



# The Invisible Patients

Revealing the state of neurology services

January 2015

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## About us

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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## Foreword

The publication of *The Invisible Patients: Revealing the state of neurology services* rounds off a hugely busy 2014 for both the Neurological Alliance and the neurological community as a whole. Over the past year we have seen some enormously important developments for which we have long been campaigning, from the appointment of a National Clinical Director for Neurological Conditions to the creation of the first ever Neurological Dataset and the inaugural Neurology Intelligence Network. However, there is no time to rest on our laurels.

The unfortunate truth is that neurology is still an under-prioritised and under-resourced field within our health and care system. We know from our work with patients, the voluntary sector, clinicians and commissioners that there is far too much variation in service quality and accessibility, while neurology remains under-represented in the key incentive and accountability systems that guide NHS priorities and activities. That's why we decided to gather data from both patients and commissioners to get a clearer picture of what's really happening on the ground.

The picture that emerges is one of a system battling its own flaws and limitations. We should all be encouraged by the majority of patients who report satisfaction with the care and treatment they receive from committed professionals around the country. However, it is clear that there is far more that could be done to improve care. Until commissioners give proper attention to neurology, taking a strategic approach to designing the best possible care pathways, too many people will miss out on the care they need. Similarly, outcomes will never be as good as they should be until people have quick and routine access to all necessary care and support services, including relevant specialist expertise.

For too long, people living with neurological conditions have been the 'invisible patients', often marginalised by a system that doesn't understand their conditions or their needs. This has to change. I am delighted that this report provides a vital first step in exposing the true state of neurological services today. It is time for the health and care system to open its eyes to the needs of the millions of people who live with these complex and challenging conditions. They must be invisible no longer.

Arlene Wilkie  
Chief Executive, Neurological Alliance

## Executive summary: Key findings

### Diagnosis

- **31.5% (n=2,140)** of respondents had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist.
- **39.8% (n=2,357)** of respondents waited more than 12 months from when they first noticed their symptoms to seeing a neurological specialist.
- **58.1% (n=3,402)** of respondents have experienced problems in accessing the services or treatment they need.
- Only **26.2% (n=50)** and **20.4% (n=39)** of CCGs respectively definitively assessed the prevalence of neurological conditions and the number of people using neurological services locally.

### Treatment and care

- **71.5% (n=4,603)** of respondents have not been offered a care plan to help manage their condition.
- **37.4% (n=651)** of respondents noted that at least to some extent their care plan responds well to their changing needs.
- **60.4% (n=3,537)** of respondents noted the majority of their contact is with a GP or hospital doctor (**47.6%, n=2,788**).
- The majority of care received by respondents is at a hospital clinic (**38.6%, n=2,656**), at home (**26%, n=1,792**) or a local/GP clinic (**20.8%, n=1,432**).

### Patient satisfaction and involvement

- **72.8% (n=4,261)** of respondents reported their care and treatment as either 'some help' or 'excellent'.
- **66.9% (n=3,913)** of respondents felt that the different people treating them worked well together to at least some extent.
- **71% (n=4,539)** of respondents feel to some degree that they are involved in making choices about their care and treatment.
- **59.1% (n=3,461)** of respondents note that they have not been offered an opportunity to take part in a clinical or research study but would be interested to do so if an opportunity arose.
- Only **34.1% (n=69)** of CCGs have mechanisms in place to include patients in decision-making processes, and only **33% (n=63)** obtain feedback in regards to the services they commission.

## The 'invisible patients'

- **14.7% (n=28)** of CCGs have made an assessment of local costs relating to the provision of neurology services.
- Only **19.9% (n=38)** of CCGs have definitively been in contact with their NHS England local area team about the commissioning of neurological services in the last 12 months.

## Integration and communication

- **66.9% (n=3,913)** of respondents felt that the different people treating and caring for them worked well to at least some extent.
- Only **38.7% (n=74)** of CCGs have taken action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions.
- **44% (n=84)** of CCGs have engaged with their local strategic clinical network (SCN) regarding the commissioning of neurological services.

## Executive summary: Recommendations

- **Every CCG should collate up to date and accurate local neurology data, underpinned by routine and rigorous assessments of the prevalence of neurological conditions and of the number of people using neurological services locally.** Only with robust local information can CCGs meet the demand for per patient cost data to be available and rise to the challenge of taking more responsibility for specialised services
- **The Department of Health and NHS England should ensure that the time taken to reach a stable and accurate neurological diagnosis following first consultation is tracked and scrutinised with information shared widely to encourage and identify best practice.** The lack of progress in ensuring a good patient experience of timely and accurate diagnosis makes greater national scrutiny now essential in order to stimulate local improvement
- **NHS England should develop a robust action plan, building on the work of NHS Improving Quality, to raise usage of care plans nationally.** It is time to go beyond providing guidance on how to support the development of care plans and undertake additional activity to increase use
- **Local and national commissioners should regularly review utilisation of the care and support services available to patients and ensure that every person with a neurological condition has appropriate and rapid access to the full range of services that they need.** Only through a combination of closer review of utilisation and efforts to ensure access will capacity or ease of access barriers to services be identified and addressed
- **All CCGs should ensure that mechanisms are put in place to encourage and capture patient feedback and input in regards to the quality and development of local neurology services.** There is a danger that CCGs rely on roll-out of the Friends and Family Test to capture patient feedback, but deeper insights on experiences of neurological services are essential to drive patient-centred improvement
- **CCGs should work in partnership to identify clinical and research trial opportunities locally and support the appropriate sharing of information on such opportunities with patients.** A shift to clinicians presenting clinical trial opportunities to patients as a default part of discussions is key to ensuring that patients are aware of options and feel able to consider them without inappropriate apprehension

- **Every CCG should ensure that it has made a full assessment of costs relating to the provision of neurology services to people in their area including a clear understanding of wider costs for services commissioned by NHS England.** As the system looks for efficiencies and savings, and as consideration is given to where responsibility should lie for the commissioning of certain services, CCGs must take responsibility for equipping themselves to ensure the delivery of an efficient health and care system for neurology, further supported by the assessment of local prevalence and service usage among neurology patients
- **CCGs should engage in regular communication with their NHS England area team about the commissioning of neurological services, taking a proactive approach to ensuring a shared and full understanding of neurological service commissioning, sharing information with the Neurology Intelligence Network.** There has been too much confusion around the split of responsibilities for neurological services and it is essential that CCGs take an active role in resolving areas needing more clarity and agreement
- **CCGs should actively encourage the integration of primary, secondary, tertiary and social care services for people with neurological conditions, including those provided by the voluntary sector, supporting continuity of care across the whole patient pathway.** People with neurological conditions have a range of needs, many of which are supported from outside of formal neurological services. The wider patient experience needs a champion for integration, and CCGs are uniquely placed to take this role
- **CCGs should engage with their local dementia, mental health and neurology SCN regarding their local neurological strategy, with NHS England establishing a formal requirement for them to do so.** Only through a higher level of engagement and interaction will SCNs be able to deliver on their core purpose of improving local services



## Methodology

The purpose of this report is to provide a comprehensive picture of what is happening in relation to neurological services, patient experience and outcomes across the country. Underpinned by a neurological patient experience survey and quality of commissioning audit, the analysis has enabled the identification of discrepancies between people's experiences of services and commissioners' perceptions of how services are being delivered.

### Neurological patient experience survey

The development of the neurological patient experience survey was supported by the Neurological Alliance's steering group members. The survey was hosted online using the survey development programme, *SurveyMonkey*, and opened on 30 June 2014 until 17 September 2014.

At the survey's close the final response rate stood at 6,916.

Details of the individual patient experience survey questions can be found in **Annex 2**, with a summary of the survey responses found in **Annex 3**.

### Quality of commissioning audit

The quality of commissioning audit was undertaken using freedom of information requests under the Freedom of Information Act 2000, and was supported by the Neurological Alliance's steering group members.

A series of nine requests were submitted in total by the Neurological Alliance to all CCGs and NHS England in June 2014. Details of the information requested from commissioners can be found in **Annex 4**, with an overview of the audit's responses found in **Annex 5**.

In total, 191 responses from CCGs were received, representing a response rate of 91%. The list of those who responded is in **Annex 6**. NHS England also provided a response. Differences in the quality and quantity of information supplied by CCGs was observed. As a result of variation in the detail of responses, the information provided has been subject to analysis and interpretation in the writing of this report.

## Data

The neurological patient experience survey and quality of commissioning audit produced a wealth of data which the Neurological Alliance is committed to sharing with the neurological community, in order to support better understanding of neurology services throughout the country.

Following extensive efforts to ensure the data we have collated is entirely anonymised, including the removal of identifiable fields from the patient experience survey, such as elements of a respondent's demographic and free text boxes, we have made the data captured during the development of this report publically available, hosting the two datasets on our website ([www.neural.org.uk](http://www.neural.org.uk)).

Neurological patient experience survey: <http://bit.ly/1AXqwye>

Quality of commissioning audit: <http://bit.ly/1xl8v5B>

We fully support and encourage our members and colleagues within the community to engage with the data as they see appropriate. The key findings from both projects have been set out throughout this report, with further information available on a regional and local level including, but not limited to:

- The experiences of patients (by condition and region) throughout the diagnostic and treatment pathway
- Neurology commissioning intentions of CCGs
- CCG engagement with patients in the commissioning of neurology services

## Introduction

The last 18 months has seen a real shift in the neurological policy landscape.

To take stock for a moment: in 2013 and 2014 we saw the formation of the Mental Health, Dementia and Neurological Conditions SCN; the appointment of a National Clinical Director for Neurological Conditions, Dr David Bateman; the publication of the Health and Social Care Information Centre's *Compendium of Neurology Data*<sup>1</sup>; and the creation of Public Health England's Neurology Intelligence Network<sup>2</sup>. The Neurological Alliance called loudly for these developments, as did its member organisations and people across the neurological community. But change in policy is only meaningful if it leads to change in practice.

At the Neurological Alliance we have worked hard to engage policymakers and government to galvanise change in key areas, including the responsibilities of commissioners and policymakers, the availability and quality of neurological data, and the perception of neurology as a perennially neglected area of policy and clinical focus. But we wanted to take stock of what impact these initiatives have for patients and, ultimately, what the state of neurology services actually is in England today.

The National Audit Office's follow-up review of neurological services and assessment of progress against the Public Accounts Committee's<sup>3</sup> (PAC) 2012 recommendations on how neurological services need to be improved has been expected for some time now, but the wait continues. The importance of taking stock cannot be overstated. Only by assessing where we are can we truly know where it is we want, and how far we need, to go. With that in mind, and recognising the drive for further change in the NHS embodied in the *Five Year Forward View*<sup>4</sup> and driven by the clear funding constraints in the system, we concluded that the time for waiting in neurology was over.

Bringing together the findings of our inaugural neurological patient experience survey and quality of commissioning audit, *The Invisible Patients* seeks to undertake an assessment of the current state of neurology services across five central themes:

- Diagnosis
- Treatment and care
- Patient satisfaction and involvement
- The 'invisible patients'
- Integration and communication

What we find is an affirmation of the main criticisms of the state of neurological services, including fragmentation of patient pathways; a lack of understanding and accountability around commissioning responsibilities; and perceived 'invisible patients' not being recognised or monitored within their local health economies. However, there are also

positive findings, with a number of survey respondents citing the good quality care they are often receiving once the complex diagnostic pathway has been navigated.

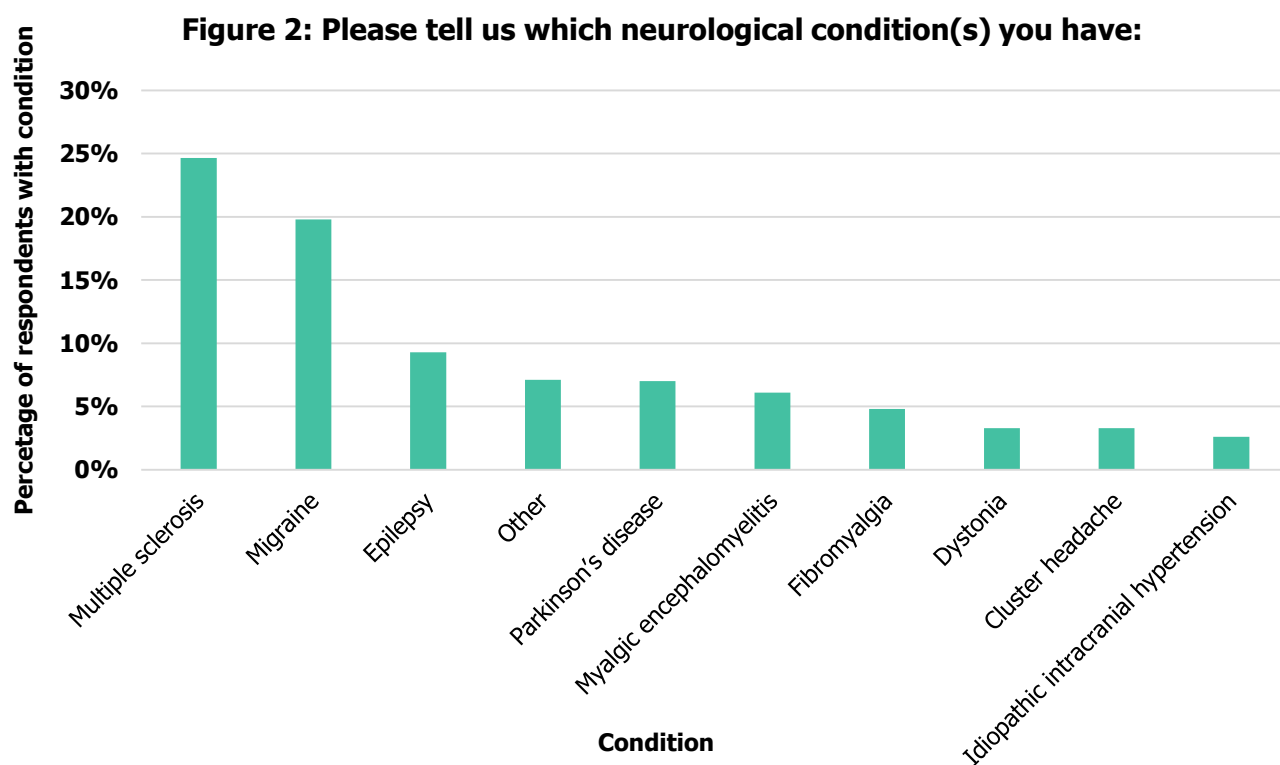
In order to address these issues, *The Invisible Patients* sets out a number of recommendations and calls to action aimed at commissioners and policymakers. It is essential that action is taken to turn policy progress into improved practice, and deliver the best possible outcomes for people living with neurological conditions.

## Demographic

Neurological conditions affect people regardless of age, gender, ethnicity or geographical location. Broadly indiscriminate and often long-term and irreversible in their impact, the demographic for a neurological patient is often hard to pinpoint and define with clarity and consistency. Figure 1 puts a face on the population responding to our survey.

Figure 1: Neurological patient experience survey profile	
Age	Between 51 to 65 years old (33.1%)
Gender	Female (71.6%)
Ethnicity	White British (90.9%)
Geographic location	East of England (12.3%)
Diagnosis	Within the last ten years (60.3%)
Impact	Frequent problems restricting activities (48.8%)

Respondents are most commonly aged between 51 and 65 years old, with a diagnosis occurring in 60% of instances within the last ten years. A plurality of respondents (**24.7%, n=1,698**) have multiple sclerosis (MS) and report that their condition causes frequent problems restricting their activities. Figure 2 below summarises the ten most common conditions among the survey's 6,916 individual respondents.



Finding migraine and epilepsy as the second and third most common diagnoses respectively is unsurprising considering the Neurological Alliance's *Neuro Numbers* publication, first developed in 2003 and refreshed in April this year<sup>5</sup>. The Alliance worked in close partnership with its colleagues from the neurological community and member organisations to calculate the number of neurological cases in England, now estimated to stand at 12.5 million, or the equivalent of 59,000 cases per CCG nationally.

**Figure 3: Neurological condition cases – *Neuro Numbers*<sup>6</sup>**

<b>Condition</b>	<b>Cases</b>
Migraine	6,720,000
Fibromyalgia	1,638,000
Essential tremor	1,417,960
Dementia	665,070
Epilepsy	504,000
Stroke	316,080
Tourette syndrome	252,000
Myalgic encephalomyelitis	215,000
Parkinson's disease	106,680
Post-polio syndrome	100,800

In *Neuro Numbers*, migraine was found to be the most common condition, with an estimate of over six and a half million cases. This was followed by essential tremor and fibromyalgia at approximately 1.5 million cases apiece, dementia and epilepsy, the latter estimated at 504,000 cases (Figure 3).

A more detailed breakdown of the responses to each survey question can be found in Annex 3.

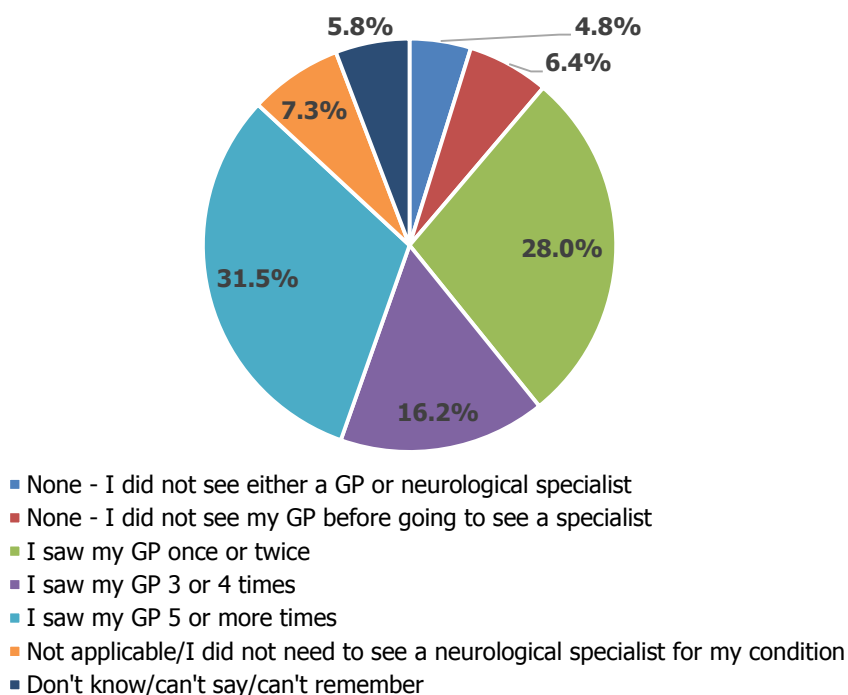
## Results and findings

### Diagnosis

A rapid and accurate diagnosis is vital in delivering high quality patient care and ensuring that patients receive the right treatment in a timely manner. At the start of their journey, patients should be provided with key information about their condition and face important decisions regarding the care and treatment they wish to receive, as should their families and carers. Rapid diagnosis and clear communication at this stage provides an opportunity for a wider variety of treatment options to be considered and provided, delivering better patient outcomes and ultimately helping to minimise overall long-term costs to the health and care system.

*"Every referral I've ever had has involved a lengthy delay due to the huge demand for the services offered. I fully understand and accept I'll have to wait, like everyone else, but that doesn't make it any easier"*

**Figure 4: Before you were told you needed to see a neurological specialist about your condition, how many times did you see your GP (family doctor) about the health problems caused by your condition?**



With that in mind it is a cause for concern that nearly one third of respondents (**31.5%, n=2,140**) had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist. A further two-fifths of

respondents (**39.8%, n=2,357**) waited more than 12 months from when they first noticed their symptoms to see a neurological specialist.

These findings support all-too familiar concerns about systemic delays in the neurological pathway. The importance of prioritising a rapid and accurate diagnosis was clearly stated in the 2005 *National Service Framework for Long-term Conditions*<sup>7</sup>, recognising the importance of early diagnosis “to reduce neurological damage, slow down the rate of disease progression, increase survival rates and improve the person’s quality of life.”<sup>8</sup>

***“Waiting times for some assessments or appointments can be stupidly long, often due to funding issues. For example, I often have to wait around six months between appointments with my specialist”***

Almost a decade on it would appear that such a clear call to action has not been heeded with **58.1% (n=3,402)** of respondents having experienced problems in accessing the services or treatment they need. Respondents’ comments highlighted the issue of long waiting times for patients, particularly when transitioning from general practice to specialist settings.

It is imperative that the pathway to diagnosis aligns with an individual’s particular condition and needs so that patients can access relevant expertise in a timely manner.

Motor neurone disease (MND) provides a strong case study to explore this further. With a very rapid disease progression in which damage to the nervous system can quickly reduce an individual’s motor neurone control, reducing their ability to walk, speak and breathe<sup>9</sup>, the timeframes for patients accessing services and receiving a confirmation of their diagnosis is tight and should be prioritised by health care professionals and commissioners.

Looking at the experiences of MND patients, around half of respondents (**48.4%, n=60**) saw their GP once or twice about the health problems caused by their condition before being told they would need to see a specialist. However, analysing the specific timeframe for accessing the care they needed,

**44.4% (n=55)** had to wait 6 to 12 months before being able to see their neurological specialist for the first time from when they first noticed their symptoms.

***“It was exemplary. The neurologist personally phoned me on my mobile to tell me the results of the MRI scan I’d had that week”***

Furthermore, **42.7% (n=53)** of individuals with MND noted they had experienced distinct problems or delays in accessing the services or treatment they needed. This included GPs not having knowledge or awareness of the signs and implications of MND, which resulted in delayed diagnosis, and a lack of urgency in transitioning from primary to specialist appointments and care.



Given MND's rapid progression in many cases, early interventions and support are vital. It is concerning that appropriate clinical support is not in place early on.

Further assessment of the timeframes for patients with particular neurological conditions across the four *Neuro Numbers* categorisations accessing services can be found in Figure 5 below, using epilepsy, cerebral palsy and traumatic brain injury as additional case studies to map:

- The number of times patients had to see their GP before being referred to a specialist
- The timeframe for patients first seeing a neurological specialist
- The proportion of patients experiencing problems or delays in accessing services

**Figure 5: Diagnostic pathways**

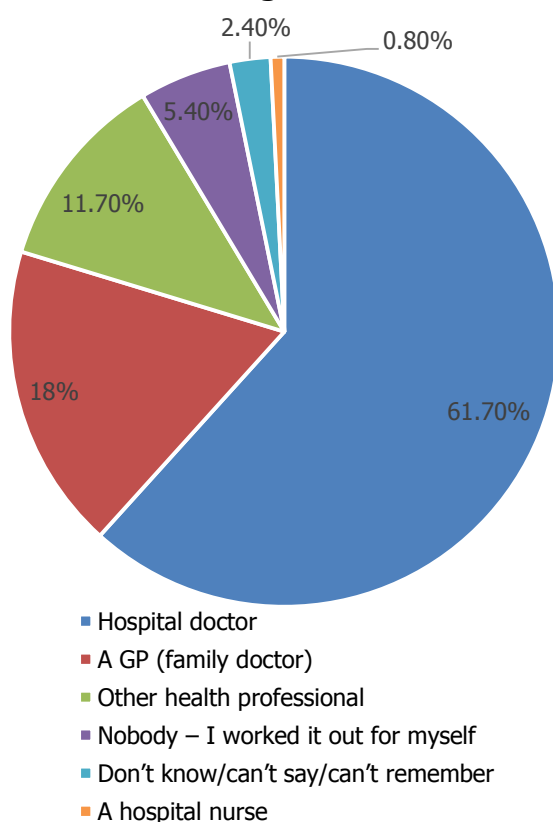
Condition	Categorisation <sup>10</sup>	Number of times GP was seen prior to neurological specialist referral	Time taken to see neurological specialist following first notice of symptoms	Problems/delays experienced in accessing services/treatment to manage condition
Epilepsy	Intermittent	I saw my GP once or twice <b>(30.3%, n=192)</b>	Less than 3 months <b>(35.3%, n=202)</b>	Yes <b>(55.2%, n=291)</b>
Motor neurone disease	Progressive	I saw my GP once or twice <b>(48.4%, n=60)</b>	6 – 12 months <b>(44.4%, n=55)</b>	Yes <b>(42.7%, n=53)</b>
Cerebral palsy	Stable with changing needs	None – I did not see my GP <b>(27.7%, n=18)</b>	Less than 3 months <b>(43.3%, n=26)</b>	Yes <b>(76.9%, n=40)</b>
Traumatic brain injury	Sudden onset	None – I did not see my GP <b>(17.7%, n=20)</b>	Less than 3 months <b>(43.1%, n=31)</b>	Yes <b>(60.4%, n=61)</b>

### Confirmation of diagnosis

The speed of a patient's diagnosis is absolutely critical to support an effective care plan being put in place. It is also important that diagnoses of complex and sometimes rare neurological conditions are confirmed by a professional with the relevant specialist expertise.

The majority of respondents (**61.7%, n=4,152**) noted their diagnosis was confirmed by a hospital doctor. Where **11.7%** of respondents noted 'other health professional', in the majority of cases additional reference is made to specialist neurologists within a hospital setting and as such can be captured within this bracket. It is interesting to note that whilst neurological diagnostic pathways are often characterised as being fragmented and uncertain for patients, overall patient satisfaction regarding the communication of their final diagnosis is quite encouraging at **57.2% (n=3,573)**.

**Figure 6: Confirmed neurological diagnosis**



### Local commissioning

CCGs have an important role to play in the commissioning of neurology services, including community physiotherapy and specialist nursing services.

Addressing the need for improvements in diagnosis is a matter for professional education but also for the configuration of services. Just over a quarter (**26.2%, n=50**) of CCGs that responded to our quality of commissioning FOI audit have definitively assessed the prevalence of neurological conditions within their locality, while just over a fifth (**20.4%, n=39**) actively assessed the number of people using neurological services locally. Such low level of informed scrutiny is concerning.

The collection of outcomes data is also an essential part of a modern day health and care system, supporting an evidence-based approach allowing commissioners to justify, tailor and develop local treatment and care processes based on their measured effectiveness. Despite this, our quality of commissioning audit has found concerning patterns with very few CCGs collecting localised outcomes data on the quality of neurological services they are commissioning, with only **9.9% (n=19)** of CCGs collecting localised outcomes data specific to neurology.

***"It would have been useful to receive more information at the time, and hear of local support groups plus national charities"***

If CCGs do not assess their patient populations and the burden of neurological conditions, they cannot be in a position to accurately and reliably ensure the infrastructure is in place to support the appropriate provision of local services. Furthermore, without understanding the number of patients using services locally, or the outcomes being achieved, CCGs will struggle to assess needs and priorities for improvement, or to accurately and reliably measure service quality and effectiveness.

## Recommendations

- ***Every CCG should collate up to date and accurate local neurology data, underpinned by routine and rigorous assessments of the prevalence of neurological conditions and of the number of people using neurological services locally. Only with robust local information can CCGs meet the demand for per patient cost data to be available and rise to the challenge of taking more responsibility for specialised services***
- ***The Department of Health and NHS England should ensure that the time taken to reach a stable and accurate neurological diagnosis following first consultation is tracked and scrutinised with information shared widely to encourage and identify best practice. The lack of progress in ensuring a good patient experience of timely and accurate diagnosis makes greater national scrutiny now essential in order to stimulate local improvement***

## Treatment and care

Neurological conditions affect people from all walks of life, and treatment and care needs vary considerably between different conditions and individuals. As such, the importance of tailoring treatment and care to the individual needs of the patient cannot be overstated, with a failure to access specialist care at the right time potentially leading to poorer outcomes for people with neurological conditions and putting pressure on other parts of the health and social care system.

**Majority (38.6%) of care and treatment received at a hospital clinic**

**Care plans were offered in only the minority (19.1%) of instances**

Neurological conditions vary widely in terms of their impact; they include progressive conditions, stable conditions, relapsing and remitting conditions, and also sudden-onset neurological incidents that can severely affect a person's life.

All types of neurological condition require life-long support. The complex nature of these conditions means that healthcare professionals with specific expertise and training are needed to help diagnose and manage them.

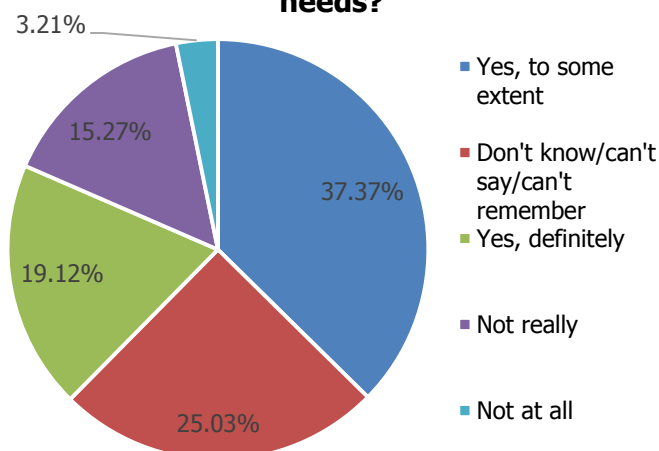
In order to support bespoke treatment regimes, the role of tailored care plans is recognised as being absolutely vital. They were identified by NHS England's National Director for Patient and Information, Tim Kelsey, as an essential part of giving patients control of their own health<sup>11</sup>, and commissioners "must now ensure that every person with a long-term illness or disability has a personalised care plan suited to their needs."<sup>12</sup>

In practice, over two-thirds of survey respondents (**71.5%, n=4,603**) have not been offered a care plan to help manage their condition. Whilst not statutory, there are clear

benefits of having a care plan in place and the right for patients to be offered a plan is enshrined in the NHS Constitution<sup>13</sup>.

Indeed, where a care plan is in place it would appear to be beneficial. Nearly two-fifths of respondents (**37.4%, n=651**) noted that, at least to some extent, their plan responds well to their changing needs, **19.1% (n=333)** noted it definitely responds well whilst a significant proportion (**25%,**

**Figure 7: Do you feel your care plan responds well to your changing needs?**



**n=436**) were unable to say or specifically remember. Such a finding only serves to reaffirm the rationale for ensuring care plans are in place and raises serious questions as to why they are not being implemented more widely.

Given that neurological conditions in particular can often progress unpredictably and suddenly, it is essential that care plans are regularly updated and reviewed. Furthermore, accurate care planning plays an important part in securing financial and efficiency savings, through the reduction of hospital admissions, and the better targeting and delivery of effective care.

### Suitability of care

Neurological conditions affect people in different ways. As such, the clinical point of contact often varies considerably patient-to-patient and on a case-by-case basis.

***43.3% of respondents see between 2 and 5 health and social care professionals a year to help manage their condition***

**60.4% (n=3,537)** of respondents noted the majority of their contact is with a GP or hospital doctor (**47.6%, n=2,788**). Interestingly, the range of care and support services you would expect to be aligned with neurological conditions

seems not to be fully utilised. Fatigue management teams (**1.3%, n=77**) and pain services (**2.7%, n=161**) for example would appear to be under-represented in responses which, given the commonality of pain and fatigue as neurological symptoms, is potentially of concern.

Looking at the individual conditions most commonly using such services according to the survey, **1.7% (n=29)** of respondents with MS and **5.4% (n=23)** with ME often come into contact with fatigue management teams as part of their care. Furthermore, **2.4% (n=40)** of respondents with MS and **3.4% (n=46)** of those with migraine come into contact with pain services to support the management of their condition. With recent policy shifts towards a focus on self-management, and the critical need to optimise appropriate use of healthcare professionals with different skills and focuses, the lack of uptake around pain and fatigue management services is disappointing and should be a priority area for improvement among commissioners and clinicians alike.

***Majority of respondents (58.13%) experienced a problem or delay in accessing services or treatments for their condition***

The majority of care received by respondents is at a hospital clinic (**38.6%, n=2,656**), at home (**26%, n=1,792**) or a local/GP clinic (**20.8%, n=1,432**). Just over a quarter of respondents receiving their care at home is encouraging and we would hope to see this trend continue. Particularly at a time when GP practices and hospitals are under increasing workforce and financial pressures, the benefits of home care – where possible

and appropriate – are clear, helping patients maintain some degree of independence and delivering savings of up to 80% when viewed in tandem with comparable in-hospital services<sup>14</sup>.

### Recommendations

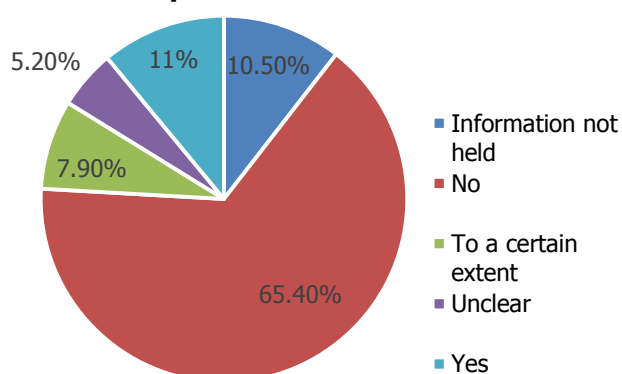
- ***NHS England should develop a robust action plan, building on the work of NHS Improving Quality, to raise usage of care plans nationally. It is time to go beyond providing guidance on how to support the development of care plans and undertake additional activity to increase use***
- ***Local and national commissioners should regularly review utilisation of the care and support services available to patients and ensure that every person with a neurological condition has appropriate and rapid access to the full range of services that they need. Only through a combination of closer review of utilisation and efforts to ensure access will capacity or ease of access barriers to services be identified and addressed***

## Patient satisfaction and involvement

A recurring theme throughout the patient experience survey is the perceived weakness of the patient pathway, including delays in diagnosis and accessing specialist expertise. Despite this however, the majority of respondents (**72.8%, n=4,261**) report their care and treatment as either 'some help' or 'excellent', with over two-thirds (**66.9%, n=3,913**) feeling that the different people treating them worked well together to at least some extent.

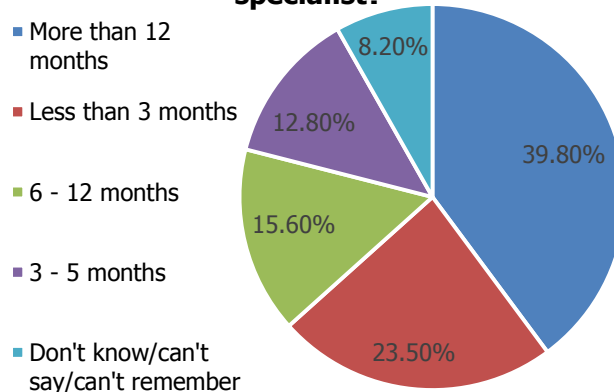
However, if the NHS is to be true to the principle of "no decision about me without me"<sup>15</sup> we should be aiming higher, and patient views should be actively included in the design of services. In reality only **34.1% (n=69)** of CCGs have mechanisms in place to include patients in decision-making processes and only **33% (n=63)** obtain vital feedback in regards to the services they commission.

**Figure 9: Percentage of CCGs collecting neurological patient experience data**



experience survey (**71%, n=4,539**) feel to some degree that they are involved in making choices about their care and treatment. Individual clinicians seem to be taking

**Figure 8: How long was it from when you first noticed your symptoms until you first saw a neurological specialist?**



At a time of financial constraint and pressure on health services, seeking patient feedback and insight appears to have fallen down the priority list for commissioners, behind national targets, clinical outcomes and financial performance. However, this can lead to a one-size fits all approach to commissioning, impacting on the quality of treatment and care patients receive.

Despite the lack of CCG engagement with patients, or patients not having care plans in place, over 70% of respondents to the neurological patient

responsibility for engaging with individual patients despite the lack of formal mechanisms being in place.

### Clinical and research studies

Clinical trials and research studies are an important step in discovering new treatments for neurological conditions, as well as new ways to detect, diagnose and reduce the risk of diseases. The Neurological Alliance's 2015 election manifesto calls for greater investment into new and effective treatments for neurological conditions moving forward<sup>16</sup>.

***"One priority for health and social care services in my area? To stop cutting funds and invest more in clinical research"***

At present however, only **20.7% (n=1,209)** of respondents confirm that they have accepted an opportunity to take part in a clinical or research study. Both acutely frustrating and encouraging in equal measure, a further **59.1% (n=3,461)** of respondents note that they have not been offered an opportunity to take part in a clinical or research study but would be interested to do so if an opportunity arose in the future.

#### Recommendations

- ***All CCGs should ensure that mechanisms are put in place to encourage and capture patient feedback and input in regards to the quality and development of local neurology services. There is a danger that CCGs rely on roll-out of the Friends and Family Test to capture patient feedback, but deeper insights on experiences of neurological services are essential to drive patient-centred improvement***
- ***CCGs should work in partnership to identify clinical and research trial opportunities locally and support the appropriate sharing of information on such opportunities with patients. A shift to clinicians presenting clinical trial opportunities to patients as a default part of discussions is key to ensuring that patients are aware of options and feel able to consider them without inappropriate apprehension***

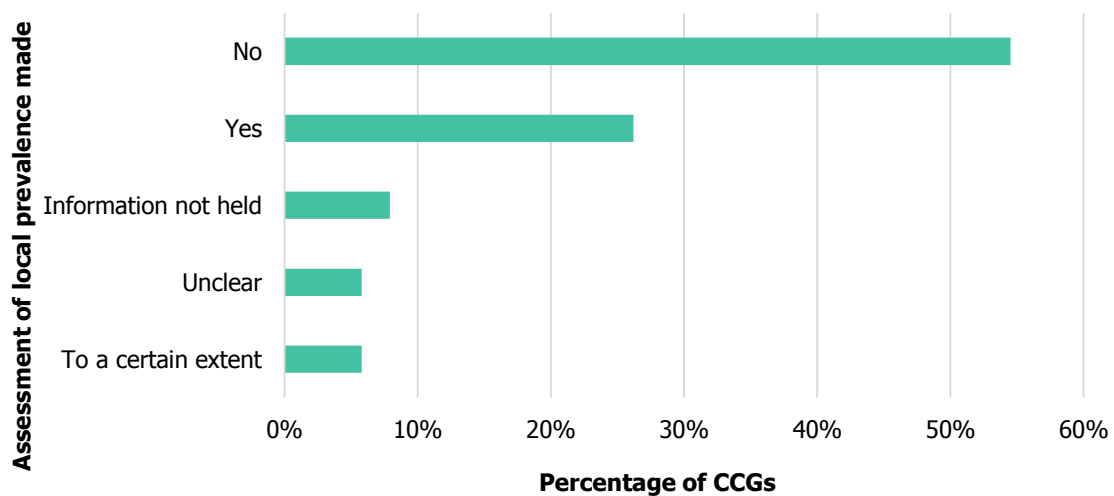


## The 'invisible patients'

The findings of our quality of commissioning audit present real concerns that many people with neurological conditions are effectively 'invisible patients', accessing and utilising local health and social care services in the absence of effective commissioning oversight and strategy mechanisms.

Only **14.7% (n=28)** of CCGs have made an assessment of local costs relating to the provision of neurology services. At a time when NHS finances are under significant strain, it is of real concern that so few CCGs are getting to grips with their local health economies. A key objective for NHS England, as set out in its recent *Five Year Forward View* publication<sup>17</sup>, is the "need to evaluate new care models to establish which produce the best experience for patients and the best value for money." Such an evaluation will be impossible without a clear understanding of the costs associated with different conditions.

**Figure 10: CCGs having made a local assessment of the prevalence of neurological conditions**



Furthermore, only **26.2% (n=50)** and **20.4% (n=39)** of CCGs have definitively assessed the prevalence of neurological conditions and the number of people using neurological services within their area.

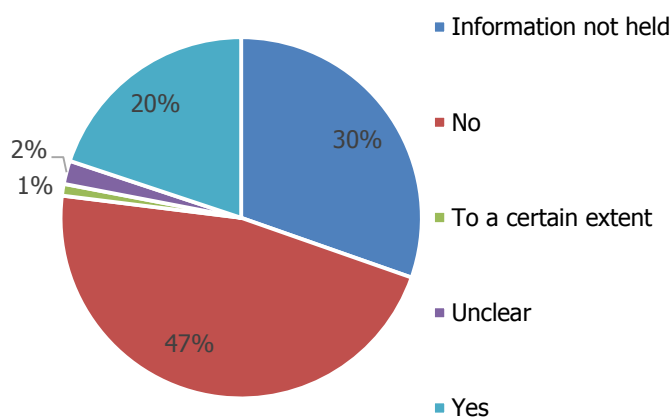
At a time when NHS England is looking to address its specialised commissioning overspend, totalling at least £450m in 2012/14<sup>18</sup>, and with CCGs expected to take on increased responsibilities for commissioning specialised services<sup>19</sup>, coupled with warnings of a £5bn specialised commissioning funding gap in the next five years<sup>20</sup>, concerns regarding the preparedness of CCGs to take such responsibilities forward are rearing their head.

CCGs don't appear to have a grasp of their local health economies or populations, at least in regards to neurology services, and are signing off commissioning plans without understanding how they will fit into the existing system. This prevents CCGs from engaging strategically with the challenge of meeting the complex needs of the local patient population.

### National engagement

For a long time there has been real confusion and uncertainty around the commissioning arrangements for neurology. In particular, and as set out in the Neurological Alliance's own submission to the NHS England Specialised Services Taskforce in July 2014<sup>21</sup>, there is a lack of clarity over which neurology services should be commissioned centrally by NHS England, with inconsistencies in the current Manual for Prescribed Specialised Services<sup>22</sup> and the Neurosciences Service Specification<sup>23</sup> in particular.

**Figure 11: Percentage of CCGs communicating with their NHS England local area team within the last 12 months**



With such a fragmented and uncertain system it is concerning that only **19.9% (n=38)** of CCGs have definitively been in contact with their NHS England local area team about the commissioning of neurological services in the last 12 months. This reflects a lack of clear system leadership for neurology, as referred to in the PAC's 2012 inquiry<sup>24</sup>, with NHS England appearing to fall short with regards to providing clarity for commissioners and patients, undermining confidence in the system resulting in CCG uncertainty and lack of drive moving forward.

There should be a clear expectation that, for the benefit of patients and protection of services that are vital to them, conversations are occurring between local commissioners and NHS England. This is not the case.

## Recommendations

- ***Every CCG should ensure that it has made a full assessment of costs relating to the provision of neurology services to people in their area including a clear understanding of wider costs for services commissioned by NHS England. As the system looks for efficiencies and savings, and as consideration is given to where responsibility should lie for the commissioning of certain services, CCGs must take responsibility for equipping themselves to ensure the delivery of an efficient health and care system for neurology, further supported by the assessment of local prevalence and service usage among neurology patients***
- ***CCGs should engage in regular communication with their NHS England local area team about the commissioning of neurological services, taking a proactive approach to ensuring a shared and full understanding of neurological service commissioning, sharing information with the Neurology Intelligence Network. There has been too much confusion around the split of responsibilities for neurological services and it is essential that CCGs take an active role in resolving areas needing more clarity and agreement***

## Integration and communication

Integrated care has been identified as being vitally important to the delivery and maintenance of an effective and efficient health and social care system. In May 2013 NHS England signed *Integrated Care and Support: Our Shared Commitment*<sup>25</sup>, the framework document which sets out how local areas can use existing structures to make further steps towards integration.

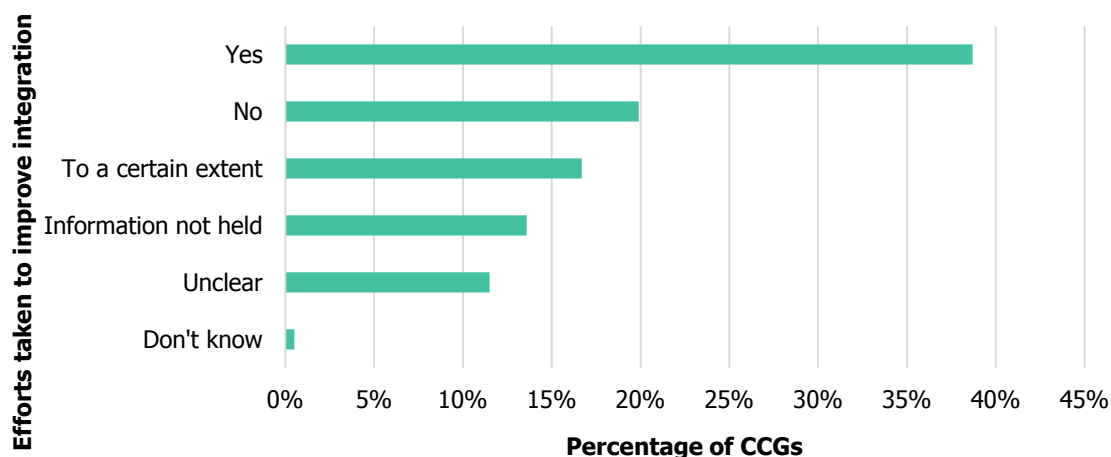
*Integrated Care and Support* sets out ten succinct “shared commitments”, focusing on:

- Pursuing a common purpose
- National resources for local ambitions
- Providing practical tools to localities
- Integrating information
- Accelerating learning across the system

***“One priority for health and social care services in my area? Better working together of all services with integrated care planning”***

Recognising the “significant challenges ahead”, a “culture of cooperation and coordination” is acknowledged as being vital in order to help identify new and effective ways of working, deliver seamless care and good outcomes for patients and secure financial efficiencies and savings through the delivery of effective care pathways. Despite the apparent benefits of integration however, only **38.7% (n=74)** of responding CCGs have taken action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions.

**Figure 12: CCGs taking action to promote integration across primary, secondary, tertiary and social care services**



Findings from the Neurological Alliance’s *Measuring up: improving the quality of neurological data and intelligence* report<sup>26</sup>, and supporting *Neuro Numbers* factsheet,<sup>27</sup> indicate that the number of neurological cases now stands at approximately 12.5 million

– or the equivalent of 59,000 cases per CCG. Coupled with the number of emergency hospital admissions recorded for people with a neurological diagnosis standing at over 700,000 as of 2012/13 and NHS expenditure on neurological conditions increasing by over 200% between 2003/4 and 2012/13, implementing the integration agenda to help mitigate such system pressures has arguably never been more important.

Despite CCGs failing on the whole to engage around the integration agenda with key clinical services locally, **66.9% (n=3,913)** of respondents felt that the different people treating and caring for them worked well to at least some extent. Once again, it would appear that in spite of the system clinicians and patients are finding a way to work well together to deliver high quality patient care.

Further regarding the integration and interaction of services, only **44% (n=84)** of CCGs have engaged with their local SCN regarding the commissioning of neurological services. As reaffirmed in the Alliance's *Navigating neurology services: helping strategic clinical networks to be a success story*<sup>28</sup>, published in September 2013, SCNs are intended to help make improvements in areas where there are currently major challenges to delivering the best possible care for patients and support CCGs in the delivery of their neurology functions<sup>29</sup>. The fact that less than half of CCGs are making use of this facility is a concern.

### Recommendations

- ***CCGs should actively encourage the integration of primary, secondary, tertiary and social care services for people with neurological conditions, including those provided by the voluntary sector, supporting continuity of care across the whole patient pathway. People with neurological conditions have a range of needs, many of which are supported from outside of formal neurological services. The wider patient experience needs a champion for integration, and CCGs are uniquely placed to take this role***
- ***CCGs should engage with their local dementia, mental health and neurology SCN regarding their local neurological strategy, with NHS England establishing a formal requirement for them to do so. Only through a higher level of engagement and interaction will SCNs be able to deliver on their core purpose of improving local services***

## Conclusion

The patient is the focus of all that we do at the Neurological Alliance. We work hard to ensure that everyone living with a neurological condition receives appropriate and effective care and support, and secures the best possible outcomes. It is therefore very encouraging that a majority of respondents to our patient experience survey feel that the care they receive is of a good quality. However, this should not disguise the fact that our survey and commissioning audit reveal some significant problems.

It is clear that key mechanisms and processes to ensure ongoing service improvement and development are simply not in place. Patients aren't being offered care plans; CCGs are failing to understand the prevalence of neurological patients within their area; patients are not being involved in the commissioning process; and CCGs are almost entirely failing to assess local costs relating to the provision of neurology services. This is simply not good enough.

At a time of financial pressure on the health and social care system, pursuing efficiency gains has rightly been acknowledged as a vital step to supporting the longevity of high quality care. While CCGs fail to take their statutory commissioning responsibilities seriously, this process will continue to be undermined.

Throughout this report, we have set out what we feel are entirely reasonable and attainable recommendations for commissioners to take forward in order to improve services. If they are heeded, we are confident that commissioning improvements will translate to patient care, and the apparent lottery of care, with 'invisible patients' passing along the patient pathway unchecked, will no longer be the case. In its current state, sooner or later, the system will give way with patients tumbling through the gaps. We cannot, and will not, let this happen.

## Annex 1: Key terms

**Care plan:** A care plan is a written statement of a patient's individual needs identified during a care assessment. It sets out what support is required, why, when, and details of who is meant to provide it.<sup>30</sup> It should be designed in collaboration with the individual concerned, and subject to regular review.

**Clinical commissioning group (CCG):** A clinical commissioning group (CCG) commissions (purchases) most of the hospital and community NHS services in the local areas for which they are responsible. Commissioning involves deciding what services are needed, and ensuring they are provided. There are 211 CCGs in total.<sup>31</sup>

**Clinician:** A clinician can be defined as a medical professional, such as general practitioner (GP), psychiatrist, hospital consultant, nurse or physiotherapist, who specialises in engaging directly with a patient as part of their diagnosis, treatment and ongoing care.

**Health and Social Care Information Centre (HSCIC):** The Health and Social Care Information Centre (HSCIC) is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care.<sup>32</sup>

**National Audit Office (NAO):** The National Audit Office (NAO) scrutinises public spending on behalf of parliament and has two main aims in holding Government departments and bodies to account for the way they use public money and helping public service managers improve performance and service delivery.<sup>33</sup>

**Neurological condition:** Neurological conditions result from disorders of the brain, spinal cord or nerves. Causes include illness, injury or genetic factors; in some cases the causes are unknown. There are many neurological conditions<sup>34</sup>. Some are common, such as dementia, stroke and epilepsy, whilst others are rare and poorly understood such as muscular dystrophy, dystonia and Huntingdon's disease.

**NHS England:** Formerly established as the NHS Commissioning Board in October 2012, NHS England is an independent body at arms-length to the Government. Its main role is to improve health outcomes for people in England, providing national leadership for improving outcomes and driving up the quality of care.<sup>35</sup>

**Public Accounts Committee (PAC):** The Public Accounts Committee (PAC) is a parliamentary committee appointed by the House of Commons to examine "the accounts showing the appropriation of the sums granted to Parliament to meet the public expenditure, and of such other accounts laid before Parliament as the Committee may think fit."<sup>36</sup>

**Public Health England (PHE):** Public Health England (PHE) protects and improves the nation's health and wellbeing and reduces health inequalities by advising Government, supporting local action and educating the general population.<sup>37</sup>

**Strategic clinical network (SCN):** Strategic clinical networks (SCN) are designed to help local commissioners of NHS care to reduce unwarranted variation in services and encourage innovation. Covering conditions or patient groups where improvements can be made through an integrated, whole system approach, a dedicated SCN exists for mental health, dementia and neurological conditions.<sup>38</sup>

**Specialised commissioning:** Specialised commissioning is the purchasing of particular services that can be expensive to provide and may be described as high cost/low value, treating often rare and uncommon conditions among small patient populations. It is currently carried out by NHS England with specialised services accounting for approximately 10% of the total NHS budget.<sup>39</sup>



## Annex 2: Neurological patient experience survey questions

### About you

**1. How did you hear about this survey?**

**2. In which age bracket are you?**

- 15 or under
- 16 – 25
- 26 – 35
- 36 – 50
- 51 – 65
- 66 – 75
- 76+

**3. Are you male or female?**

- Male
- Female

**4. To which of these ethnic groups would you say you belong?**

- White British
- White Irish
- Any other White background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background
- Caribbean
- African
- Any other Black background
- Chinese
- Other

**5. In which part of England do you live?**

- **North East, North Cumbria and the Hambleton and Richmondshire districts of North Yorkshire**  
(County Durham, Hambleton and Richmondshire districts of North Yorkshire, North Cumbria, Northumberland, Teeside, Tyne & Wear)
- **Yorkshire and the Humber**  
(North Yorkshire excluding Hambleton and Richmondshire districts, East Riding and Humberside, South Yorkshire, West Yorkshire)
- **Greater Manchester, Lancashire and South Cumbria**

- (Greater Manchester, Lancashire, South Cumbria)
- **Cheshire and the Mersey**  
(Cheshire, Merseyside)
- **East Midlands**  
(Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire, Northamptonshire, Rutland)
- **West Midlands**  
(Birmingham, Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire)
- **East of England**  
(Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk, Suffolk)
- **London**
- **Thames Valley**  
(Berkshire, Buckinghamshire, Oxfordshire)
- **Wessex**  
(Dorset, Hampshire, Isle of Wight)
- **South East Coast**  
(Kent, Medway, Surrey and Sussex)
- **South West**  
(Bristol, Cornwall, Devon, Gloucestershire, Somerset, Wiltshire)

**6. Please tell us which neurological condition(s) you have by ticking all that apply below:**

- I am awaiting a diagnosis
- Acoustic neuroma
- Ataxia
- Batten disease
- Brain tumour
- Carpal tunnel syndrome
- Causalgia
- Cavernoma
- Cerebral palsy
- Charcot-Marie-Tooth disease
- Chronic inflammatory demyelinating polyneuropathy (CIDP)
- Cluster headache
- Congenital hemiplegia
- Dementia (includes Alzheimer's)
- Dystonia
- Encephalitis
- Epilepsy
- Essential tremor
- Fibromyalgia
- Guillain-Barre syndrome
- Haemorrhagic leukoencephalitis
- Huntington's disease

- Idiopathic intracranial hypertension
- Malignant neuroleptic syndrome
- Meningitis
- Migraine
- Motor neurone disease
- Multiple sclerosis
- Multiple system atrophy
- Muscular dystrophy
- Myalgic encephalomyelitis
- Myasthenia
- Myelopathy
- Myositis
- Myotonic disorders
- Narcolepsy
- Neurodegeneration with brain iron accumulation
- Neurofibromatosis
- Neuromyelitis optica
- Parkinson's disease
- Poliomyelitis
- Post-Polio syndrome
- Progressive supranuclear palsy
- Radiculopathy
- Refsum's disease
- Rett syndrome
- Somatoform disorders
- Spina bifida and hydrocephalus
- Spinal tumour
- Spinal muscular atrophy
- Spondylosis
- Stroke
- Tarsal tunnel syndrome
- Tourette syndrome
- Transverse myelitis
- Traumatic brain injury
- Traumatic spinal injury
- Trigeminal neuralgia
- Tuberous sclerosis
- Other

If you have more than one neurological condition, please indicate which condition you feel affects you the most and to which your survey answers will be most relevant:

**7. When were you diagnosed with your neurological condition?**

- Less than 1 year ago
- 1 – 5 years ago

- 6 – 10 years ago
- More than 10 years ago
- Don't know/can't say/can't remember

**8. How affected are you by your neurological condition?**

- My condition does not affect me
- My condition causes occasional problems
- My condition causes frequent problems restricting my activities
- My condition causes constant problems that confine me most or all of the time
- Don't know/can't say/can't remember

**9. Where do you receive the majority of care and treatment for your neurological condition?**

- At home
- Hospital clinic
- Specialist rehabilitation centre
- Residential care home
- At my local/GP clinic
- Other

## Diagnosis

**10. Before you were told you needed to see a neurological specialist about your condition, how many times did you see your GP (family doctor) about the health problems caused by your condition?**

- None – I did not see either a GP or neurological specialist
- None – I did not see my GP before going to see a specialist
- I saw my GP once or twice
- I saw my GP 3 or 4 times
- I saw my GP 5 or more times
- Not applicable/I did not need to see a neurological specialist for my condition
- Don't know/can't say/can't remember

**11. How long was it from when you first noticed your symptoms until you first saw a neurological specialist?**

- Less than 3 months
- 3 – 5 months
- 6 – 12 months
- More than 12 months
- Not applicable/I did not need to see a neurological specialist for my condition
- Don't know/can't say/can't remember

**12. Who first confirmed your clinical diagnosis of a neurological condition?**

- A hospital doctor (including neurological specialist)
- A hospital nurse (including neurological specialist)
- A GP (family doctor)
- Other health professional
- Nobody – I worked it out for myself

- Don't know/can't say/can't remember

**13. How do you feel about the way you were told you had a neurological condition?**

- It was done appropriately
- It should have been done a bit more appropriately
- It was not done at all appropriately
- Don't know/can't say/can't remember

**14. What, if anything, do you feel could have improved your experience of diagnosis?**

**Provision of information**

**15. How satisfied are you with the type of information that you have received from healthcare professionals (eg doctors or nurses) about the following?**

What the information was about	How satisfied you were with the information (please tick the relevant box for each category)						
	Very satisfied	Satisfied	Neither satisfied nor unsatisfied	Unsatisfied	Very unsatisfied	No information received	Don't know/can't say/ can't remember
Your condition							
Your care and treatment options							
Risks and benefits of different types of treatment							
Contact details for a named healthcare professional in charge of your care							
Additional sources of support eg details of charity, patient support group or financial advice							

## Care planning

**16. Have you been offered a care plan to help manage your neurological condition?**

- Yes
- Yes, but I refused
- No
- Don't know/can't say/can't remember

**17. Do you feel the care plan responds well to your changing needs?**

- Yes, definitely
- Yes, to some extent
- Not really
- Not at all
- Not applicable
- Don't know/can't say/can't remember

**18. Do you feel that you are fully involved in making choices about your care and treatment?**

- Yes, definitely
- Yes, to some extent
- No, my views are often not taken into account
- No, my views are never taken into account
- Don't know/can't say/can't remember

## Ongoing care and treatment

**19. Overall, how do you rate the care and treatment you have received for your neurological condition?**

- Excellent
- Good
- Some help
- Not much help
- No help
- Don't know/can't say/can't remember

**20. In an average year, how many health and social care professionals do you come into contact with to help manage your condition?**

- Fewer than 2
- Between 2 and 5
- Between 6 and 10
- More than 10

**21. Which of the following do you regularly have contact with to help manage your condition? Please tick all that apply:**

- GP

- A hospital doctor (including neurological specialist)
- Specialist nurse
- District nurse
- Carer
- Care home staff
- Physiotherapist
- Occupational therapist
- Counsellor
- Speech and language therapist
- Fatigue management team
- Dietician
- Pharmacist
- Palliative care team
- Wheelchair/mobility aids specialist
- Psychologist
- Social worker
- Pain service
- Tissue viability service
- Continence advisor
- Family member/care giver
- Charity group/voluntary organisation
- Other

**22. Do the different people treating and caring for you work well together to give you the best possible care?**

- Yes, always
- Yes, most of the time
- Yes, some of the time
- No, never
- Don't know

**23. Have you experienced any problems or delays in accessing care or treatment to help manage your condition?**

- Yes
- No

**24. If there could be one priority for health and social care services for people with neurological conditions in your area, what would it be?**

**25. Have you ever been offered the opportunity to take part in a clinical/research study based on your neurological condition?**

- Yes and I have accepted it
- Yes, but I declined
- No, but I would be interested
- No and I would not be interested
- Don't know/can't say/can't remember

**26. Would you be happy to be contacted by the Neurological Alliance to discuss your answers to some of the above questions in more detail?**

- Yes
- No



## Annex 3: Neurological patient experience survey results

**1. How did you hear about this survey?** Multiple free text responses provided

**2. In which age bracket are you?**

- 15 or under (2.4%, n=167)
- 16 – 25 (5.7%, n=392)
- 26 – 35 (12.7%, n=872)
- 36 – 50 (30.2%, n=2,078)
- 51 – 65 (33.1%, n=2,279)
- 66 – 75 (12.5%, n=855)
- 76+ (3.6%, n=245)

**3. Are you male or female?**

- Male (28.4%, n=1,957)
- Female (71.6%, n=4,931)

**4. To which of these ethnic groups would you say you belong?**

- White British (90.9%, n=6,261)
- White Irish (1.3%, n=91)
- Any other White background (3.3%, n=225)
- White and Black Caribbean (0.3%, n=20)
- White and Black African (0.2%, n=10)
- White and Asian (0.3%, n=17)
- Any other mixed background (0.3%, n=23)
- Indian (0.9%, n=63)
- Pakistani (0.3%, n=19)
- Bangladeshi (0.1%, n=6)
- Any other Asian background (0.2%, n=13)
- Caribbean (0.3%, n=23)
- African (0.2%, n=12)
- Any other Black background (0.1%, n=3)
- Chinese (0.2%, n=13)
- Other (1.3%, n=89)

**5. In which part of England do you live?**

- **North East, North Cumbria and the Hambleton and Richmondshire districts of North Yorkshire** (5.8%, n=384)  
(County Durham, Hambleton and Richmondshire districts of North Yorkshire, North Cumbria, Northumberland, Teeside, Tyne & Wear)
- **Yorkshire and the Humber** (6.1%, n=408)  
(North Yorkshire excluding Hambleton and Richmondshire districts, East Riding and Humberside, South Yorkshire, West Yorkshire)
- **Greater Manchester, Lancashire and South Cumbria** (6.3%, n=421)  
(Greater Manchester, Lancashire, South Cumbria)
- **Cheshire and the Mersey** (6.4%, n=429)

- (Cheshire, Merseyside)
- **East Midlands** (6.9%, n=459)  
(Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire, Northamptonshire, Rutland)
- **West Midlands** (7.7%, n=516)  
(Birmingham, Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire)
- **East of England** (8.0%, n=536)  
(Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk, Suffolk)
- **London** (8.7%, n=579)
- **Thames Valley** (9.5%, n=635)  
(Berkshire, Buckinghamshire, Oxfordshire)
- **Wessex** (10.9%, n=726)  
(Dorset, Hampshire, Isle of Wight)
- **South East Coast** (11.6%, n=770)  
(Kent, Medway, Surrey and Sussex)
- **South West** (12.3%, n=821)  
(Bristol, Cornwall, Devon, Gloucestershire, Somerset, Wiltshire)

**6. Please tell us which neurological condition(s) you have by ticking all that apply below:**

- I am awaiting a diagnosis (2.6%, n=178)
- Acoustic neuroma (0.4%, n=24)
- Ataxia (2.4%, n=164)
- Batten disease (0.1%, n=9)
- Brain tumour (1.0%, n=71)
- Carpal tunnel syndrome (1.8%, n=122)
- Causalgia (<0.1%, n=2)
- Cavernoma (1.9%, n=129)
- Cerebral palsy (1.0%, n=69)
- Charcot-Marie-Tooth disease (1.1%, n=72)
- Chronic inflammatory demyelinating polyneuropathy (CIPD) (0.7%, n=50)
- Cluster headache (3.3%, n=228)
- Congenital hemiplegia (0.2%, n=15)
- Dementia (includes Alzheimer's) (0.5%, n=31)
- Dystonia (3.3%, n=229)
- Encephalitis (1.0%, n=66)
- Epilepsy (9.3%, n=641)
- Essential tremor (0.5%, n=33)
- Fibromyalgia (4.8%, n=333)
- Guillain-Barre syndrome (1.7%, n=115)
- Haemorrhagic leucoencephalitis (<0.1%, n=1)
- Huntington's disease (0.6%, n=39)
- Idiopathic intracranial hypertension (2.6%, n=182)
- Malignant neuroleptic syndrome (0.1%, n=4)

- Meningitis (0.6%, n=40)
- Migraine (19.8%, n=1,364)
- Motor neurone disease (1.8%, n=124)
- Multiple sclerosis (24.7%, n=1,698)
- Multiple system atrophy (0.6%, n=42)
- Muscular dystrophy (0.2%, n=12)
- Myalgic encephalomyelitis (6.1%, n=422)
- Myasthenia (1.8%, n=122)
- Myelopathy (0.1%, n=5)
- Myositis (0.1%, n=5)
- Myotonic disorders (0.1%, n=5)
- Narcolepsy (0.1%, n=8)
- Neurodegeneration with brain iron accumulation (<0.1%, n=1)
- Neurofibromatosis (0.2%, n=13)
- Neuromyelitis optica (0.1%, n=9)
- Parkinson's disease (7.0%, n=479)
- Poliomyelitis (1.1%, n=74)
- Post-Polio syndrome (1.5%, n=106)
- Progressive supranuclear palsy (1.8%, n=121)
- Radiculopathy (0.2%, n=15)
- Refsum's disease (<0.1%, n=1)
- Rett syndrome (<0.1%, n=2)
- Somatoform disorders (0.2%, n=12)
- Spina bifida and hydrocephalus (0.4%, n=30)
- Spinal tumour (0.1%, n=9)
- Spinal muscular atrophy (0.1%, n=5)
- Spondylosis (1.0%, n=62)
- Stroke (2.3%, n=158)
- Tarsal tunnel syndrome (0.1%, n=5)
- Tourette syndrome (1.1%, n=78)
- Transverse myelitis (1.8%, n=123)
- Traumatic brain injury (1.7%, n=115)
- Traumatic spinal injury (0.3%, n=19)
- Trigeminal neuralgia (1.4%, n=95)
- Tuberous sclerosis (0.1%, n=5)
- Other (7.1%, n=488)

If you have more than one neurological condition, please indicate which condition you feel affects you the most and to which your survey answers will be most relevant:

- 7. If you have more than one neurological condition, please indicate which condition you feel affects you the most and to which your survey answers will be most relevant:** Multiple free text responses provided

## **8. When were you diagnosed with your neurological condition?**

- Less than 1 year ago (9.7%, n=670)
- 1 – 5 years ago (32.7%, n=2,250)
- 6 – 10 years ago (17.9%, n=1,213)
- More than 10 years ago (37.7%, n=2,598)
- Don't know/can't say/can't remember (2.0%, n=139)

## **9. How affected are you by your neurological condition?**

- My condition does not affect me (1.4%, n=98)
- My condition causes occasional problems (22.4%, n=1,543)
- My condition causes frequent problems restricting my activities (48.8%, n=3,361)
- My condition causes constant problems that confine me most or all of the time (26.8%, n=1,847)
- Don't know/can't say/can't remember (0.6%, n=39)

## **10. Where do you receive the majority of care and treatment for your neurological condition?**

- At home (26.0%, n=1,792)
- Hospital clinic (38.6%, n=2,656)
- Specialist rehabilitation centre (2.3%, n=157)
- Residential care home (0.9%, n=64)
- At my local/GP clinic (20.8%, n=1,432)
- Other (11.4%, n=787)

## **Diagnosis**

## **11. Before you were told you needed to see a neurological specialist about your condition, how many times did you see your GP (family doctor) about the health problems caused by your condition?**

- None – I did not see either a GP or neurological specialist (4.8%, n=325)
- None – I did not see my GP before going to see a specialist (6.5%, n=438)
- I saw my GP once or twice (28.0%, n=1,902)
- I saw my GP 3 or 4 times (16.2%, n=1,103)
- I saw my GP 5 or more times (31.5%, n=2,140)
- Not applicable/I did not need to see a neurological specialist for my condition (7.3%, n=495)
- Don't know/can't say/can't remember (5.8%, n=391)

## **12. How long was it from when you first noticed your symptoms until you first saw a neurological specialist?**

- Less than 3 months (23.5%, n=1,392)
- 3 – 5 months (12.8%, n=759)
- 6 – 12 months (15.6%, n=925)
- More than 12 months (39.8%, n=2,357)
- Don't know/can't say/can't remember (8.2%, n=484)

**13. Who first confirmed your clinical diagnosis of a neurological condition?**

- A hospital doctor (including neurological specialist) (61.7%, n=4,152)
- A hospital nurse (including neurological specialist) (0.8%, n=55)
- A GP (family doctor) (18.0%, n=1,214)
- Other health professional (11.7%, n=787)
- Nobody – I worked it out for myself (5.4%, n=365)
- Don't know/can't say/can't remember (2.4%, n=161)

**14. How do you feel about the way you were told you had a neurological condition?**

- It was done appropriately (57.2%, n=3,573)
- It should have been done a bit more appropriately (18.9%, n=1,183)
- It was not done at all appropriately (14.3%, n=892)
- Don't know/can't say/can't remember (9.6%, n=597)

**15. What, if anything, do you feel could have improved your experience of diagnosis?** Multiple free text responses provided

**16. How satisfied are you with the type of information that you have received from healthcare professionals (eg doctors or nurses) about the following?**

What the information was about	How satisfied you were with the information (please tick the relevant box for each category)						
	Very satisfied	Satisfied	Neither satisfied nor unsatisfied	Unsatisfied	Very unsatisfied	No information received	Don't know/can't say/ can't remember
Your condition	16.2% (n=1044)	33.8% (n=2173)	17.5% (n=1123)	14.5% (n=935)	9.0% (n=578)	7.9% (n=509)	1.2% (n=74)
Your care and treatment options	14.6% (n=938)	29.9% (n=1917)	18.0% (n=1151)	17.9% (n=1147)	11.5% (n=739)	7.1% (n=455)	1.0% (n=62)
Risks and benefits of different types of treatment	11.4% (n=728)	24.9% (n=1591)	21.2% (n=1351)	15.8% (n=1010)	8.2% (n=520)	15.9% (n=1014)	2.6% (n=165)
Contact details for a named healthcare professional in charge of your care	19.9% (n=1277)	27.4% (n=1751)	14.6% (n=937)	11.9 (n=761)	7.8% (n=499)	16.4% (1052)	2.0% (126)
Additional sources of support eg details of charity, patient support group or financial advice	12.4% (n=796)	20.5% (n=1313)	16.7% (n=1068)	15.3% (n=982)	8.7% (n=556)	24.8% (n=1591)	1.5% (n=98)

## Care planning

### 17. Have you been offered a care plan to help manage your neurological condition?

- Yes (19.1%, n=1,231)
- Yes, but I refused (1.2%, n=80)
- No (71.5%, n=4,603)
- Don't know/can't say/can't remember (8.1%, n=524)

### 18. Do you feel the care plan responds well to your changing needs?

- Yes, definitely (19.1%, n=333)
- Yes, to some extent (37.4%, n=651)
- Not really (15.3%, n=266)
- Not at all (3.2%, n=56)
- Don't know/can't say/can't remember (25.0%, n=436)

### 19. Do you feel that you are fully involved in making choices about your care and treatment?

- Yes, definitely (28.9%, n=1,856)
- Yes, to some extent (41.8%, n=2,683)
- No, my views are often not taken into account (15.5%, n=994)
- No, my views are never taken into account (7.5%, n=484)
- Don't know/can't say/can't remember (6.2%, n=400)

## Ongoing care and treatment

### 20. Overall, how do you rate the care and treatment you have received for your neurological condition?

- Excellent (15.5%, n=909)
- Good (30.9%, n=1,807)
- Some help (26.4%, n=1,545)
- Not much help (17.5%, n=1,021)
- No help (8.5%, n=499)
- Don't know/can't say/can't remember (1.2%, n=71)

### 21. In an average year, how many health and social care professionals do you come into contact with to help manage your condition?

- Fewer than 2 (42.9%, n=2,510)
- Between 2 and 5 (43.3%, n=2,535)
- Between 6 and 10 (8.7%, n=509)
- More than 10 (5.1%, n=298)

### 22. Which of the following do you regularly have contact with to help manage your condition? Please tick all that apply:

- GP (60.4%, n=3,537)
- A hospital doctor (including neurological specialist) (47.6%, n=2,788)
- Specialist nurse (30.7%, n=1,797)

- District nurse (4.1%, n=237)
- Carer (8.8%, n=517)
- Care home staff (1.8%, n=106)
- Physiotherapist (17.1%, n=999)
- Occupational therapist (10.3%, n=602)
- Counsellor (3.5%, n=205)
- Speech and language therapist (5.5%, n=321)
- Fatigue management team (1.3%, n=77)
- Dietician (3.0%, n=175)
- Pharmacist (10.6%, n=618)
- Palliative care team (1.2%, n=71)
- Wheelchair/mobility aids specialist (6.4%, n=377)
- Psychologist (3.8%, n=225)
- Social worker (3.6%, n=208)
- Pain service (2.8%, n=161)
- Tissue viability service (0.4%, n=25)
- Continence advisor (4.8%, n=281)
- Family member/care giver (23.9%, n=1,398)
- Charity group/voluntary organisation (16.0%, n=935)
- Other (12.2%, n=712)

**23. Do the different people treating and caring for you work well together to give you the best possible care?**

- Yes, always (18.9%, n=1,106)
- Yes, most of the time (24.5%, n=1,433)
- Yes, some of the time (23.5%, n=1,374)
- No, never (18.3%, n=1,068)
- Don't know (14.9%, n=871)

**24. Have you experienced any problems or delays in accessing care or treatment to help manage your condition?**

- Yes (58.1%, n=3,402)
- No (41.9%, n=2,450)

**25. If there could be one priority for health and social care services for people with neurological conditions in your area, what would it be?** Multiple free text responses provided

**26. Have you ever been offered the opportunity to take part in a clinical/research study based on your neurological condition?**

- Yes and I have accepted it (20.7%, n=1,209)
- Yes, but I declined (4.0%, n=235)
- No, but I would be interested (59.1%, n=3,461)
- No and I would not be interested (11.0%, n=642)
- Don't know/can't say/can't remember (5.2%, n=305)

**27. Would you be happy to be contacted by the Neurological Alliance to discuss your answers to some of the above questions in more detail?**

- Yes (71.7%, n=4,197)
- No (28.3%, n=1,655)



## Annex 4: Quality of commissioning audit questions

### Clinical commissioning groups (CCGs)

1. Please confirm whether your CCG commissions services for people with neurological conditions
  - a. If confirmed, please state which of the conditions listed in Annex A are included in these services
2. Please confirm whether your CCG has made an assessment of the prevalence of neurological conditions in your area
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
3. Please confirm whether your CCG has made an assessment of the number of people using neurological services in your area
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
4. Please confirm whether your CCG has made an assessment of i) the total costs ii) the per patient costs of neurological services in your area
  - a. If confirmed, please provide details of the assessment
5. Please confirm whether your CCG collects data on the experience of patients using neurological services
  - a. If confirmed, please provide details
6. Please confirm whether your CCG i) includes service users in decision-making on the commissioning of neurological services ii) includes service users in providing ongoing feedback on the quality of neurological services iii) takes any specific measures to support participation of people with neurological conditions in decision-making or providing feedback
  - a. If confirmed, please provide details
7. Please confirm whether your CCG collects outcomes data on the quality of neurological services in your area
  - a. If confirmed, please provide details of the quality measures that you use
8. Please confirm whether your CCG has taken any action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions
  - a. If confirmed, please provide details of what action has been taken
9. Please confirm whether your CCG has had any communications with i) the Strategic Clinical Network for Neurological Conditions ii) NHS England local area team about the commissioning of neurological services in the last 12 months

- a. If confirmed, please provide details of these communications

## NHS England

1. Please confirm whether NHS England has made an assessment of the prevalence of neurological conditions in each NHS England commissioning region (North of England, Midlands and East of England, London, South of England)
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
2. Please confirm whether NHS England has made an assessment of the number of people using neurological services in each NHS England commissioning region (North of England, Midlands and East of England, London, South of England)
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
3. Please confirm whether NHS England has made an assessment of i) the total costs ii) the per patient costs of neurological services that it commissions
  - a. If confirmed, please provide details of the assessments
4. Please confirm whether NHS England has had any communications with area teams on neurological services in the last 12 months
  - a. If confirmed, please provide details of these communications
5. Please confirm whether NHS England has developed any guidance to support CCGs and area teams in the commissioning of neurological services, aside from the service specification for specialised neurology (adult) and other policies available on the website of the Neurosciences Clinical Reference Group
  - a. If confirmed, please provide details
6. Please confirm whether NHS England has taken any action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions
  - a. If confirmed, please provide details of what action has been taken
7. Please confirm whether NHS England collects data on the experience of patients using neurological services
  - a. If confirmed, please provide details
8. Please confirm whether NHS England i) includes service users in decision-making on the commissioning of neurological services ii) includes service users in providing ongoing feedback on the quality of neurological services iii) takes any specific measures to support participation of people with neurological conditions in decision-making or providing feedback
  - a. If confirmed, please provide details

9. Please confirm whether NHS England collects outcomes data on the quality of neurological services that it commissions
  - a. If confirmed, please provide details of the quality measures that you use

## Annex 5: Quality of commissioning audit findings

### Clinical commissioning groups (CCGs)

1. Please confirm whether your CCG commissions services for people with neurological conditions
  - a. If confirmed, please state which of the conditions listed in Annex A are included in these services
    - Information not held: 7.9%, n=15
    - No (1.6%, n=3)
    - To a certain extent (1.6%, n=3)
    - Unclear (12.6%, n=24)
    - Yes (76.4%, n=146)
2. Please confirm whether your CCG has made an assessment of the prevalence of neurological conditions in your area
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
    - Information not held (7.9%, n=15)
    - No (54.5%, n=104)
    - To a certain extent (5.8%, n=11)
    - Unclear (5.8%, n=11)
    - Yes (26.2%, n=50)
3. Please confirm whether your CCG has made an assessment of the number of people using neurological services in your area
  - a. If confirmed, please provide details of the assessment, including the individual conditions assessed
    - Information not held (7.9%, n=15)
    - No (56.5%, n=108)
    - To a certain extent (5.2%, n=10)
    - Unclear (9.9%, n=19)
    - Yes (20.4%, n=39)
4. Please confirm whether your CCG has made an assessment of
  - i) the total costs of neurological services in your area
    - a. If confirmed, please provide details of the assessment
      - Information not held (9.4%, n=18)
      - No (62.8%, n=120)
      - To a certain extent (8.4%, n=16)
      - Unclear (4.2%, n=8)
      - Yes (15.2%, n=29)
  - ii) the per patient costs of neurological services in your area
    - a. If confirmed, please provide details of the assessment
      - Information not held (10.5%, n=20)
      - No (71.2%, n=136)

- To a certain extent (6.3%, n=12)
  - Unclear (5.2%, n=10)
  - Yes (6.8%, n=13)
5. Please confirm whether your CCG collects data on the experience of patients using neurological services
- a. If confirmed, please provide details
- Information not held (10.5%, n=20)
  - No (65.4%, n=125)
  - To a certain extent (7.9%, n=15)
  - Unclear (5.2%, n=10)
  - Yes (11.0%, n=21)
6. Please confirm whether your CCG i) includes service users in decision-making on the commissioning of neurological services
- a. If confirmed, please provide details
- Information not held (11.0%, n=21)
  - No (23.6%, n=45)
  - To a certain extent (17.8%, n=34)
  - Unclear (11.5%, n=22)
  - Yes (36.1%, n=69)
- ii) includes service users in providing ongoing feedback on the quality of neurological services
- a. If confirmed, please provide details
- Information not held (10.5%, n=20)
  - No (26.2%, n=50)
  - To a certain extent (16.2%, n=31)
  - Unclear (14.1%, n=27)
  - Yes (33.0%, n=63)
- iii) takes any specific measures to support participation of people with neurological conditions in decision-making or providing feedback
- a. If confirmed, please provide details
- Information not held (12.0%, n=23)
  - No (28.3%, n=54)
  - To a certain extent (17.3%, n=33)
  - Unclear (13.1%, n=25)
  - Yes (29.3%, n=56)
7. Please confirm whether your CCG collects outcomes data on the quality of neurological services in your area
- a. If confirmed, please provide details
- Information not held (11.5%, n=22)
  - No (62.8%, n=120)
  - To a certain extent (6.8%, n=13)
  - Unclear (8.9%, n=17)
  - Yes (9.9%, n=19)

8. Please confirm whether your CCG has taken any action to promote integration across primary, secondary, tertiary and social care services for people with neurological conditions
  - a. If confirmed, please provide details
    - Information not held (13.6%, n=26)
    - No (19.9%, n=38)
    - To a certain extent (15.7%, n=30)
    - Unclear (12.0%, n=23)
    - Yes (38.7%, n=74)
  
9. Please confirm whether your CCG has had any communications with i) the Strategic Clinical Network for Neurological Conditions about the commissioning of neurological services in the last 12 months
  - a. If confirmed, please provide details
    - Information not held (14.7%, n=28)
    - No (35.1%, n=67)
    - To a certain extent (3.1%, n=6)
    - Unclear (3.1%, n=6)
    - Yes (44.0%, n=84)
  
- ii) NHS England local area teams about the commissioning of neurological services in the last 12 months
  - a. If confirmed, please provide details
    - Information not held (30.3%, n=58)
    - No (46.6%, n=89)
    - To a certain extent (1%, n=2)
    - Unclear (2.1%, n=4)
    - Yes (19.9, n=38)

## NHS England

**NHS England's response was received on 30<sup>th</sup> September 2014. The response can be found in full below.**

*In response to Questions 1 & 2, 7 & 9, we understand that the Health and Social Care Information Centre (HSCIC) may hold data relevant to your request.*

*The "Compendium of Neurology Data, England - 2012-13" and its associated files are available from: <http://www.hscic.gov.uk/catalogue/PUB13776> and we understand you will find the majority of the information you requested here. For more detailed information we would recommend you resubmit your questions to the HSCIC. Further details for submitting an FOI request to the HSCIC can be found here: <http://www.hscic.gov.uk/foi>*

*In response to Question 3, the NHS England Programme Budgeting holds information relevant to your request, and the website is:*

*<http://www.england.nhs.uk/resources/resources-for-ccgs/prog-budgeting/>*

*It includes providers' expenditure by condition including Neurological, and includes Primary Care Trust level expenditure. Please note the latest data available is 2012/13.*

*In response to Question 4, NHS England has through the Neurological Alliance, NHSIQ and the Strategic clinical networks and via the NCD for neurology had a number of communications about the development of neurological services and about data and information. It was NHS Improving Quality who provided secretariat. Any presentations that were undertaken by NHS England at these meetings have been attached (see attached items listed 4a-4e)*

*NHS England, trauma programme of care, has been working closely with the area teams and has regular teleconferences with the teams updating them on progress and developments for neurosciences. In addition NHS England works with the strategic clinical network for mental health, dementia and neurology.*

*In response to Question 5:*

*In 2013 NHS England funded the Health and Social Care Information Centre (HSCIC) to gather some key neurological indicators to start a neurological dataset, collating information by trust and Clinical Commissioning Group (CCG). This has developed into the Neurological Intelligence Network in collaboration with Public Health England (PHE), HSCIC, and strategic clinical networks, CCGs and Area Teams and the Neurological. The initial data is mainly HES information, some cost and prescribing data, and data on variation in admission rates. This is reported by CCG and Area team, and the information*

*available has started with particular neurological conditions; epilepsy and headache but will eventually encompass the others. Please find attached the notes of these meetings (see items listed 5a-5e.)*

*The NHS England Medical Directorate are not aware of specific commissioning guidance which has been developed for neurological conditions although NHS England's approach to the management of long term conditions encompasses the many of the needs of people with neurological conditions.*

*This includes the NHS England publication 'Commitment to Carers', the web based resource on the House of Care model with commissioning support for commissioning services for people with long term conditions. Work is ongoing in the development of personalised care planning and personal health budgets. The Strategic Clinical Networks (SCNs) with the National Clinical Director (NCD) for Neurology are working with the Neurological Alliance to develop commissioning support for people with long term neurological conditions. Please see various links below, which can provide additional information which we hope you find of use:*

*Year of care link <http://www.yearofcare.co.uk/>*

*Personalised care planning <http://www.england.nhs.uk/2013/09/25/tim-kelsey-2/>*

*Simon Stevens' announcement on personalisation*

*<http://www.communitycare.co.uk/2014/07/09/radical-plan-integrated-health-social-care-personal-budgets-unveiled-nhs-chief/>*

*In response to Question 6, NHS England wholly supports integration of health and care services. Health and Wellbeing boards have developed five year plans for how the joint health and social care fund- the Better Care Fund will be used to integrate care. In addition the chief executive of NHS England has announced a new Integrated Personal Commissioning (IPC) programme, a combined NHS and social care funding endowment which will blend health and social care funding for individuals, and allow them to direct how it is used based on each individual's annual care needs.*

*Individuals enrolled in the programme will be able to decide how much personal control to assume over how services are commissioned and arranged on their behalf. This work extends and combines current work on 'year of care' NHS commissioning, personal budgets in 'continuing care', and the early experience of 14 'integrated care pioneers'.*

*The new neurological intelligence network data will provide invaluable information to support commissioning of services for people with neurological conditions.*

*Neurological Intelligence Network Website <http://www.yhpho.org.uk/mhdnln>*

*Neurological Alliance <http://www.neural.org.uk/>*



*Integrated Care Pioneers* <http://www.england.nhs.uk/2013/11/01/interg-care-pioneers/>

*In response to Question 8, each Clinical Reference Group (CRG) has representation from services users. The Adult neuroscience CRG has 8 patient and public representatives who work with the CRG to develop commissioning policy, feedback and involvement in stakeholder engagement. These Patient and Public Voice (PPV) representatives come from a variety of backgrounds, either service users or representatives of patient support groups.*

## **Annex 6: List of CCGs which responded to the quality of commissioning audit**

NHS Airedale, Wharfedale and Craven CCG  
NHS Ashford CCG  
NHS Aylesbury Vale CCG  
NHS Barking and Dagenham CCG  
NHS Barnsley CCG  
NHS Basildon and Brentwood CCG  
NHS Bath and North East Somerset CCG  
NHS Bedfordshire CCG  
NHS Bexley CCG  
NHS Birmingham Crosscity CCG  
NHS Birmingham South Central CCG  
NHS Blackburn with Darwen CCG  
NHS Blackpool CCG  
NHS Bolton CCG  
NHS Bradford City CCG  
NHS Bradford Districts CCG  
NHS Brent CCG  
NHS Brighton and Hove CCG  
NHS Bristol CCG  
NHS Bromley CCG  
NHS Bury CCG  
NHS Calderdale CCG  
NHS Cambridgeshire and Peterborough CCG  
NHS Camden CCG  
NHS Cannock Chase CCG  
NHS Canterbury and Coastal CCG  
NHS Castle Point, Rayleigh and Rochford CCG  
NHS Central London (Westminster)  
NHS Central Manchester CCG  
NHS Chiltern CCG  
NHS Chorley and South Ribble CCG  
NHS City and Hackney CCG  
NHS Coastal West Sussex CCG  
NHS Corby CCG  
NHS Coventry and Rugby CCG  
NHS Crawley CCG  
NHS Croydon CCG  
NHS Cumbria CCG  
NHS Darlington CCG

NHS Dartford, Gravesham and Swanley CCG  
NHS Doncaster CCG  
NHS Dudley CCG  
NHS Durham Dales, Easington and Sedgefield CCG  
NHS Ealing CCG  
NHS East and North Hertfordshire CCG  
NHS East Lancashire CCG  
NHS East Leicestershire and Rutland CCG  
NHS East Riding of Yorkshire CCG  
NHS East Staffordshire CCG  
NHS East Surrey CCG  
NHS Eastbourne, Hailsham and Seaford CCG  
NHS Eastern Cheshire CCG  
NHS Enfield CCG  
NHS Erewash CCG  
NHS Fareham and Gosport CCG  
NHS Fylde and Wyre CCG  
NHS Gateshead CCG  
NHS Gloucestershire CCG  
NHS Great Yarmouth and Waveney CCG  
NHS Greater Huddersfield CCG  
NHS Greater Preston CCG  
NHS Greenwich CCG  
NHS Guildford and Waverley CCG  
NHS Halton CCG  
NHS Hambleton, Richmondshire and Whitby CCG  
NHS Hammersmith and Fulham CCG  
NHS Haringey CCG  
NHS Harrogate and Rural District CCG  
NHS Harrow CCG  
NHS Hartlepool and Stockton-on-Tees CCG  
NHS Hastings and Rother CCG  
NHS Havering CCG  
NHS Herefordshire CCG  
NHS Herts Valleys CCG  
NHS Heywood, Middleton and Rochdale CCG  
NHS High Weald Lewes Havens CCG  
NHS Hillingdon CCG  
NHS Horsham and Mid Sussex CCG  
NHS Hounslow CCG  
NHS Hull CCG  
NHS Ipswich and East Suffolk CCG

NHS Isle of Wight CCG  
NHS Islington CCG  
NHS Kernow CCG  
NHS Kingston CCG  
NHS Knowsley CCG  
NHS Lambeth CCG  
NHS Lancashire North CCG  
NHS Leeds North CCG  
NHS Leeds South and East CCG  
NHS Leeds West CCG  
NHS Leicester City CCG  
NHS Lewisham CCG  
NHS Lincolnshire East CCG  
NHS Lincolnshire West CCG  
NHS Liverpool CCG  
NHS Luton CCG  
NHS Mansfield and Ashfield CCG  
NHS Medway CCG  
NHS Merton CCG  
NHS Mid Essex CCG  
NHS Milton Keynes CCG  
NHS Nene CCG  
NHS Newark and Sherwood CCG  
NHS Newcastle North and East CCG  
NHS Newcastle West CCG  
NHS Newham CCG  
NHS North Durham CCG  
NHS North East Essex CCG  
NHS North East Hampshire and Farnham CCG  
NHS North East Lincolnshire CCG  
NHS North Hampshire CCG  
NHS North Lincolnshire CCG  
NHS North Manchester CCG  
NHS North Norfolk CCG  
NHS North Somerset CCG  
NHS North Staffordshire CCG  
NHS North Tyneside CCG  
NHS North West Surrey CCG  
NHS North, East, West Devon CCG  
NHS Northumberland CCG  
NHS Nottingham City CCG  
NHS Nottingham North and East CCG

NHS Nottingham West CCG  
NHS Oxfordshire CCG  
NHS Portsmouth CCG  
NHS Redbridge CCG  
NHS Redditch and Bromsgrove CCG  
NHS Richmond CCG  
NHS Rotherham CCG  
NHS Rushcliffe CCG  
NHS Salford CCG  
NHS Sandwell and West Birmingham CCG  
NHS Sheffield CCG  
NHS Solihull CCG  
NHS Somerset CCG  
NHS South Cheshire CCG  
NHS South Devon and Torbay CCG  
NHS South East Staffs and Seisdon and Peninsula CCG  
NHS South Eastern Hampshire CCG  
NHS South Gloucestershire CCG  
NHS South Kent Coast CCG  
NHS South Lincolnshire CCG  
NHS South Manchester CCG  
NHS South Norfolk CCG  
NHS South Sefton CCG  
NHS South Tees CCG  
NHS South Tyneside CCG  
NHS South Warwickshire CCG  
NHS South West Lincolnshire CCG  
NHS South Worcestershire CCG  
NHS Southampton CCG  
NHS Southend CCG  
NHS Southport and Formby CCG  
NHS Southwark CCG  
NHS St Helens CCG  
NHS Stafford and Surrounds CCG  
NHS Stockport CCG  
NHS Stoke on Trent CCG  
NHS Sunderland CCG  
NHS Surrey Downs CCG  
NHS Surrey Heath CCG  
NHS Sutton CCG  
NHS Swale CCG  
NHS Swindon CCG

NHS Tameside and Glossop CCG  
NHS Telford and Wrekin CCG  
NHS Thanet CCG  
NHS Thurrock CCG  
NHS Trafford CCG  
NHS Vale of York CCG  
NHS Vale Royal CCG  
NHS Wakefield CCG  
NHS Walsall CCG  
NHS Waltham Forest CCG  
NHS Warrington CCG  
NHS Warwickshire North CCG  
NHS West Cheshire CCG  
NHS West Essex CCG  
NHS West Hampshire CCG  
NHS West Kent CCG  
NHS West Lancashire CCG  
NHS West Leicestershire CCG  
NHS West London CCG  
NHS West Norfolk CCG  
NHS West Suffolk CCG  
NHS Wigan Borough CCG  
NHS Wiltshire CCG  
NHS Wirral CCG  
NHS Wolverhampton CCG  
NHS Wyre Forest CCG

## Annex 7: Previous report recommendations, aspirations and calls to action

The Neurological Alliance have developed a suite of materials, outlining key recommendations to support making life better for the millions of people in England with a neurological condition. A consolidated overview of these recommendations and calls to action can be found below:

### [\*Navigating neurology services: helping strategic clinical networks to be a success story \(September 2013\)\*](#)

#### Gathering data and intelligence

The SCN should:

- Quickly establish processes and procedures for assessing the needs of people with neurological conditions, benchmarking current performance and measuring outcomes;
- Measure emergency admissions and readmissions for people with neurological conditions, and the primary and secondary causes of admission, to identify problem areas;
- Inform the development of a national neurological dataset by submitting data on neurological services and outcomes to NHS England on a regular basis;
- Inform the development of Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies to ensure that the needs of people with neurological conditions are accurately represented and appropriately prioritised.

#### Involving and empowering patients and carers

The SCN should:

- Look to organisations such as the Neurological Alliance and its members to support patient involvement and co-creation of services through their networks and existing channels for seeking insights from people with neurological conditions;
- Involve patients in developing clear, written or web-based neurological pathways, which can be tailored to each of the 12 SCN regions, signposting to local sources of advice and support;
- Work with providers to ensure that people with neurological conditions are offered a care plan and that this is developed in such a way that it supports them to navigate services.

#### Delivering high quality community services

The SCN should:

- Explore how community-based neurological services can be supported and promoted to deliver high quality care, for example through the development of community 'neuro-care teams', which provide an avenue for inter-referral and patient support.

## Raising awareness of neurological conditions in primary and community care

The SCN should:

- Prioritise education and support to raise awareness of neurological conditions among non-specialist professionals, in particular, primary care clinicians.

## Supporting the implementation of national guidance

The SCN should:

- Support the translation and implementation of national guidance relating to neurological conditions, for example NICE guidance, at a local level and lead on measuring progress in achieving the aspirations set out in guidance documents.

## Delivering integrated care

The SCN should:

- Facilitate and promote joined-up working between the different specialisms that people with neurological conditions may come into contact with. As a first step, the SCN should focus on mapping and communicating examples of current best practice in multidisciplinary working.

## Encouraging innovation

The SCN should:

- Encourage the spread of best practice by bringing together those involved in running SCNs in different condition areas to discuss successes and challenges and to learn from each other, for example, by holding a biannual best practice seminar;
- Engage closely with Academic Health Science Networks to provide neurological expertise and encourage them to allocate some of their resources to focusing on neurology.

## Measuring success

The SCN should:

- Have a robust plan in place, from very early on in its development, for how it will measure and report its achievements;
- Undertake an annual audit of progress which reflects the priority areas set out in its original strategy and workplan;
- Link closely with NHS England, CCGs and commissioning support units and help them to report successes in the commissioning of neurological services.

NHS England should:

- Ensure there are mechanisms in place through which the SCN will be held to account for its performance, both nationally and regionally;
- Establish a reciprocal requirement on CCGs to engage with SCNs across all the condition areas they cover to ensure that they are fulfilling their core purpose of quality improvement.



## **Measuring up: improving the collection of neurological data and intelligence** **(April 2014)**

### **Short-term goals**

- Development of the first iteration of the national neurological minimum dataset
- Buy-in secured for dataset from all relevant bodies
- Publication of the dataset by the Health and Social Care Information Centre providing baseline neurological data
- Creation of the national Mental Health, Dementia and Neurological Intelligence Networks by Public Health England
- Buy-in and resources secured for the Neurology Intelligence Network from all relevant bodies
- Launch of the Neurology Intelligence Network and publication of its priorities by Public Health England
- Publication of findings of the pilot national neurological patient experience survey

### **Medium-term goals**

- Publication of the inaugural annual Atlas of Variation on neurological conditions by Public Health England
- Funding secured from NHS England to support sustained expansion and development for the dataset in the long term
- Development and piloting of routine outpatient coding in neurology
- Commitment from NHS England to run annual national neurological patient experience survey
- Commitment from the Department of Health to develop new neurological measures in the NHS Outcomes Framework and CCG Outcomes Indicator Set and to track generic measures in the Adult Social Care Outcomes Framework for neurological conditions
- Development of additional Neurology Intelligence Network resources and tools (such as e-Atlas and GP practice profiles)

### **Long-term goals**

- Creation of a neurological conditions registry, hosted by the Neurology Intelligence Network
- National roll out of routine outpatient coding in neurology
- Expansion of national clinical audit programme to include a range of neurological conditions
- Range of neurological clinical audits included in quality accounts reporting process
- 100% rate of data returns secured for the neurological dataset
- Publication of findings of first NHS funded national neurological patient experience survey

## **[Going the distance: national calls to action to drive neurological service improvement in England \(March 2014\)](#)**

### **NHS Mandate**

- 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.

### **NHS Outcomes Framework**

- 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 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**

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

### **NICE quality standards and clinical guidelines**

- 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.

### **Clinical audit, data and intelligence**

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

## Commissioning for Quality and Innovation

- NHS England should provide guidance on the use of Commissioning for Quality and Innovations (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

- 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.

## *Manifesto 2015: a call to action for neurology (September 2014)*

### **Data and intelligence on neurological conditions** must:

- Cover all aspects of neurological care and outcomes
- Be collected and published at least annually
- Be routinely used to improve service

### **Access to specialist care** must be:

- A reality for all people with neurological condition, from diagnosis to end of life
- Available across all care settings – in the home, in the community and in hospital

### **Research into new and better treatments for neurological conditions** must:

- Receive ring-fenced UK Government and leadership to match the burden and full spectrum of neurological conditions
- Be encouraged as part of an environment that promotes clinical trials in the UK

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