

Sue Ryder



Going the Distance 2

National calls to action to improve neurology services
in England

June 2017

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About us - The Neurological Alliance

We are the collective voice of more than 80 national and regional organisations working together to make life better for the millions of 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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About us - Sue Ryder

Sue Ryder is a charitable provider of health and social care services across the UK. We care for people with long term or complex conditions and disabilities providing specialist palliative and neurological care. We operate in a range of environments with community and home-based care delivery alongside our hospices and neurological care centres.

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Introduction

The Neurological Alliance published our first *Going the Distance* report in 2014. In this report, we sought to quantify the extent to which neurology was prioritised within the NHS improvement and accountability architecture. Set out under 'five key tests' for neurology, our findings showed significant under-representation of neurology, given the level of spend on neurology and prevalence of neurological conditions. There have been significant changes in the health and care policy environment since then and this new report gives an overview of the new structures and initiatives, and how neurology services are currently represented and prioritised within them. *Going the Distance 2* assesses the position of neurology services within the NHS of 2017.

The introduction of the previous report included reference to, among other things, the National Clinical Director (NCD) for Neurological Conditions and the establishment of a strategic clinical network (SCN) for neurology. Both the NCD post and SCNs have gone, although there is now an alternative national leadership structure in place.

The previous report also greeted the launch of the Neurology Intelligence Network (NIN) as a key step forward. We are pleased to report that the NIN, part of Public Health England, has gone from strength to strength since 2014. Its funding however is dependent on year-on-year business planning cycles at Public Health England. We believe it requires a long term settlement to be able to deliver a robust programme of work to support service improvement.

Potentially one of the most significant additions to the prioritisation given to neurology at national level is the creation of the NNAG – National Neuro Advisory Group – set up with NHS England's support in 2016 as an alternative leadership and advisory structure for neurology in the absence of the NCD role. The core NNAG group brings together all the different parts of the health system that need to work together to achieve improvement in neurology - clinicians, patients, commissioners and academia – and the group aims to develop a system-wide national approach for neurology. Other positive developments have been the focus packs sent out by RightCare as part of its Commissioning for Value Programme, and NICE's progress on the development of a guideline on assessment, diagnosis and referral for neurological conditions.

Another significant change to the health and social care system is the introduction of STPs - sustainability and transformation plans, now referred to as sustainability and transformation partnerships - which represent a longer-term, place-based approach to planning services. There are 44 of these partnerships, or 'footprints', each of which has

now issued first drafts of their plans. Sue Ryder has undertaken an assessment of these plans and the extent to which neurology is represented. We present the results of this work with a new chapter and the addition of a key test about the extent to which neurology is prioritised at local and regional level – see key test six.

Previously we called for “the health and social care system to go the distance on neurological service improvement and implement our national calls to action.” We have revised our calls to action to reflect changes to the health and social care system. Our calls are practical actions which can improve the services available to and outcomes for the millions of patients with neurological conditions.

This report:

- Critically examines neurology’s representation within the health and social care quality improvement system, applying six key tests to assess how well it is set up to drive neurological service improvement;
- Recommends practical calls to action for national adoption by key stakeholders such as NHS England and National Institute for Clinical Excellence (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 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 six key tests to assess the progress of England’s neurological service improvement drive.
- using the 2017 post-election period to engage with the new ministerial team and shadow cabinet, new MPs and our other parliamentary contacts.

The policy context

Neurological conditions are disorders of the brain, spinal cord or nerves. The total number of neurological cases in England is estimated to be as high as 12.5 million, or 59,000 cases per clinical commissioning group (CCG). This includes a number of diverse conditions, as set out in the Neurological Alliance publication *Neuro Numbers* (2014). Many neurological conditions are incurable and the majority require life-long support. Almost all neurology patients require prompt access to specialist expertise in order to obtain a diagnosis and begin managing the condition effectively. Whereas more people are coming to survive diseases that have historically been key drivers of mortality (e.g. COPD/cancer) deaths associated with neurological conditions are rising.

The NHS spent over £4.1 billion on neurology services in 2013/14, including funding for over 827,000 emergency admissions. In the opening to the previous *Going the Distance* report, we wrote that “there has been a continuing lack of focus on using this money more effectively to deliver better services.” Unfortunately, this still seems to be true today.

Back in 2012, the Public Accounts Committee (PAC) concluded in its review of neurology services: “services remain well below the quality requirements... coordination of care for individuals is poor, and there is a lack of integration between health and social services....” In 2015 the National Audit Office undertook a progress review of neurology services and the PAC wrote a follow up report in 2016. In its response, the Government failed to commit to several of the PAC recommendations and the neurology community feared much of the progress would stall. However, Public Health England’s commitment, at least until March 2018, to the Neurology Intelligence Network and the establishment of the National Neuro Advisory Group – which is chaired by Professor Adrian Williams, also chair of the Neurology Clinical Reference Group, with secretariat provided by NHS England – provides new momentum and room for optimism.

These two national initiatives also sit alongside NHS England’s RightCare programme and the relatively new NHS Improvement GIRFT (Getting It Right First Time) programme. RightCare is focused on “reducing unwarranted variation to improve people’s health”. Neurology is now included in the RightCare Commissioning for Value packs sent every year to each CCG, enabling the comparison of CCG performance against similar CCGs against a limited set of indicators.¹ RightCare also plans to include migraine and epilepsy

¹ NHS England Commissioning for Value <https://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

in its optimal value solutions pathways work in 2017/18.

Earlier this year, the RightCare program also produced a 'top 5 opportunities' list for each Sustainability and Transformation Plan (STP) area and issued packs highlighting specific healthcare areas with potential to achieve significant improvements. As well as allowing for comparison between peers, it also allows for engagement with STPs in supporting development of future iterations of the plans.

The establishment of the NHS Improvement GIRFT programme is also welcome. The programme will examine patient pathways and the need to address delayed transfers in care, among other things, and will focus on a number of specialties over the course of 2017, including neurology, and has completed its review of neurosurgery. This has the potential to help drive improvements, although it's unlikely that any data for neurology services will be available before 2018.

Despite these new national initiatives, it remains the case that, as reported in 2014, neurology remains virtually invisible under the nationally-set quality and accountability mechanisms set up following the NHS reforms of 2012-13. These are referred to throughout this report as the health and social care quality improvement system. These key mechanisms and incentives are designed to influence the priorities and behaviour of commissioners and providers. The neurological community is deeply concerned that the underrepresentation of neurology across this system has contributed to the lack of attention paid by NHS decision-makers to neurology improvement. One of the areas NNAG is likely to consider is the development of outcome indicators for neurology; this is encouraging and could potentially pave the way for inclusion of neurology-specific measures within national accountability frameworks.

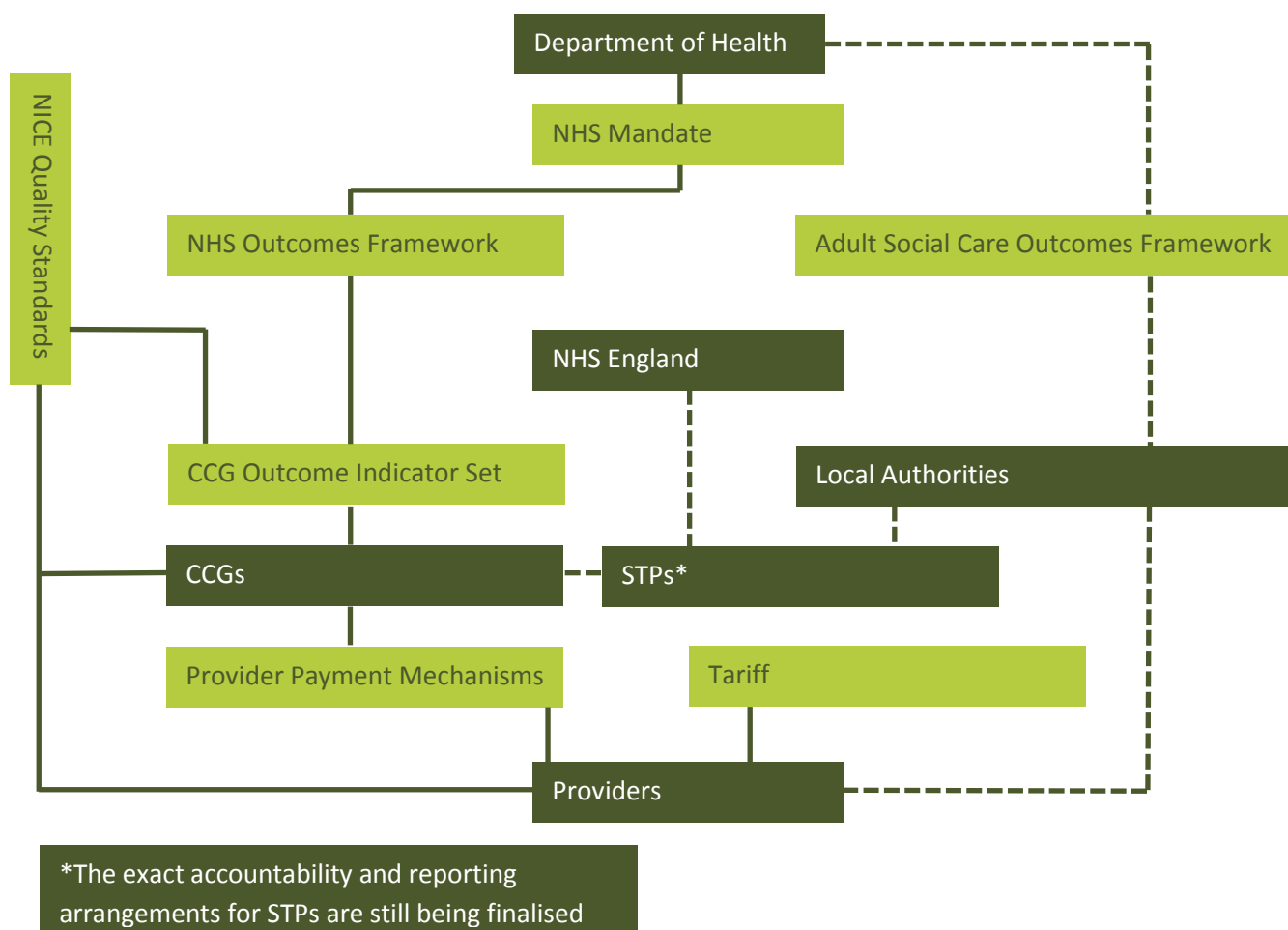
It has become clear that NHS England is reluctant to separate out neurological conditions from the very broad long term conditions banner for the purposes of accountability. Although cross-cutting initiatives aimed at improving long term conditions care may help to drive up the quality of neurological services, these alone will not address the problems that are preventing people with neurological conditions from securing the best possible outcomes. As set out in the report, the evidence is overwhelming that incentives based around the long term conditions grouping have not succeeded in improving commissioning of neurology services.

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 structured

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.

Figure 1:



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

In order to assess how neurological conditions are currently represented within the nationally determined health and social care improvement system, we developed five key tests for the original publication of *Going the Distance* in 2014, and marked current progress using a star rating. In this report we reapply these tests to assess whether the situation has improved or deteriorated in the last two years. We have also added a sixth

test which reflects the new status of Sustainability and Transformation Partnerships as a key element of the health care system. These tests are set out below:

Our six 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.
6. Neurological services are proportionately prioritised in local and regional plans

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



NHS Mandate

The NHS Mandate is the key document by which the Secretary of State for Health holds NHS England to account.² Since 2012, the Mandate has set out the Government's main objectives for the NHS and any further requirements for NHS England, as well as its budget. Every year, the Secretary of State must publish a renewed mandate to ensure that NHS England's objectives remain up to date. The 2017-18 mandate sets out seven headline objectives to steer NHS England's activity and priorities until 2020.

When comparing the 2017-18 Mandate to the 2013-15 Mandates³ assessed in the original *Going the Distance*, it is disappointing to see that only one neurological condition, dementia, is mentioned by name. Until 2015-16 both dementia and stroke were specifically covered in the Mandate. It is positive to see that, as in the 2016-17 document, the Mandate supports the 2020 Dementia Challenge, alongside an expectation for NHS England "to make measurable improvement in the quality of care and support for people with dementia and to increase public awareness." However, this desire for improvement is not extended to all neurology services as a whole.

Similarly, it is positive that the new Ofsted-style CCG assessment framework for 2016-17 proposed in the previous Mandate includes health economy metrics on dementia, alongside cancer, maternity, mental health, learning disabilities and diabetes. However, it is again disappointing that these metrics do not extend further and include a generic neurological measure. As set out in the following section of this report, there is clear evidence that CCGs are underperforming in relation to neurology services, and are not giving them sufficient priority at the local level.

A high proportion of neurology patients have a co-morbid mental health condition. This means that the national priority status afforded to mental health has the potential to

² NHS Mandate 2017-18, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/601188/NHS_Mandate_2017-18_A.pdf

³ A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf

benefit many of the neurology patient group. To date however we have not found this to be the case, in part because there are distinct cognitive, emotional and mental health needs among the neurology patient population. In July 2017 The Neurological Alliance will publish a report highlighting the actions and opportunities to move closer to parity of esteem for neurology patients.

There are a range of other cross-cutting objectives in the Mandate with the potential to support people living with neurological conditions. These include objectives to “achieve better integration of health and social care”, develop “new models of care and General Practice” to improve access and quality of services, and improve the experience for those living with long term conditions. However, experience shows that neurology services do not always benefit from cross-cutting initiatives as they are squeezed out in favour of higher-profile condition groups.

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.

NHS Five Year Forward View

The NHS Five Year Forward View, published in October 2014, was developed by NHS England and its partner organisations such as the Care Quality Commission and Public Health England. It set out a vision for the future of the NHS based around the development of new models of care. It articulates the key NHS priorities for the next few years, and as such is an important document for influencing the priorities of decision-makers throughout the system.

An up-date to the Forward View document was published earlier this year. NHS England released “Next Steps on the NHS Five Year Forward View” which “reviews the progress made since the launch of the NHS Five Year Forward View ... and sets out a series of practical and realistic steps for the NHS to deliver a better, more joined-up and more responsive NHS in England.”

Neither document specifically addresses neurology services, but include cross-cutting objectives such as proposals to expand “multidisciplinary primary care”; better “patient flow” in urgent and emergency care; and improved integration of local care.

To support these developments, the original Five Year Forward View sets out a number of new care delivery models which can be piloted and tested in local areas, known as 'vanguard sites'.

Vanguard sites

NHS England vanguard sites are local areas piloting the development of new models of care.⁴ The first vanguard sites were chosen in 2015 and there are now a total of 50 sites covering five vanguard types: integrated primary and acute care systems; enhanced health in care homes; multispecialty community provider vanguards; urgent and emergency care vanguards; and acute care collaborations.

One of the acute care collaborations is the Neuro Network based around the Walton Centre in Liverpool.

The Neuro Network (The Walton Centre, Liverpool) (Neurology and spinal multi-speciality franchise)

Patient population: 3 million

The Neuro Network aims to develop a high quality and cost effective neuroscience service chain. It is a partnership between the Walton Centre NHS Foundation Trust; Warrington and Halton Hospitals NHS Foundation Trust; Liverpool CCG; Warrington CCG and NHS England Specialised Services Commissioning Team (North). It sits within the Cheshire and Merseyside Sustainability and Transformation Plan (STP) footprint area. As detailed below, this area provided an example of an STP that engaged robustly with neurological conditions.

The programme is building on partners' extensive experience in developing the network models for neurology and spinal services in Cheshire and Merseyside. It is also strengthening the neurological support provided by the Walton Centre to local hospitals, GPs and patients, and extending the spinal model in partnership with The Royal Liverpool & Broadgreen University Hospitals and Aintree University Hospital. This approach is enabling patients to have rapid access, locally, to high quality care from a regional specialist centre.

⁴ NHS England Vanguards <https://www.england.nhs.uk/ourwork/new-care-models/vanguards>

It is positive that neurology is included within the vanguard programme and the results of the initiative will be of great interest to acute neurology services across the NHS. By developing a network model with local providers in the Cheshire and Merseyside area, the vanguard aims to enable people to access specialist neurological expertise closer to their own home, without necessarily having to travel to the Walton Centre itself. NHS England should ensure that neurology continues to be represented and included in the development of new models of care through the vanguard programme.

NNAG

The National Neuro Advisory Group (NNAG) was created in 2016. This group is chaired by Professor Adrian Williams, also chair of the Neurology Clinical Reference Group, with secretariat provided by NHS England. It is intended to provide an alternative leadership and advisory structure for neurology in the absence of the National Clinical Director role. NHS England has committed to provide NNAG's secretariat for two years in order for it to become a self sustaining part of the health system. As a relatively new initiative, NNAG is still developing its work programme, but it is a positive development and has the potential to deliver real change for people with neurological conditions.

Calls 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 neurological conditions, such as early diagnosis or access to rehabilitation services.
- NHS England should ensure that neurology services are included in future vanguard initiatives, with a particular focus on strengthening community provision and access to multidisciplinary care teams.

Key Test 2: Neurological services are explicitly represented in the nationally set health and social care accountability systems



NHS Outcomes Framework

The NHS Outcomes Framework, first developed in 2010 and updated annually,⁵ sets out a range of measurable outcomes and corresponding indicators that can be used to hold NHS England to account for improvements in health outcomes. The Outcomes Framework also plays a pivotal role in steering CCG priorities as it is one of only two sources used to populate the CCG Outcomes Indicator Set (CCGOIS) (see below and Figure 1).

The NHS Outcomes Framework is organised around five major domains, which are also reflected in NHS England's organisational structure:

1. Preventing people from dying prematurely.
2. Enhancing quality of life for people with long term conditions.
3. Helping people to recover from episodes of ill health or following injury.
4. Ensuring that people have a positive experience of care.
5. Treating and caring for people in a safe environment and protecting them from avoidable harm.

As set out in previous Neurological Alliance reports,⁶ there are measures within each of the five domains of the Outcomes Framework that could support improvements in the services provided to people living with neurological conditions. However, generic measures will have no impact on the level of attention paid to neurology by commissioners and providers unless the measures are specifically disaggregated for neurological conditions. It is therefore especially disappointing to note that there has been no improvement in the number of neurology-specific indicators since 2014.

Of the 66 indicators included in the 2016-17 Outcomes Framework, just two active

⁵ NHS Outcomes Framework 2016 to 2017 <https://www.gov.uk/government/publications/nhs-outcomes-framework-2016-to-2017>

⁶ Neurological Alliance, *Measuring Up: improving the collection of neurological data and intelligence*, 2014, <http://www.neural.org.uk/store/assets/files/380/original/Final - Measuring up 30 April 2014 .pdf>

indicators relate to neurological conditions.⁷ These are:

- (2.3 ii) Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s;
- (2.6 i) Estimated diagnosis rate for people with dementia

In addition, there are two additional indicators in development. These are:

- (2.6 ii) A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia
- (3.4) Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months.

Although it is positive to see that dementia, epilepsy (under the age of 19) and stroke have been drawn out for specific focus within this Outcomes Framework, they are just a fraction of the whole family of neurological conditions. Consequently, this Outcomes Framework provides no clear incentive to focus on improving neurology services as a whole. If NHS England, commissioners and clinicians are to successfully work together to improve neurological outcomes, it is vital that neurology-wide 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.
- NNAG should urgently look into the development of outcome measures for neurology

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. Updated annually, it is used by NHS England to hold CCGs to account for their contribution towards achieving the ambitions set out in the NHS Outcomes Framework. CCGOIS indicators are drawn largely from the NHS Outcomes Framework, as well as from NICE quality standards.

As the key decision-makers on locally commissioned health services, CCGs play a crucial role within the NHS and are well-placed to have a positive impact on the quality of

⁷ Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) <http://content.digital.nhs.uk/ccgois>

neurology services within their localities.

However, since publication of the original Going the Distance report in 2014, a new structure is in place within the healthcare system – STPs or Sustainability and Transformation Plans, now known as Sustainability and Transformation Partnerships. There is more detail on STPs in Key Test 6 but it is currently unclear what the expected metrics and benchmarking for STPs will be, although it is believed that the NHS will publish metrics later this year that will align with NHS Improvement's Single Oversight Framework.

The existing metrics for CCGs will remain in place for the foreseeable future.

Unfortunately, there has been no improvement in the representation of neurology in the CCGOIS since 2014. Nine indicators specifically related to neurological conditions are included within a total of 71 in the 2016-17 CCGOIS. These again relate only to three conditions: dementia, epilepsy in under 19s, and stroke. As with the NHS Outcomes Framework, it is essential that more neurology-wide measures are included to cover the spectrum of neurological conditions so that commissioners and clinicians are incentivised appropriately to improve outcomes for the whole neurological patient community.

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.

Adult Social Care Outcomes Framework

The majority of measures included in the annually-reviewed Adult Social Care Outcomes Framework⁸ are generic and apply to people of all ages with all types of conditions and disabilities. There is one indicator relating specifically to neurology, which is currently a placeholder only (i.e. a need to measure this outcome has been identified, and one or more potential sources have been identified, but an indicator is yet to be developed, and publication is not imminent). This is Placeholder 2F: A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia.

⁸ The Adult Social Care Outcomes Framework 2015/16
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375431/ASCOF_15-16.pdf

The NAO reported⁹ that there was £8.2 billion spending by local authorities on social care services for adults with a physical disability in 2013-14. It is estimated that around a quarter of these adults live with a neurological condition. As social services data is not usually broken down by condition, it is not possible to determine precisely the amount of social care spending related to neurological conditions. Failing to gather this information makes it impossible both to measure how the Outcomes Framework is helping people with neurological conditions and to identify improvement areas. Research conducted by Sue Ryder 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.¹⁰

In this context, and given the complex nature of many neurological conditions, there is a clear argument for focusing more closely on the question of whether people with neurological conditions are adequately supported by the social care system. Delays in accessing social care can have major ramifications for NHS services as well, as patients are unable to be discharged from acute settings until arrangements are made for their social care, creating blockages and delays throughout the system.

However, in addition to the ideal of having a neurology-specific measure, there would also be considerable benefit in capturing data on the long term conditions those receiving adult social care live with. A field on long term conditions added to the demographic data questions in just one of the surveys that feeds into the Adult Social Care Outcomes Framework could capture data on many neurological conditions and other long term conditions, allowing for a clearer picture of the context for and needs of those requiring social care.

Call to action

- A selection of 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 problem areas that need to be addressed.
- A long term condition specific measure should be included in at least one of the surveys informing the Adult Social Care Outcomes Framework, to provide better data on the needs of those with long term neurological conditions.

⁹ National Audit Office, *Services for people with neurological conditions: progress review*, 2015
<https://www.nao.org.uk/report/services-for-people-with-neurological-conditions-progress-review/>

¹⁰ Sue Ryder, *The forgotten millions: Social care for people living with neurological conditions – a blueprint for reform*, 2012, <http://www.sueryder.org/how-we-help/policy-and-campaigns/our-campaigns/past-campaigns/forgotten-millions>

Key Test 3: NICE quality standards, clinical guidelines and support for commissioners have been developed covering the range and breadth of neurological conditions



NICE quality standards and clinical guidelines

NICE develops a range of materials aimed at setting and improving service standards across both health and social care. The most significant in the context of this report are quality standards and clinical guidelines. Quality standards are a concise set of prioritised statements designed to drive measurable improvements relating to a particular aspect of 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', which are web-based resources that assist quality improvement and service redesign.

All three are significant mechanisms for setting standards of care that patients can expect, and ensuring that commissioners and providers understand the needs of patients and 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.

As of May 2017, there were 22 published clinical guidelines relating to neurological conditions, covering 17 different conditions (including stroke and dementia). In addition, there are several guidelines currently in development.¹¹

It is particularly positive that in 2015 NICE began work on a clinical guideline covering suspected neurological conditions in primary care, as recommended by the PAC in 2012. This guideline is scheduled for publication in January 2018 and will aim to support primary care practitioners to provide an initial assessment of patients presenting with possible symptoms of a neurological conditions, and to refer them to the right specialist for further investigation if required. Given the complexity and comparative rarity of many neurological conditions, this is a very welcome source of support for clinicians. To have the strongest impact, this should be a symptom-led guideline, supporting primary care

¹¹ NICE guidance, <https://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions>

practitioners to take the right steps for further investigation, without excluding any possible neurological conditions.

As of August 2016 there are 15 published quality standards relating to neurology (including stroke and dementia).¹² This represents a small but welcome improvement compared to 2014, when only eight published quality standards related to neurology. However, there are still major gaps in clinical guidance and quality advice across the spectrum of neurological conditions. This means that too often, commissioners are not supported to understand the needs of neurology patients and the requirements expected of services.

The lack of commissioning guidance, health quality standards and guidelines for the vast majority of neurological conditions means that commissioners are lacking the vital support they need to commission these services effectively. NICE must continue to develop clinical guidance and quality standards to ensure that the full range of neurological conditions is covered.

Calls to action

- NICE's generic clinical guideline covering suspected neurological conditions in primary care should take a symptom-led approach, and should not exclude any neurological conditions (including those with existing guidance).
- 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 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.

¹² NICE guidance, <https://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions>

Key Test 4: There are nationally collated, reliable, consistent and useful data on all neurological conditions, services and outcomes



Clinical audit, data and intelligence

The lack of reliable data available on neurology within NHS health and social care is a key cause of the under-representation of neurology in accountability and quality improvement systems, which rely on high-quality data to benchmark service standards and measure progress in patient outcomes and experiences of care. This is a longstanding issue which was noted by the PAC in its 2012 neurology review, finding that the lack of data meant that there was “no empirical baseline from which progress could be measured nationally or locally for health and social care, and the Department (of Health) has no way of assessing what resources and activities result in the best outcomes.” The PAC recommended that the Department should develop a neurological data set covering resources, services and outcomes to help address this deficiency.

Since that recommendation was made there have been some important steps forward on data and intelligence for neurology services. In 2013, the Health and Social Care Information Centre (HSCIC) published the Compendium of Neurology Data 2012-13¹³, which collated national-level data on neurology. This was supported by the establishment of the NIN, supported by Public Health England and NHS England, which presented the HSCIC data, along with supporting briefings to explain the significance of the data collected. Its outputs so far include:

- Profiles with data about emergency hospital admissions for twelve common neurological conditions
- A detailed data profile and analysis of an epilepsy care pathway
- Disease classification codes used when processing data sets for neurological diseases and conditions in England
- Data briefing and tables investigating adult neurology outpatient services in England including the availability of locally-provided services.

¹³ Health and Social Care Information Centre, Compendium of Neurology Data 2012-13, www.hscic.gov.uk/catalogue/PUB13776

In addition to national-level data and analysis, the NIN has also contributed to NHS England's RightCare programme. RightCare is an initiative to reduce "unwarranted variation to improve people's health". It makes use of lots of data sets to identify areas where individual CCGs and STPs could save money and deliver better outcomes by comparing performance with 'demographically similar peers'.

Neurology is now included in Commissioning for Value packs sent every year by NHS England to each CCG, which enables the comparison of CCG performance against similar CCGs against a limited set of indicators.

Earlier this year, the program also produced a 'top 5 opportunities' list for each STP and issued packs highlighting specific healthcare areas with potential to achieve significant improvements. RightCare also plans to include migraine and epilepsy in its optimal value solutions pathways work in 2017/18.

The establishment of the NHS Improvement GIRFT (getting it right first time) programme is also a welcome and promising development. The programme will examine patient pathways and the need to address delayed transfers in care, among other things, and will focus on a number of specialties over the course of 2017, including neurology. It has already completed its review of neurosurgery. This has the potential to help drive improvements, although it's unlikely that any data for neurosurgery services will be available before 2018.

The work of the NIN has been an extremely positive development which has allowed more scrutiny of the performance of neurology services than was previously possible. The collection and publication of accurate, consistent and regular data on neurological conditions, services and outcomes is critical to identifying areas for improvement and encouraging the spread of best practice among commissioners and providers. It also enables patients, carers and their representatives to play an active part in examining performance data and holding local areas to account. The work of the NIN has been significant in enabling effective scrutiny of performance and outcomes, but must be regarded as a foundation on which to build a comprehensive system of neurological data capture and analysis in the coming years. While we now know that the NIN is funded until March 2018, it requires a long term, multi-year funding settlement in order to be able to plan and deliver a robust, long term programme of work.

As well as supporting and expanding the work of the NIN, NHS England should develop improved mechanisms to capture the experience of people living with neurological conditions. There is currently no official survey of neurology patients, despite the clear value provided by patient surveys in other condition areas, such as cancer. Although

neurology patients are surveyed as part of cross-cutting measures such as the NHS-led GP Patient Survey,¹⁴ the published results are not broken down by condition. The Neurological Alliance undertook a survey in 2016 of those living with neurological conditions with responses from 7,048 people. This resulted in the report *Falling Short: How has neurology patient experience changed since 2014?*¹⁵ This was a repeat of the survey carried out in 2014, with responses from almost 7,000 people living with neurological conditions, published in 2015 as *The Invisible Patients: Revealing the state of neurology services*.¹⁶ The data captured over these two surveys provides a wealth of insight into neurology services from the perspective of those who use them, revealing major issues in areas such as access to a diagnosis and to appropriate specialist care and support.

However, an NHS England-led patient survey would be likely to reach a larger audience and produce even more detailed data to guide neurology service improvement in the future.

Call to action

- Public Health England and NHS England should jointly develop a funding plan to ensure support for the NIN beyond 2017-18, for a minimum of five years, providing sufficient capacity to produce ongoing data and intelligence outputs for neurology at the national level.
- NHS England should carry out an annual Neurology Experience Survey of patients living with neurological conditions, similar to its Cancer Experience Survey, and publish the results in an accessible and timely fashion.

¹⁴ GP Patient Survey, <https://gp-patient.co.uk/>

¹⁵ Neurological Alliance, *Falling Short: How has neurology patient experience changed since 2014?*, 2017, <http://www.neural.org.uk/updates/278-New-Neurological-Alliance-patient-experience-report-2017>

¹⁶ Neurological Alliance, *The Invisible Patients: Revealing the state of neurology services*, 2015, <http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report>

Key Test 5: Improvements to neurological services are being incentivised through provider payment and incentive schemes



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 key 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 quality improvement objectives. CQUIN payments play an increasingly important role in driving quality improvements in the NHS, and constituted 2.5% of provider tariff in 2015-16, as they will in 2017-19.¹⁷ The 2015-16 national CQUIN scheme was available only to providers that chose the Enhanced Tariff Option (ETO) for the year. 88% of trusts and foundation trusts selected the ETO and are therefore eligible for the scheme.¹⁸

The majority of CQUIN goals are selected locally. Although there is no comprehensive database of locally-set CQUINs, the evidence suggests that there is relatively low representation of neurology. An analysis of local CQUINs utilised by trusts in 2010-11 revealed that less than 1% of the indicators were related to neurology.¹⁹ The majority of neurological conditions are not well-represented through CQUINs although improvements to the acute/urgent care pathway for stroke have featured with a number of providers. In addition, a 2014 analysis of a local CQUIN for measuring and improving the quality of inpatient care for Parkinson's disease in Sunderland Royal Hospital found that it led to 'a

¹⁷ Commissioning for Quality and Innovation (CQUIN) <https://www.england.nhs.uk/wp-content/uploads/2016/11/cquin-2017-19-guidance.pdf>

¹⁸ Commissioning for Quality and Innovation (CQUIN) – guidance for 2015-16 <https://www.england.nhs.uk/wp-content/uploads/2015/03/9-cquin-guid-2015-16.pdf>

¹⁹ NHS Institute for Innovation and Improvement, Commissioning for Quality and Innovation (CQUIN) payment framework, 2010/11 Summary of indicators, via: http://www.institute.nhs.uk/commissioning/pct_portal/cquin.html

sustained improvement in quality of care', and concluded that 'it is possible to demonstrably improve quality of care in patients with complex long term neurological conditions.'²⁰ To encourage wider use of local CQUINs relating to neurology, NHS England should develop additional guidance to support commissioners to develop and use neurology CQUINs effectively.

A number of CQUINs are set nationally. In 2016, for the first time, NHS England published "a two year scheme" to "provide greater certainty and stability". The Guidance for 2017-19²⁷ sets out 13 national indicators. One of the goals for 2015-16²⁸ focused specifically on improving the identification, assessment and support of patients with dementia and other causes of cognitive impairment. This is not reproduced in the 2017-19 guidance. The 2017-19 guidance does include two measures that could arguably be helpful in supporting those with neurological conditions:

6. Offering Advice and Guidance - improve GP to access consultant advice prior to referring patients in to secondary care.
11. Personalised care and support planning - to identify the groups of patients who would benefit most from the delivery of personalised care and support planning and provide this support to them.

However, the lack of a specific measure for neurology is disappointing and a missed opportunity to help secure improvements in patient care for those living with a neurological condition.

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.
- The next CQUIN guidance document should include a dementia CQUIN goal, as per the 2015-16 guidance, or similar to help support improvements in care for the neurology patient population.

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. A tariff for Parkinson's disease was

²⁰ *Measuring and Improving quality of inpatient care for Parkinson's disease in Sunderland Royal Hospital: the CQUIN PD report*, December 2014, <http://www.nescn.nhs.uk/wp-content/uploads/2014/05/CQUIN-PD-Feb-2015.pdf>

announced in 2013, setting out a range of standards aimed at improving patients' experience of care and their health outcomes.²¹ In addition, a tariff for acute stroke care has been developed which aims to support patients' access to an acute stroke unit and to brain imaging within an appropriate timeframe. Providers which can prove they meet these levels of care will qualify for greater funding.²²

Research in 2012 on best practice tariffs by the Audit Commission found mixed results.²³ While they were shown to focus attention on particular aspects of clinical practice, they can be complex to implement.

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.

²¹ New Best Practice Tariff announced by the Government for Parkinson's
<http://www.parkinsons.org.uk/professionals/news/5-march-2013/new-best-practice-tariff-announced-government-parkinsons>

²² Department of Health best practice tariffs <https://www.gov.uk/government/news/update-to-best-practice-tariffs>

²³ Audit Commission, Best practice tariffs and their impact, November 2012
<http://webarchive.nationalarchives.gov.uk/20150211161456/http://archive.audit-commission.gov.uk/auditcommission/nationalstudies/health/financialmanagement/Pages/Bestpracticetariffs.aspx.html>

Key Test 6: Neurological services are proportionately prioritised in local and regional plans



Clinical Commissioning Groups (CCGs) – Neurological Alliance audit data

Clinical Commissioning Groups came into being in 2013, following the passing of the 2012 Health and Social Care Act. CCGs are clinically-led statutory NHS bodies responsible for the commissioning of health care services for their local area. There are now 207 CCGs in England (as of April 2017). Given that they are responsible for commissioning which accounts for approximately two thirds of the total NHS England budget²⁴, it is important to understand how they commission services for the local population and how neurology is prioritised and supported at CCG level.

In 2016 the Neurological Alliance carried out a quality of commissioning audit, issuing Freedom of Information requests to all CCGs in England. The results show that:

- 17% (n=36) of CCGs have made an assessment of the total costs of neurological services in their area
- 20.5% (n=43) of CCGs have made an assessment of the prevalence of neurological conditions in their area
- 21% (n=44) have made an assessment of the number of people using neurological services in their area

The conclusion is that CCG engagement with neurology is poor, compared to other condition groups.

This exercise was a repeat of the first CCG audit carried out by the Alliance in 2014 and disappointingly there's very little change, with the 2014 figures – given immediately below - also indicating low CCG engagement with neurology:

- Only 14.7% of CCGs had made an assessment of local costs relating to the provision of neurology services.
- 26.2% and 20.4% of CCGs had definitively assessed the prevalence of neurological conditions and the number of people using neurological services within their area.

²⁴ NHS Clinical Commissioners - About CCGs <https://www.nhscc.org/ccgs/>

These results reflect neurology's low representation in the CCGOIS (CCG Outcomes Indicator Set, as referred to in section 2) and again demonstrate the need for measures to be included in the CCGOIS covering the spectrum of neurological conditions.

However, there may be some moves in the right direction as the 2016 audit included a new question on whether or not CCGs had received and reviewed their "neurology focus pack", as sent out by RightCare in April 2016 as part of its Commissioning for Value Programme:

- 159 CCGs (76%) reported receiving the pack
- 151 CCGs (72%) have reviewed the pack
- 58 CCGs (28%) have taken specific action on neurology as a result

Sustainability and Transformation Plans (STPs) – Sue Ryder audit

In 2016 NHS England introduced sustainability and transformation plans - now often referred to as sustainability and transformation partnerships - which represent a longer-term, place-based approach to planning services. Commissioners and providers came together to form 44 local partnerships, or 'footprints', charged with co-producing five-year plans to narrow the gaps in the quality of care, their population's health and wellbeing, and in NHS finances. In late 2016, the first drafts of these plans were made public.

There are no specific requirements relating to neurology for STPs. However, the introduction of longer-term strategic planning covering all commissioned services is potentially a step forward for neurology services, which have suffered from fragmentation and confusion over the division of commissioning responsibilities.

To understand how STPs are engaging with neurology Sue Ryder audited the plans in three different areas: 1) neurology (including all of neurology and neurological conditions but excluding stroke and dementia), 2) stroke and 3) dementia. (See the next section for details of the methodology.) The audit found:

- STPs most commonly engaged with neurology by engaging with stroke/dementia
 - Stroke and dementia are mentioned more times throughout the STP documents than all the rest of neurology combined (see table below).
 - Other than stroke and dementia, individual neurological conditions were overlooked in STPs (with the partial exception of brain/spine services)
 - Stroke and dementia aside, STPs took a more general approach to neurology, focusing on "neurology" or "neuro-" services e.g "neuro-rehab".

- The quality of STPs plans for neurology was poor overall, although plans for stroke and dementia were stronger.
 - About 40% of STPs included no substantive plans for neurology. 14 and 20% included no substantive plans for dementia or stroke respectively.
 - Under 20% of STPs contained plans for neurology that were rated as 'medium' or 'high' in terms of substantiveness. The quality of STPs' engagement with stroke and dementia was stronger: a little over 40% of the plans for both were awarded a 'medium' or 'high' rating for substantiveness in the audit.
- STPs that had more substantive plans for neurology were more likely to have stronger plans for stroke, and for dementia.
- Cheshire & Merseyside STP, containing the Walton Centre neuro network vanguard, had well-rated plans for engaging with stroke, dementia and neurology/other neurological conditions.

Area	Total mentions across all STPs	Quality of STP engagement with this area, by number of STPs	Recurring themes connected to this area in STPs
Neurology (excluding dementia/stroke)	134	High - 3 (6.82%) Medium - 5 (11.36%) Low - 19 (43.18%) None - 17 (38.64%)	Specialised service reconfiguration
Dementia taken on its own	306	High - 4 (9.09%) Medium - 15 (34.09%) Low - 19 (43.18%) None - 6 (13.64%)	Maintaining or meeting national dementia diagnosis target
Stroke taken on its own	302	High - 4 (9.09%) Medium - 14 (31.82%) Low - 18 (40.91%) None - 8 (18.18%)	Acute service reconfiguration / pathway review

What NHS RightCare tells us about neurology and STPs

As noted above, neurology is one of the condition areas covered by the RightCare programme's analysis, and this provides additional context for STPs and their engagement with neurology. Each STP footprint now has a RightCare pack which highlights key potential opportunities for improving outcomes and spend. The RightCare initiative identified a 'top five' list of priority areas for each STP to investigate for potential improvements across three areas: 'Spend', 'Outcomes' and "Spend and Outcomes". These packs were not available when STPs were being drafted, but do provide an important picture of the challenges that STPs have inherited and give a sense of their opportunities for improvement going forwards.

- 31/43 (72%) of STPs had at least one mention of neurology as a top five potential priority improvement area in their RightCare packs.
- The RightCare programme mentions neurology as a potential priority opportunity area for spend in 26 STPs and for outcomes in 13 STPs.
- 8 STPs had improvement opportunities for neurology flagged by RightCare across each of the three areas it looked at.
- 7 STPs had neurology mentioned as a top five priority in two out of the three areas it looked at.

STPs and the processes surrounding them are changing at pace. They are not bound by many of the mechanisms and frameworks that constrain CCGs or channel their activities. The data that RightCare provides is vital for helping STPs steer and refine their future plans. It also helps articulate the need for improving neurological services, and prompts practical follow through on these conversations (e.g. by examining what one's demographic peers are doing).

Decision-makers in STPs that did not engage robustly with neurology might believe that there are more pressing issues to address as a priority, or they might be unaware of the issues for neurological services in their area. Now that RightCare data exists for STPs, the importance of engaging with neurology is made clear.

Call to action

- STPs should engage more with neurology and replicate existing good practice.
- Additional clarity is needed urgently regarding the division of responsibilities for specialised commissioning, given that a significant number of STPs mention neurology in connection to specialised service reconfiguration.

- NHSE should actively support STPs to engage with the RightCare programme to implement improvements to neurological services.
- NNAG should lead a piece of work encouraging and supporting STPs and CCGs to follow-through on opportunities identified by RightCare.
- The wider neurological community should help identify good practice, as well as highlighting difficulties or gaps that STPs seem to be running up against.
- Further analysis should be conducted of the strongest STPs to see what lessons there are that might be replicated elsewhere.
- STPs should engage with individuals with neurological conditions in working up their new plans.
- Given the strong plans for neurology in the STP near the existing neuro vanguard site, additional vanguard sites should be created to help drive further improvements in neurological care.
- When the accountability measures for STPs are developed, they should reflect the Right Care assessments sent to each STP and detail the steps taken to address the top 5 areas identified for improvement.

STP audit methodology

A 'keyword search' was conducted for each STP document, looking for "neurology", any other terms that began with "neuro" (e.g. neuro-rehabilitation), and some major neurological conditions (spinal, spine, brain, Epilepsy, Multiple Sclerosis, Motor Neurone Disease, Huntington's, Migraine, Parkinson's, Stroke and Dementia.) This gave an initial indication of the distribution of plans connected to neurology across STPs.

Each STP was examined on the basis of the substantiveness of its plans for neurology. STPs were separately audited by two people, with disagreements reconciled afterwards. Grades were awarded as follows:

- None: Either not mentioned at all, or not mentioned as part of an actual plan (this rules out content that is, for example, part of a case study)
- Low: Mentioned without any expanded detail or context, and/or only included under a broad aim e.g. specialised service reconfiguration)
- Medium: Some specificity of targets mentioned, but incomplete array of measures and lack of detail.
- High: Expanded detail in dedicated section including specific targets, aims and timescale(s).

Summary of test scores

Test	'Going the Distance' 2014	'Going the Distance 2' 2017
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.	★☆☆☆☆	★☆☆☆☆
6. Neurological services are proportionately prioritised in local and regional plans	Test not included in 2014 report	★★☆☆☆

Conclusion

Overall, while it is encouraging that in two areas (key tests three and four, relating to NICE and data) there has been some improvement since 2014, there has been a disappointing lack of progress in terms of national incentives since we last assessed neurology's level of representation in the NHS.²⁵ In addition, the new test that we have introduced in this report - looking at the prioritisation of neurological services in local and regional plans – identified considerable room for improvement. It remains the case that neurology is heavily under-represented in the incentive and accountability architecture created following the NHS reforms of 2012-13. It is crucial that NHS England considers how to incentivise local commissioners to focus on improving their neurology service offer, and works with the Department of Health to develop appropriate indicators for inclusion in the NHS Outcomes Frameworks and other incentive frameworks. The current focus on dementia, epilepsy and stroke only, while positive for those conditions, leaves a vast spectrum of neurological conditions with no representation whatsoever.

In addition, it is essential that neurology services are supported by effective clinical leadership, accessible and accurate data, and strong local and regional networks capable of spreading best practice throughout the system. The establishment of the National Neuro Advisory Group is welcome in this respect, we would like to see NNAG playing a leading role in developing a set of outcome measures for neurology. We also call on NHS England and Public Health England to develop a clear long term funding plan for the NIN to ensure an ongoing supply of vital data and intelligence on neurological conditions and services. We would also like to see this data and intelligence, along with the Right Care packs, used by both CCGs and STPs to understand the need for and opportunities to prioritise improvements in the services for those with neurological conditions, thus supporting the thousands of people within each CCG area who live with such a condition.

We believe it is essential that key stakeholders such as the Department of Health, NHS England, Public Health England and NICE use the recommendations in this report to “go the distance” on neurological service improvement. The six key tests set out in this report 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 to see significant improvement in star ratings in future assessments, reflecting far-reaching improvements throughout the health and social care system.

²⁵ Neurological Alliance, *Going the distance: National calls to action to drive neurological service improvement in England*, 2014, <http://www.neural.org.uk/updates/233-New-report-on-driving-neurological-service-improvement-launched>

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<https://www.england.nhs.uk/wp-content/uploads/2015/03/9-cquin-guid-2015-16.pdf>

¹⁹ NHS Institute for Innovation and Improvement, Commissioning for Quality and Innovation (CQUIN) payment framework, 2010/11 Summary of indicators, via:
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²⁰ *Measuring and Improving quality of inpatient care for Parkinson's disease in Sunderland Royal Hospital: the CQUIN PD report*, December 2014,
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