the neurological alliance

Going the distance

National calls to action to drive neurological service improvement in England

March 2014

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Acknowledgement

The Neurological Alliance received unrestricted funds via its Industry Reference Group from Allergan, Genzyme, Novartis, and UCB to support the publication of this report. The Neurological Alliance retains independent control over the direction, activities and content of its work.

Foreword

Neurology is at a crossroads. Over the past two years, there have been some major developments; a strategic clinical network has been set up, a National Clinical Director for neurological conditions has been appointed and the first neurological minimum dataset has just been launched. There is no question that these initiatives, hard won by the neurological community, are hugely positive and have a major role to play in enhancing neurological care and support.

Alone, however, they cannot deliver what people with neurological conditions urgently need: a successful national improvement drive that lifts neurological services up to the standard we would expect for people with other life changing conditions.

In the context of a devolved NHS, the national initiatives introduced for neurology will only become powerful drivers of change if they are supported by the accountability and incentive mechanisms that influence what every level of the health and social care system prioritises. The fact that neurology barely features in all such mechanisms means that the growing desire at national level to address the underperformance of neurology services is being lost in translation, leaving key decision making bodies such as clinical commissioning groups without support to play an active role in improving neurological care and support.

It's therefore apparent that behind the scenes neurology still has a long way to go and that the Government and national NHS bodies have a clear choice ahead of them. They can down tools on improving neurological services now that the headline grabbing initiatives have been put in place and allow the health and social care system to perform much as it has before. Alternatively, they can knuckle down and go the distance on neurological service improvement, building on the solid foundations that they have put in place over the past two years.

The former is the easy option and it wouldn't be without precedent; the National Service Framework for Long Term Conditions stalled in its early stages too. However, with the number of people with neurological conditions increasing and the financial squeeze on health and social care budgets set to continue, going the distance this time round is undoubtedly the necessary option for patients and the NHS.

In this report we urge the Government, the Department of Health and other national NHS organisations to do the right thing and seize the readymade opportunity to fundamentally transform neurological services. The report's five key tests set out the conditions necessary for neurological improvement efforts to achieve success and how this environment can be created in the months ahead. While the health and social care system doesn't score top marks in 2014, adoption of our practical calls to action can ensure an outstanding result in 2015. As always, we offer our full partnership in this endeavour.

Arlene Wilkie
Chief Executive, Neurological Alliance

Introduction

It is now two years since the Public Accounts Committee (PAC) published its report on services for people with neurological conditions, which shone a much needed spotlight on the historic neglect of neurology and the consequent impact on care and support for people with neurological conditions, including lengthy diagnosis, poor care coordination and unacceptable variation in services[1].

Since then, the health service has undergone a major reorganisation and a new system of incentives, accountability and quality measures has been introduced to drive improvements in patient outcomes and value for money.

The Government is yet to report on its progress against the PAC's recommendations, but when it does we expect it to paint a picture of neurological services having turned a corner. We agree that the appointment of the National Clinical Director, the establishment of the strategic clinical network (SCN) for mental health, dementia and neurological conditions and the launch of the first neurological minimum dataset for England represent key milestones in England's neurological service improvement drive. However, these promising developments are set against a backdrop of a health and social care system in which neurological conditions remain under-prioritised at a national level.

This is most clearly evidenced by the absence of neurology specific indicators across the quality, accountability and incentive system of the reformed health and social care system. These centrally set mechanisms are some of the best possible ways to achieve change within the health and social care system by ensuring that all levels of the NHS and social care system get behind efforts to improve outcomes and enhance value for money in particular clinical areas. Explicit inclusion and proportionate representation across the new quality, accountability and incentive architecture must be the starting point for improving neurology services and outcomes.

With a National Audit Office (NAO) review of neurological services anticipated in 2014, we are urging the health and social care system to go the distance on neurological service improvement by implementing our national calls to action over the next 12 months and we offer our full partnership in supporting the relevant organisations to do this.

This report:

- takes a critical look at the new health and social care quality improvement system, applying five key tests to assess how well it is set up to drive neurological service improvement;
- recommends practical calls to action for national adoption by NHS England, the Department of Health and NICE .

The primary audience for the report is NHS England and the Department of Health but it is also intended to help central and local government, policymakers, clinicians and professionals to prioritise quality through policies and practice. It can also help patients

with neurological conditions, their carers and patient organisations to understand how good quality care is assessed and promoted in the reformed NHS.

We will use this report by:

- sharing it with key influencers and decision makers and campaigning for adoption of all the calls to action outlined;
- supporting the relevant organisations to implement our calls;
- using the five key tests to assess the progress of England's neurological service improvement drive one year following publication of this report.

The policy context

There are approximately 10 million people with a neurological condition in England today. This is more than the number of people living with cancer (or beyond cancer)[2], coronary heart disease[3], and diabetes[4] combined. In spite of this, there has been a continuing lack of national prioritisation to deliver better outcomes for people with neurological conditions.

The need for a far more urgent focus on quality in relation to neurological conditions was clearly articulated in the PAC report, *Services for people with neurological conditions*, which was published in March 2012[5]. In this report, the PAC concluded:

"..services remain well below the quality requirements set out in the [National Service Framework for Long Term Conditions]…coordination of care for individuals is poor, and there is a lack of integration between health and social services…There is still a lack of neurological expertise, both in hospitals and in the community, and access to services varies widely."

This clear statement around the need for quality improvement was made in the context of the significant structural and organisational changes to the health and social care environment in England, legislated for in the Health and Social Care Act 2012.

The Government committed to take forward a number of the PAC's recommendations around how the outcomes and effectiveness of neurological care could be improved. This included committing to developing a neurological minimum dataset. Recommendations around national leadership and clinical networks were also adopted in the months following the publication of the Government's official response to the PAC, despite having initially been rejected.

However, behind these headline commitments, neurology is virtually invisible under the nationally set quality and accountability mechanisms of the reformed health and social care system, referred to throughout this report as the health and social care quality improvement system. It is the mechanisms and incentives that comprise the quality improvement system that influence the priorities of commissioners and providers. The neurological community is deeply concerned that the underrepresentation of neurology across this system will fundamentally undermine the capability of the National Clinical Director for neurological conditions and SCN covering neurology to play the transformative role they were instated to deliver.

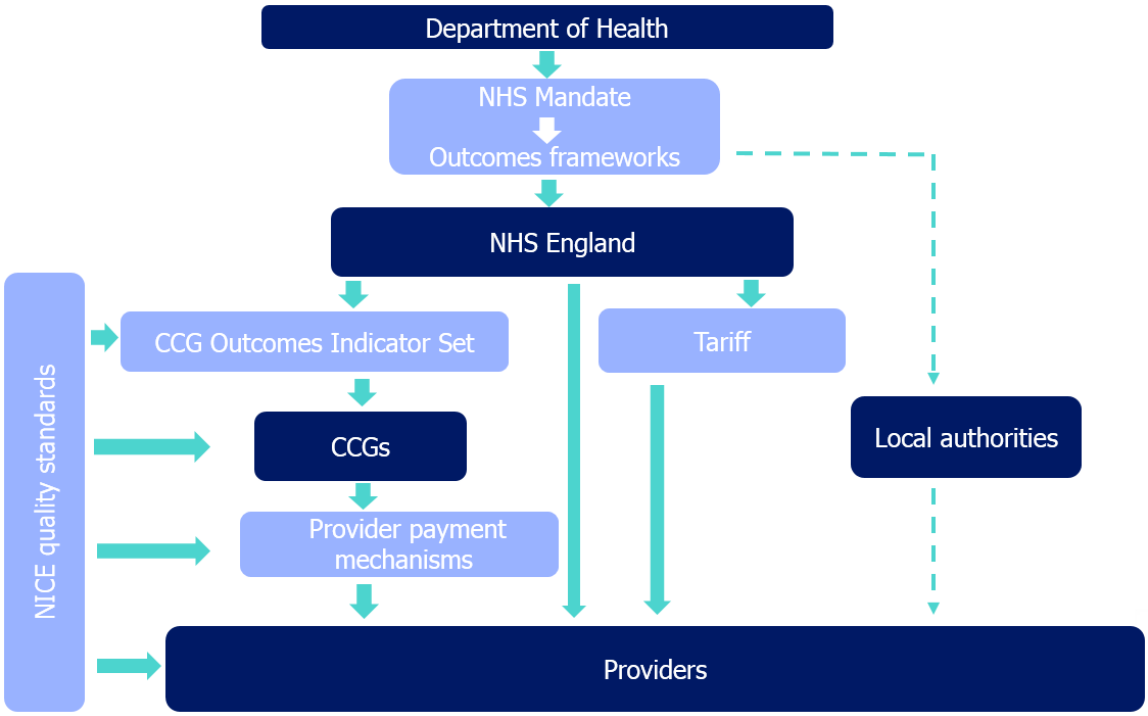
One of the main challenges in taking the neurological service improvement drive to the next level has been an apparent reluctance by NHS England to separate out neurological conditions from the very broad 'long term conditions' banner. We recognise that cross-cutting initiatives aimed at improving long term conditions care may help to drive up the quality of neurological services. Nonetheless, these alone will not address the problems that are preventing people with neurological conditions from securing the best possible outcomes.

A condition-specific approach is possible and practical, and already happening within the reformed NHS for conditions such as cancer, stroke, liver disease and diabetes, all of which have dedicated national outcomes strategies or action plans already in existence or in development. This approach ensures that the priority areas for these conditions are reflected in the various layers of the health and social care quality improvement system. It also ensures that clinicians, commissioners and patients alike are aware of where the priority areas for improvement are and what action needs to be taken to ensure these are addressed.

In the following pages, we look at how neurological conditions are currently reflected in the different strands of the health and social care quality improvement system, and identify where and what action needs to be taken to ensure that it is properly rigged to drive neurological service improvement.

Figure 1 sets out the different parts of this system that are of key relevance to neurological services. These are the areas that we focus on in this report. The NHS Outcomes Framework (influenced by the Mandate between the Secretary of State for Health and NHS England) sets the tone for a system of guidance and mechanisms to drive high quality care and services across the NHS in England. The arrows in the diagram show the lines of influence between the different bodies, sets of guidance and mechanisms.

Figure 1: The health and social care quality improvement system



The success of the system set out in Figure 1 is central to improving services and outcomes in the NHS and social care system. How neurology features across this system is therefore a litmus test for whether the reformed NHS is capable of addressing the legacy of neurological neglect highlighted by the PAC two years ago.

Assessing the reformed health and social care system's ability to achieve neurological service improvements: five key tests

In order to assess how neurological conditions are currently represented within the nationally determined health and social care improvement system, we have applied five key tests across it and marked current progress using a star rating. These tests are set out below:

Our five key tests

1. Neurological conditions are proportionately prioritised at a national level
2. Neurological services are explicitly represented in the nationally set health and social care accountability frameworks
3. NICE quality standards, clinical guidelines and support for commissioners have been developed covering the range and breadth of neurological conditions
4. There are nationally collated, reliable, consistent and useful data on all neurological conditions, services and outcomes
5. Improvements to neurological services are being incentivised through provider payment and incentive schemes

Where we identify that the nationally set elements of the health and social care quality improvement system do not currently pass a key test, we have issued a call to action. These are designed to be realistic solutions that can be adopted at national level to better equip the system as a whole to undertake the vital task of improving neurological services.

KEY TEST 1

Neurological conditions are proportionately prioritised at a national level

Test score: ★☆☆☆☆

NHS Mandate

The NHS Mandate is the route through which the Secretary of State for Health holds NHS England to account for its performance[6]. It sets a number of objectives for NHS England and describes the Government's expectations of what it will achieve. The current Mandate corresponds to the five domains of the NHS Outcomes Framework (see below) and sets out a number of priority areas where it is expecting particular progress to be made.

It is positive to see that two types of neurological condition – dementia and stroke – are highlighted in the Mandate. However, only dementia has specific objectives attached to it. There are also a number of cross-cutting measures relating to long term conditions, for example, the proportion of people feeling supported to manage their condition, which should broadly help to drive improvements to neurological services.

However, neurology has always lacked visibility under the long term conditions umbrella, which it shares with many higher profile and better understood condition groups such as diabetes and cardiovascular disease. As such, unless neurological conditions are drawn out specifically underneath these generic measures, the potential of these measures to act as effective improvement drivers for the millions of people in England living with a neurological condition is limited.

While we recognise that the Mandate is not intended to be exhaustive, it is important to note that, although dementia and stroke account for a large proportion of people with neurological conditions, they represent just a small part of the range and breadth of conditions that come under the neurological banner. It is essential that the broader indicators that are included, for example in relation to reducing emergency admissions and readmissions, are specifically applied to, and measured, for neurological conditions.

By separating out single conditions in the Mandate, the ability of NHS England to focus on long term conditions equitably is significantly undermined.

Call to action

- The Secretary of State for Health should use the Mandate to highlight a small number of key improvement areas applicable to all or a significant proportion of long term conditions, such as early diagnosis or access to rehabilitation services, to give NHS England a thematic rather than condition specific focus to its work. This will achieve improved outcomes for a far greater number of individuals.

KEY TEST 2

Neurological services are explicitly represented in the nationally set health and social care accountability systems

Test score: ★☆☆☆☆

NHS Outcomes Framework

Alongside the Mandate, the NHS Outcomes Framework sets out the outcomes and corresponding indicators that will be used to hold NHS England to account for improvements in health outcomes. In addition to determining NHS England's key foci, the Outcomes Framework also plays a pivotal role in steering clinical commissioning group (CCG) priorities as it is one of only two sources used to populate the CCG Outcomes Indicator Set (CCGOIS) (see below and Figure 1).

As we set out in a report we published in summer 2012[7], there are measures within each of the five domains of the Outcomes Framework that should help to drive improvements to neurological services, but they will only succeed in doing so if the measures are specifically disaggregated for neurological conditions.

Similar to the Mandate, of the 65 indicators included in the 2014/15 Outcomes Framework, just four relate to neurological conditions. These are:

- Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s;
- Enhancing quality of life for people with dementia (two indicators);
- Improving recovery from stroke.

Again, it is positive to see that dementia, epilepsy (though only in people aged 19 or under) and stroke have been drawn out for specific focus within this Framework. However they are just three of the 324[8] known neurological conditions. Given the size of the neurological patient population and the amount of money that the NHS spends on neurology – it is the seventh largest category spend[9] – neurology's underrepresentation in the Outcomes Framework is both conspicuous and highly inadvisable.

If NHS England, commissioners and clinicians are to be part of a coordinated and concerted effort to improve neurological outcomes, it is vital that explicit pan-neurological measures are included within the Outcomes Framework to ensure that benefits are experienced by all people with neurological conditions, regardless of the rarity of their condition.

Call to action

- Additional measures should be included in the NHS Outcomes Framework to cover the whole breadth of neurological conditions, not just a select few, so that NHS England, commissioners are mandated to make a concerted effort to improve neurological outcomes.

Adult Social Care Outcomes Framework

The majority of measures included in the Adult Social Care Outcomes Framework are generic and apply to people of all ages with all types of conditions and disabilities who have social care needs.

It has been estimated that £2.4 billion of adult social services spending is on people with neurological conditions[10]. The need to monitor performance in relation to neurological conditions specifically is illustrated by recent research conducted by Sue Ryder, which has shown that just 10% of local authorities are working with an agreed commissioning strategy for neurological conditions and only 5% know how many people with neurological conditions they are providing care for[11].

Failing to gather this information makes it impossible both to measure how the Adult Social Care Outcomes Framework is helping people with neurological conditions and to identify improvement areas.

Call to action

- The generic measures included in the Adult Social Care Outcomes Framework should be tracked for neurological conditions specifically, to ensure that local authorities are providing high quality support for people with neurological conditions and to identify problems areas that need to be addressed.

CCG Outcomes Indicator Set

NHS England, in coordination with NICE, has developed the CCGOIS to measure the health outcomes and quality of care delivered by CCGs. It will be used by NHS England to hold CCGs to account for their contribution towards achieving the ambitions set out in the NHS Outcomes Framework.

Nine indicators specifically related to neurological conditions are included within a total of 66 in the 2014/15 CCGOIS. These again relate to dementia, epilepsy (in under 19s) and stroke. As with the NHS Outcomes Framework, it is vital that more pan-neurological measures are included to cover the spectrum of neurological conditions so that commissioners and clinicians are incentivised appropriately to improve neurological outcomes in the round.

Call to action

- Additional measures should be included in the CCGOIS covering the spectrum of neurological conditions, so that commissioners are incentivised appropriately to improve neurological outcomes.

KEY TEST 3

NICE quality standards, clinical guidelines and support for commissioners have been developed covering the range and breadth of neurological conditions

Test score: ★★☆☆☆

NICE quality standards and clinical guidelines

NICE develops quality standards for both health and social care. Quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. For health, the majority of quality standards are condition specific while for social care they are mainly cross cutting. Clinical guidelines are far more detailed and set out recommendations on the appropriate treatment and care of people with specific conditions under the care of the NHS. NICE also develops 'Support for Commissioners' - these are web-based resources that assist quality improvement and service redesign.

All three are very important mechanisms for driving up health and social care quality, ensuring that patients know what type of care they are entitled to and that commissioners are have the tools to commission high-quality, evidence-based care and support.

The complexity and relative rarity of the majority of neurological conditions means that commissioners are likely to need a significant amount of guidance and support to commission neurological services effectively. However, as of March 2014:

- 17 of the 179 published clinical guidelines relate to neurological conditions; these cover 11 neurological conditions;
- Of the 57 health quality standards published to date, just eight relate to neurology; these covering five conditions and include one cross-cutting standard;
- Of the 12 NICE social care quality standards referred to NICE by the Department of Health, only four have been published to date, with the eight currently in development not due to be published until 2015 and 2016;
- NICE has developed Support for Commissioners for dementia, epilepsy and stroke but not for any other neurological conditions.

The lack of commissioning guidance, health quality standards and guidelines for the vast majority of neurological conditions, together with the lack of published NICE social care quality standards, means that commissioners are lacking the vital support they need to commission these services effectively.

It is essential that the full range of neurological conditions are reflected in the library of NICE health quality standards and clinical guidelines and that social care quality standards are developed at pace. The key measures set out in these standards and guidelines must then be reflected within the other areas of the health and social care

quality improvement system, including the outcomes frameworks and provider payment mechanisms, to ensure that their implementation is driven and incentivised.

Calls to action

- NICE should prioritise development of all undeveloped neurological quality standards and ensure these and its clinical guidelines reflect the full range of neurological conditions.
- NICE should publish pan-neurological Support for Commissioners to ensure that CCGs are adequately equipped to commission services to the highest level of quality.
- NICE should ensure that its cross-cutting social care quality standards are developed at pace so they can be used to inform the Adult Social Care Outcomes Framework and provider payment mechanisms.

KEY TEST 4

There are nationally collated, reliable, consistent and useful data on all neurological conditions, services and outcomes

Test score: ★★☆☆☆

Clinical audit, data and intelligence

A fundamental reason why neurological conditions have been poorly represented in the health and social care quality improvement system to date is the lack of available and reliable data to benchmark service standards and measure progress in achieving improved outcomes. It is clear that information drives improvement and it is this principle which underpins the Government's NHS information revolution.

The collection and publication of accurate, consistent and regular data on neurological conditions, services and outcomes will be absolutely critical to understanding more about where the problem areas are and how these should be addressed. The first neurological minimum dataset for England has just been published[12] but this resource currently has a limited scope and must be regarded as a foundation on which to build a comprehensive system of neurological data capture and analysis in the coming years.

Call to action

- NHS England should commit to the expansion and resourcing of the neurological minimum dataset for a minimum of five years.

KEY TEST 5

Improvements to neurological services are being incentivised through provider payment and incentive schemes

Test score: ★☆☆☆☆

There are a number of provider payment mechanisms in the NHS, each of which has the potential to be an effective tool for driving improvements in the outcomes and experience of people with neurological conditions. Across all indicators, though, there is room for development in terms of measurement, usability and implementation. We have detailed two examples below.

Commissioning for Quality and Innovation

The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward improvements in care, by linking a proportion of healthcare providers' income to the achievement of local quality improvement goals. CQUIN payments play an increasingly important role in driving quality improvements in the NHS, and have risen to 2.5% of provider tariff in 2013/14. The vast majority of these improvement goals are selected locally, and so not all providers will have CQUINs relating to a range of neurological conditions. An analysis of local CQUINs utilised by trusts in 2010/11 revealed that less than 1% of the indicators were related to neurology[13].

A small number of CQUINs are set nationally. There are currently four national CQUIN goals for 2013/14, one of which is designed to incentivise the identification of patients with dementia and other causes of cognitive impairment[14]. The indicator is: *"improving dementia care, including sustained improvement in finding people with dementia, assessing and investigating their symptoms and referring for support (FAIR)"*[15]. Within the total payments available for 2013/14, one-fifth should be linked to national CQUIN goals.

In practice, providers often describe this in terms of process, such as: assessment for dementia / dementia screening / dementia referral. In theory, all NHS providers, where appropriate for their service range, should be adopting this CQUIN if it is part of the contracts they have with their commissioners.

In terms of other conditions, the content, detail and measurability of CQUIN payments varies considerably. Improving the acute / urgent care pathway for stroke has featured as a CQUIN in several providers but other neurological conditions are notably absent. However, with the transfer of the relevant online CQUIN databases from the NHS Institute to NHS Improving Quality still underway, it remains difficult to develop a comprehensive and accurate national picture.

Call to action

- NHS England should provide guidance on the use of CQUINs to drive improvements in the care of people with neurological conditions – this should include developing template CQUINs that could be adopted by providers and commissioners in priority areas.

Best practice tariffs

Best practice tariffs can be used to encourage NHS providers to adopt best practice in clinical care for people with neurological conditions. Such tariffs[16] exist for acute stroke care and Parkinson's disease and set out care standards for service teams to meet. Providers which can prove they meet these levels of care will qualify for greater funding.

Research undertaken by the Audit Commission in 2012 to look at the impact that best practice tariffs have had found varying results[17]. While they were shown to focus attention on particular aspects of clinical practice, they can be complex to implement and difficult to understand.

Call to action

- The Department of Health should assess whether existing best practice tariffs for neurological conditions are improving the quality of services and outcomes, and use the findings of its assessment to inform the development and expansion of best practice tariffs for other neurological conditions.

Conclusion

This assessment of how neurological service improvement is being prioritised reveals an alarming underrepresentation of neurology across the board. The scope and range of neurology-specific accountability and incentive mechanisms are significantly limited under the arrangements that came into operation in April 2013. Where they exist, they largely relate to dementia, stroke and epilepsy in under 19s. It is really positive to see these conditions being given profile under the health and social care quality improvement system, but given the vast spectrum of neurological conditions, they must be viewed as the foundation for a much broader range of neurological indicators and standards rather than neurology's lot.

This situation is particularly concerning given work by the PAC, which identified a lack of accountability at national and local level as leading to underperformance of neurological services. With the NAO due to conduct a progress review this year in follow up to the PAC's report, there is a real risk that the evidence will point to a fundamentally cosmetic commitment to neurological service improvement that has not equipped the NHS to tackle the enduring problems identified in 2012.

We urge the Department of Health, NHS England and NICE to use the recommendations in this report to go the distance on neurological service improvement. We are confident that the five key tests that we have developed will provide a practical benchmarking tool by which Government, the NHS and patient organisations can track improvements in neurological services and outcomes in the years ahead. We hope that in reviewing the star ratings in a year's time, we will see far-reaching improvements throughout the health and social care system.

About us

The Neurological Alliance is the collective voice of more than 80 national and regional brain and spine organisations working together to make life better for the 10 million people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, from their first symptoms, and throughout their life.

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