

Focusing on the invisible patients



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The controversial 2012 Health and Social Care Act introduced major changes to key structures and processes in health and social care. For neurology in particular – a historically neglected grouping of conditions, which consumes an ever-expanding portion of the NHS budget – the reforms represented both a challenge and an opportunity. Would the creation of a new cohort of clinical commissioning groups (CCGs) lead to disruption of existing services? Or could the new commissioners lead the development of new and better pathways of care for the 10 million people living with a neurological condition in England?

Reform of this magnitude will always carry both risks and benefits. Clinical commissioners have faced the difficult task of taking on a swathe of new commissioning responsibilities at a time when funding is stretched and the NHS is grappling with the challenges of an ageing population. There is little doubt that the transition to clinical commissioning has led to disruption which has, in some cases, impeded the NHS's efforts to develop more effective, better-integrated services with a stronger preventative focus.

At the same time, clinical commissioners find themselves faced with a huge opportunity to transform care and outcomes for the people living in their area. With a stronger local presence than their Primary Care Trust predecessors, CCGs are well-placed to take a strategic approach to service improvement, based on a better understand of local needs and priorities. Unfortunately, the available evidence suggests that many CCGs are failing to engage with the challenge of improving neurological services.

For its report *The Invisible Patients: Revealing the state of neurology services*, the Neurological Alliance carried out a Freedom of Information audit of all CCGs in July 2014. 91% of CCGs responded, but the replies showed that far too many are not carrying out the key processes that enable a strategic approach to service improvement in neurology. For example, as few as 20% of CCGs have ever carried out an assessment of the number of people using neurological services in their area, while fewer than 15% have assessed the costs relating to the provision of neurological services locally. Only a third of CCGs have mechanisms in place to obtain feedback from people living with neurological conditions locally regarding their experiences of the services they receive.

This represents a major missed opportunity. NHS spending on neurological conditions has soared by 200% over the past ten years, which also saw a dramatic rise in emergency hospital admissions for neurological conditions, reaching 700,000 in 2012/13. A recent Neurological Alliance survey of just under 7,000 neurological patients found that almost 40% of people diagnosed with a neurological condition waited at least a year for that diagnosis,

while over 30% saw their GP five or more times before finally accessing a specialist Neurologist. Care coordination is often very poor, and over 70% of people with neurological conditions do not receive a care plan, even though the majority of neurological conditions are long-term. There is clear scope to improve outcomes and alleviate pressure on budgets through better designed pathways of care, but only a minority of CCGs appear to be engaging with this challenge.

This is partly the result of neurology's lack of representation in the quality and improvement architecture of the NHS. In its 2012 review of service for people with neurological conditions, the Public Accounts Committee identified a profound lack of accountability for neurology services at all levels of the health and care system, to the detriment of patient outcomes, quality of care and value for money. Unfortunately, little progress has been made in this area since 2012. For example, both the NHS Outcomes Framework and the Clinical Commissioning Group Outcomes Indicator Set make reference to only three neurological conditions (dementia, stroke, and epilepsy in children), and neither make any reference to neurology as a whole. Consequently, CCGs have little incentive to devote appropriate attention to local neurological services.

Neurology is also disadvantaged by the shortage of available data that would guide local commissioning decisions. Despite the creation in 2014 of the first minimum dataset for neurological conditions and the establishment of the Neurology Intelligence Network, neurology continues to lag behind other condition areas in the accuracy and consistency of data and intelligence collected. The shortage of reliable local data covering (for example) prevalence, costs and outcomes relating to neurological services inhibits CCG understanding of neurology and impedes service improvement. Given the spiralling costs of treating neurological conditions, there is a clear need for accurate and comparable local data, in order to improve understanding of local needs and identify areas requiring improvement.

It is now time for these issues to be addressed. At a time when NHS England is planning to expand CCGs' commissioning responsibilities for neurology to include involvement in specialised commissioning, it has never been more important for local commissioners to actively improve their engagement with and understanding of neurological conditions. It can no longer be acceptable for people living with these conditions to be 'invisible patients,' overlooked by the key decision-makers and budget holders within today's NHS. It is vital that both CCGs and central organisations such as NHS England and the Department of Health recognise the need for service improvement in neurology, and work together to deliver it across the country. Only then will the millions of people with neurological conditions receive the care they need and deserve.