MS Society

Pam Macfarlane, Chief Executive, MS Trust

Peter McCabe, Chief Executive, Headway

Philip Lee, Chief Executive, Epilepsy Action

Philip Smith, President, Association of British Neurologists

Preston Keeling, Chair, Lincolnshire Neurological Alliance

Preth Rao, Head of Policy and Campaigns, Sue Ryder



Richard Penney, Acting Chief Executive, Parkinson's UK

Ruth Ingledew, Chief Executive, MyAware

Sally Light, Chief Executive, Motor Neurone Disease Association

Sue Millman, Chief Executive, Ataxia UK

Sue Wray, County Organiser, Lincolnshire Neurological Alliance

Suzanne Dobson, Chief Executive, Tourettes Action

Ted Hill, Chief Executive, British Polio Fellowship

Wendy Thomas, Chief Executive, The Migraine Trust