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## Introduction

It is estimated that eight million people in England – more than one in six – have a neurological condition and over half a million people are newly diagnosed with a neurological condition each year<sup>1</sup>.

Neurological conditions can result from damage to the brain, spinal cord or peripheral nerves. Some are life-threatening and many can severely affect a person's quality of life and cause lifelong disability. Neurological conditions, as a general rule, fall into the 'long-term condition' category and are broadly grouped as follows:

- **Sudden onset conditions** – for example, acquired brain injury or spinal cord injury, followed by a partial recovery
- **Intermittent and unpredictable conditions** – for example, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed at different times
- **Progressive conditions** – for example, motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (eg motor neurone disease) deterioration can be rapid
- **Stable neurological conditions** (but with changing needs due to development or ageing) – for example cerebral palsy in adults<sup>2</sup>

“Eight million people in England – more than one in six – have a neurological condition and over half a million people are newly diagnosed each year.”

The needs of people with neurological conditions are wide-ranging and may cross a number of different sectors, including health, social services, employment, benefits, transport, housing and education. The range of conditions that fall within this category, and their unpredictable nature, complexity and rarity, makes it difficult to reach a consensus on what type of outcomes are achievable for people with neurological conditions and how these outcomes should be measured.

The most recent evidence has shown that current spending on neurological health and social care services, estimated at £5.3billion in 2009/10, does not provide value for money<sup>3</sup>. The evidence has also highlighted a number of service failings, including delayed diagnosis, unacceptable variations in access to health and social care services, and poor care coordination<sup>4</sup>. Whilst there are pockets of good practice in neurological services, these are inconsistent and often fail to be replicated across the country.

Meeting the needs of the eight million people with a neurological condition in England will be a crucial test case for the success of the Government's health and social care reforms. These reforms are intended to free up clinicians to focus on what matters most to patients, ensuring that the convenience of organisational boundaries does not come before the needs of patients and carers.

There is real potential that the quality of care for people with neurological conditions could be undermined under the new system for the same reasons as in previous years, most importantly through the absence of robust accountability and incentive mechanisms. It is very concerning that so few of the high level outcome measures identified in the NHS Outcomes Framework relate to neurological conditions. Other important mechanisms such as the Commissioning Outcomes Framework – which will shape the priorities of clinical commissioning groups – also fail to give neurology appropriate profile.

This report is intended to illustrate how the levers of the new NHS can be applied to improving outcomes for this group of patients, addressing the legacy of neglect which has resulted in unacceptable variations in

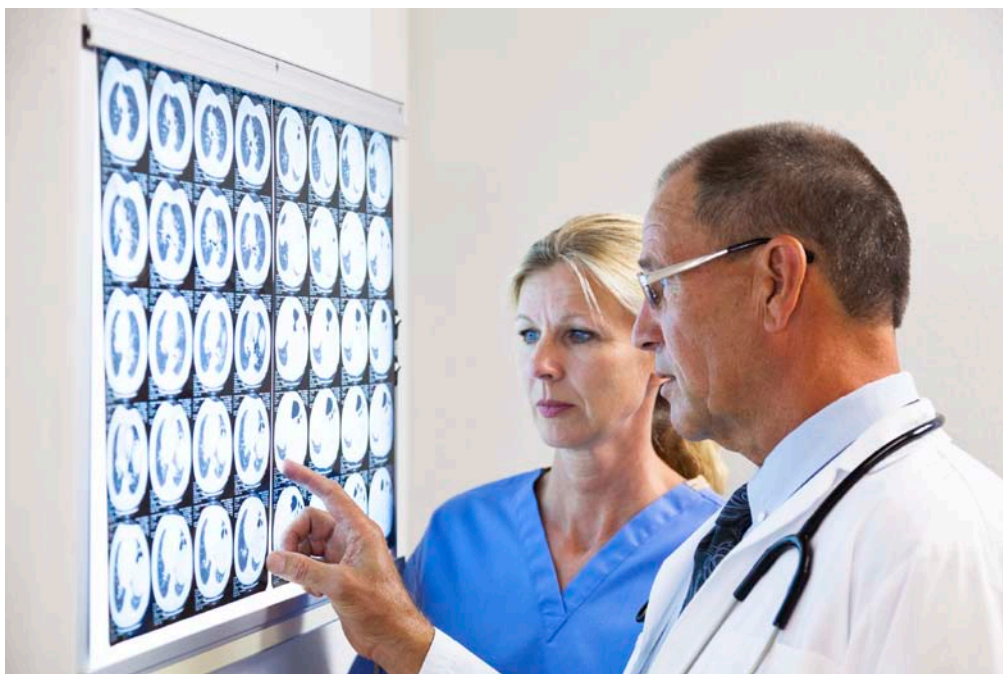
outcomes and higher than necessary costs. Its recommendations are aimed at ensuring that NHS resources are directed towards investing in quality and not paying for the cost of failure, as has happened in the past.

The report was informed by a roundtable of leading stakeholders from across the neurological community, convened by the Neurological Alliance and MHP Health Mandate. At this event, attendees discussed the delivery of high quality outcomes for people with neurological conditions within the new NHS landscape, with a view to making recommendations to Government and the NHS for how the challenges ahead can be met. A full list of attendees at the roundtable is set out in Annex 3.

“Meeting the needs of the eight million people with a neurological condition is a crucial test case for the success of the Government’s health and social care reforms.”

The resulting report and recommendations seek to make a constructive contribution to the ongoing debate on the future of neurological services within the evolving health and social care architecture. The findings from the roundtable have been supplemented by additional research, involving the members of the Neurological Alliance, to understand the outcomes that really matter for people with neurological conditions. Through this report, we have sought to define these outcomes and to prompt debate on how best the policy levers of the new NHS can be applied to improving services for people with neurological conditions.

We call on the Government, the NHS Commissioning Board and health and social care professionals to seize this important opportunity to undertake the urgent action necessary to improve the lives of the one in six people in England with a neurological condition.



## Summary of key findings and recommendations

### Key findings

1. Early evidence suggests that policy levers for improving care in the new NHS landscape are not being mobilised to support improvements to neurological services. This is despite neurological services being responsible for more than 5% of overall NHS expenditure, making it the eighth highest programme budgeting category (from a total of 23) in terms of spending<sup>5</sup>. Five of the six key policy levers, including national outcomes strategies and the Commissioning Outcomes Framework, are not currently being used to improve services for people with neurological conditions. There is therefore an important opportunity to raise the quality of neurological care through use of the relevant policy levers
2. There is significant variation in PCT expenditure on caring for people with neurological conditions across the country, according to the latest available data. The highest expenditure was in Central Lancashire PCT, which spent £11.37m per 100,000 population, whilst Haringey Teaching PCT spent £4.31m per 100,000 population<sup>6</sup>
3. On average, a third of PCT expenditure on neurological conditions falls within non-elective and emergency care. This is a higher proportion than for mental health disorders, circulatory problems and cancers, which are the three areas of highest overall spend in the NHS. This suggests that there is an opportunity to bring down this high proportion of spending on emergency neurological care
4. There is nearly a seven-fold variation in the proportion of expenditure on non-elective inpatient care and urgent/emergency care on neurological conditions across the country<sup>7</sup>. Half of PCTs spend more than a third of their total expenditure for neurological conditions on non-elective inpatient care and urgent/emergency care. In some PCTs, including Wandsworth, Sunderland and Liverpool, more than 50% of the budget for neurological conditions is spent on non-elective, urgent and emergency care<sup>8</sup>
5. Less than 1% of the Commissioning for Quality and Innovation (CQUIN) indicators utilised by trusts in 2010/11 were in the area of neurology. Just 22 of the 4,794 indicators listed for that period were within the neurology category and all of these related specifically to neurological rehabilitation<sup>9</sup>

### Recommendations

*NB: At this early stage in the NHS reform programme, the respective responsibilities of the Department of Health and the NHS Commissioning Board are still emerging, with many responsibilities not due to transfer from the Department to the Board until 2013. To reflect this, recommendations aimed at the Department of Health and NHS Commissioning Board are grouped together.*

#### **The Department of Health and NHS Commissioning Board should:**

1. Work with the neurological community to develop outcome measures that can be used to drive improvements to services for people with neurological conditions, using the measures suggested in this report as a starting point. A summary of these suggested measures can be found in Annex 2
2. Adopt a targeted approach to drive improvements to neurological services, potentially in the form of a national neurological outcomes strategy and commissioning support pack setting out how each policy lever should be applied in practice
3. Ensure that there is dedicated neurology clinical leadership and full accountability for the quality of neurological services at a national level to drive much-needed improvements to neurological services

4. Work with a lead public health observatory for neurology to develop key indicators and quality metrics relating to neurological services that can be included in the NHS and Adult Social Care Outcomes Frameworks
5. Develop neurology-specific patient reported outcome measures (PROMs) that can reach beyond current provisions in measuring the quality of life of people with neurological conditions
6. Ensure that the planned strategic clinical network for neurological conditions provides the necessary neurological expertise to inform each stage of the commissioning process on an equitable basis across the country and supports the delivery of integrated, cost effective care, and that it is sufficiently resourced to do so
7. Commission the development of a national survey for people with neurological conditions to gather insights into the care experienced by patients and to be used as the basis for patient experience measures for inclusion in future iterations of the NHS and Adult Social Care Outcomes Frameworks

**Public Health England should:**

8. Appoint a lead public health observatory for neurology to lead the way in gathering information about the outcomes that matter in neurology

**The NHS Information Centre for Health and Social Care should:**

9. Disaggregate the outcome measures in the NHS Outcomes Framework according to geography, demography and disease so that progress in specific disease areas, such as neurological conditions, can be measured and prioritised

**The National Institute for Health and Clinical Excellence (NICE) should:**

10. Incorporate a range of quality metrics relating to neurological conditions into NICE quality standards and the Commissioning Outcomes Framework

**Clinical commissioning groups should:**

11. Make use of quality incentives, such as the Commissioning for Quality and Innovation (CQUIN) scheme and year-of-care tariffs to drive improvements to neurological services

**Health and social care providers should:**

12. Utilise quality accountability tools, such as quality accounts, to drive local improvements to neurological services and to demonstrate the action they are taking to raise the quality of services

## Background

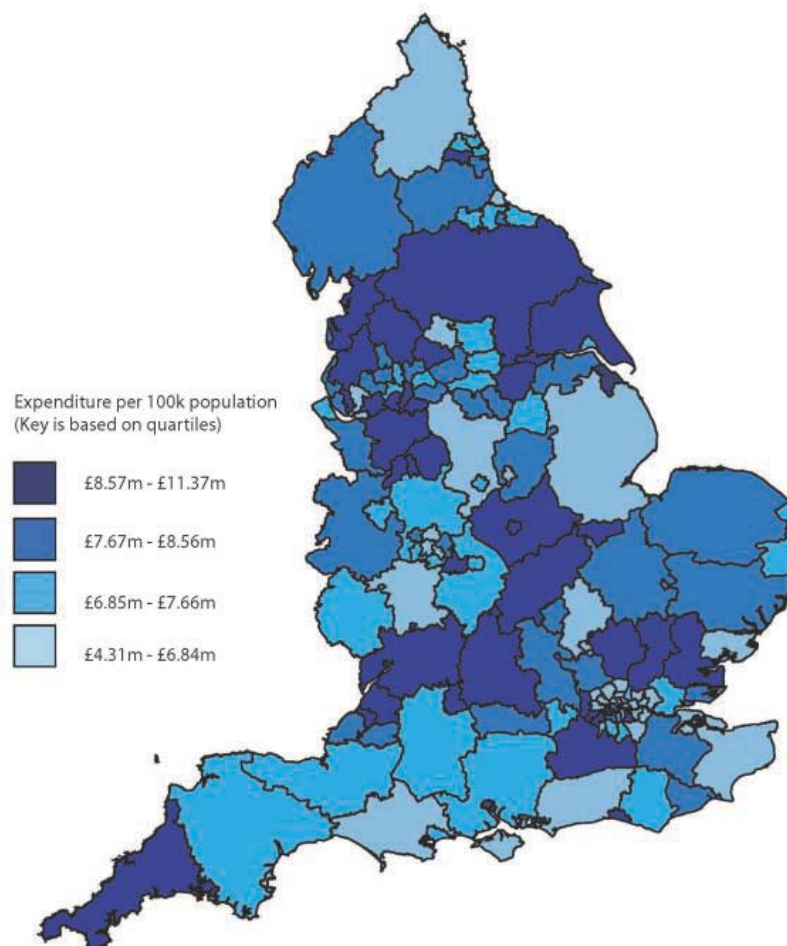
### Promising policy has not translated into action

Past efforts to drive improvements to neurological services, notably in the shape of the 2005 *National Service Framework for Long-term Conditions* (NSF), were hampered by a lack of national monitoring, targets and ring-fenced funding<sup>10</sup>. Recent reports from the National Audit Office (NAO) and Public Accounts Committee (PAC) have demonstrated that many of the problems faced by people with neurological conditions that were highlighted in 2005, such as delayed diagnosis and poor information provision, still persist<sup>11,12</sup>. In addition, pockets of good practice in neurological services have failed to be replicated<sup>13</sup>. Overall, the picture shown is that current spending on neurological health and social care services, estimated at £5.3billion in 2009/10, does not provide value for money<sup>14</sup>.

### The spiralling cost of neurological care

Expenditure on neurological conditions has grown significantly since the publication of the NSF, increasing from 2.6% to 4% of total NHS expenditure between 2005 and 2010, representing £1.7 billion in extra resources<sup>15</sup>. There is significant variation in PCT expenditure on caring for people with neurological conditions across the country, according to the latest available data. There was a more than two-fold variation in PCT spending on caring for people with neurological conditions per 100,000 population in 2010/11, as shown in the map below. The highest expenditure was in Central Lancashire PCT, which spent £11.37m per 100,000 population, whilst Haringey Teaching PCT spent £4.31m per 100,000 population<sup>16</sup>.

**Figure 1: Total expenditure on neurological conditions per 100,000 population across PCTs, 2010/11<sup>17</sup>**

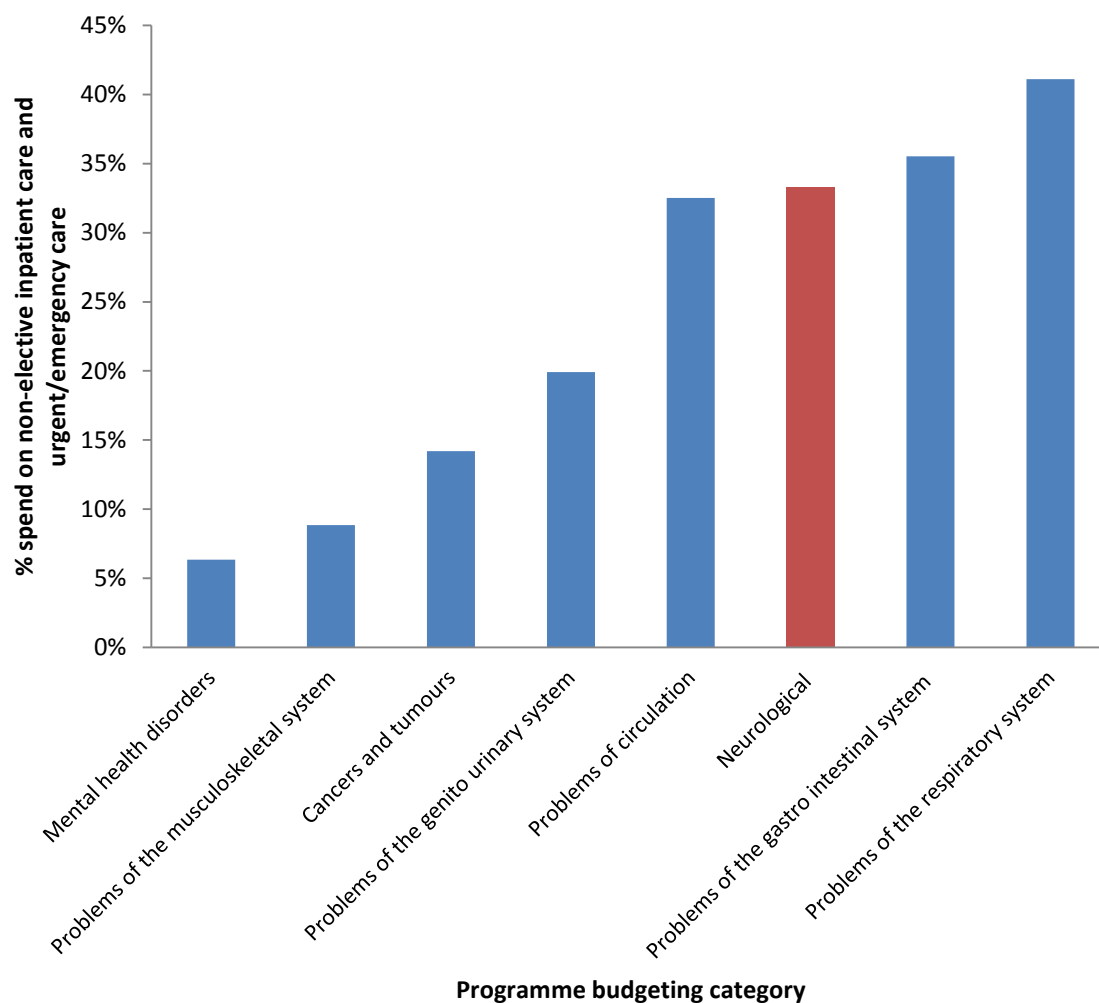


Evidence shows that there is still a lack of care coordination and poor integration between health and social care services for people with neurological conditions<sup>18</sup>. The NAO report documented a 32% rise in the number of unplanned hospital admissions for this cohort of patients in the first five years of the NSF (2005-2010), compared to 17% across the NHS as a whole<sup>19</sup>. As shown in Figure 2 below, analysis of the latest available data reveals that, on average, a third of PCT expenditure on neurological services falls within non-elective and emergency care<sup>20</sup>. This is a higher proportion than for mental health disorders, circulatory problems and cancers, which are the three areas of highest overall spend in the NHS.

Not only are emergency admissions distressing for patients and extremely costly for the NHS, but they are often an indication that conditions are not being well managed within primary care, community and social services. It is clear that targeted measures are needed to reduce this unacceptably high rate of emergency neurological admissions and the associated high level of expenditure.

“On average, a third of PCT expenditure on neurological services falls within non-elective and emergency care.”

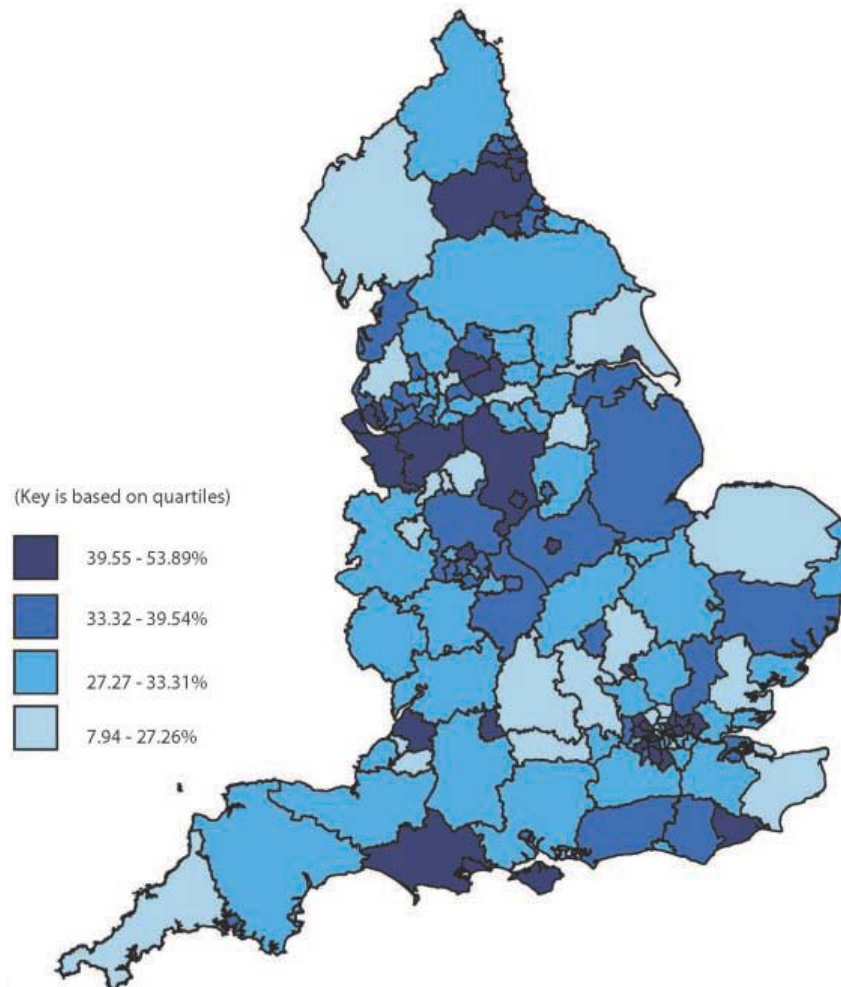
**Figure 2: Proportion of expenditure on non-elective inpatient care and urgent/emergency care across highest spending programme budgeting categories (excluding trauma and maternity care)<sup>21</sup>**





Analysis of these data at a more granular level shows a nearly seven-fold variation in the proportion of expenditure on non-elective inpatient care and urgent/emergency care across the country. As illustrated in the map below, half of PCTs spend more than a third of their total expenditure for neurological conditions on non-elective inpatient care and urgent/emergency care. In some PCTs, including Wandsworth, Sunderland and Liverpool, more than 50% of the budget for neurological conditions is spent on non-elective, urgent and emergency care<sup>22</sup>.

**Figure 3: Proportion of programme budget expenditure on neurological conditions spent on non-elective inpatient care and urgent/emergency care across PCTs, 2010/11<sup>23</sup>**



Avoiding emergency admissions is rightly a key priority for the Government and the NHS. The rationale for not implementing any measures to reduce spending on emergency neurological admissions when the level recorded is so high is unclear. There is a distinct mismatch between the high proportion of expenditure on emergency care and the lack of policy levers in place to address this. There is potential for neurology services to contribute significantly to the Government's Quality, Innovation, Productivity and Prevention (QIPP) agenda if this mismatch is addressed through application of the appropriate policy levers.

Interestingly, as shown in Figure 2, spending on non-elective and urgent care is a similar level for neurological services as it is for services for circulatory problems<sup>24</sup>. There are, however, a number of policy levers in place to address this high level of spending within the circulatory problems category, including a range of indicators in the NHS Outcomes Framework, Commissioning Outcomes Framework (COF) and

Quality and Outcomes Framework (QOF), in addition to NICE quality standards and a national outcomes strategy in development. The contrast with neurological services is stark.

### The underrepresentation of neurological conditions

The Government's recent response to the PAC report sent a worryingly signal that an important opportunity to tackle the endemic problems that currently exist in neurological services might be missed<sup>25</sup>. The PAC's recommendations mirrored the key calls of the Neurological Alliance's *Better Deal* campaign, highlighting the strong backing for the PAC's recommendations from the neurological community of patients, carers and clinicians. The Government has, however, agreed to fully implement only a handful of the PAC's recommendations, crucially rejecting the key calls for clinical leadership at a national level and joint health and social care commissioning of neurological services.

For those of the PAC recommendations that the Government has agreed to, the plans for implementation consist of very few specific measures for neurological services, reflecting instead a generalised approach to long-term conditions as a broad group. A summary of the PAC's recommendations and the Government's response can be found in Annex 1.

There is a danger that this important chance to seize the opportunities presented by the health and social care reforms to improve neurological services will be missed. Furthermore, the evidence suggests that neurological conditions are not currently afforded a profile that is proportionate to the burden they place on NHS and social care services. Neurological conditions are responsible for more than 5% of overall NHS expenditure, making up the eighth highest programme budgeting category (from a total of 23) in terms of spending. Despite this, early evidence suggests that the policy levers that are available are not being mobilised to support improvements to neurological services.

**“There is a danger that this important chance to seize the opportunities presented by the health and social care reforms to improve neurological services will be missed.”**

Figure 4 opposite illustrates how neurology compares with the other nine highest-spending programme budgeting categories in relation to current policy levers and evidence of central prioritisation. It is generally the rule that those disease or service areas that incur high expenditure in the NHS are afforded a proportionate profile by the Government, but there are exceptions to this rule, neurology being a major one. Five of the six key policy levers for improving care within the new NHS landscape, including national outcomes strategies and the COF, are not currently being utilised to improve services for people with neurological conditions.

Figure 4: Policy prioritisation across the ten programme budgeting categories incurring the highest level of NHS expenditure

Programme budgeting category	% of overall NHS spend, 2010/11	National clinical director	National outcomes strategy	Relevant condition-specific indicators in NHS Outcomes Framework	Published NICE quality standards	% of COF indicators, 2012/13 and 2013/14	% of QOF indicators
Mental health disorders	14.40%	Yes	Yes	4	3	17.62%	12.80%
Problems of circulation	9.20%	Yes	In development	3	3	16.74%	34.90%
Cancers and tumours	7.42%	Yes	Yes	2	1	5.73%	2.30%
Problems of the musculo skeletal system	6.62%	No	No	0	0	1.76%	0%
Problems of the genito urinary system	5.89%	Yes (for kidney services)	No	0	1	5.29%	5.80%
Problems of the gastro intestinal system	5.79%	Yes (for endoscopy)	No	0	0	1.76%	0%
Problems of the respiratory system	5.62%	Yes	Yes	3	1	13.66%	10.50%
Neurological	5.35%	No	No	0	0	0%	4.70%
Problems due to trauma and injuries	4.85%	Yes	No	2	1	0.44%	0%
Maternity and reproductive health	4.65%	Yes	No	1	0	2.64%	0%

Eight of the ten categories above have a national clinical director with responsibility for all (or part) of the services within that particular programme budgeting category. Clinical leadership and accountability at a national level are essential not only to gain control on spending, but also to champion the cause so that the subsequent quality improvement mechanisms that are needed are implemented throughout the system. This should then lead to good practice being replicated across the country and, crucially, national level accountability for both the quality and efficiency of neurological services.

Figure 4 also demonstrates the consistent lack of importance allotted to neurological services across a number of other areas, including the development of national outcomes strategies, the publication of NICE quality standards, and the inclusion of condition-specific indicators in the NHS Outcomes Framework, COF and the QOF. Measures to redress this inequity will be vital if the necessary improvements to neurological services are to be delivered in the near future.

Both the Secretary of State for Health, the Rt Hon Andrew Lansley MP, and the NHS Chief Executive, Sir David Nicholson, have reiterated on numerous occasions the importance of NICE quality standards in driving improvements to the commissioning and provision of health services. It is concerning that, although quality standards have been promised for a small number of neurological conditions, development is only underway for an even smaller number, and development of those outstanding is yet to be scheduled<sup>26</sup>. Quality standards are intended to form the backbone of the new NHS quality framework, so it is no surprise that those conditions for which quality standards have already been developed are now set to be translated into quality incentive schemes under development, such as the COF.

The work that is currently underway to develop the COF has shown that neurology continues to be underrepresented, with no indicators specifically relating to neurological conditions included in the proposed framework<sup>27</sup>. Notably, over half (56%) of the indicators in the framework are derived from quality standards and indicators in the NHS Outcomes Framework: clearly, a lack of prioritisation can engender a cycle of neglect, played out in the development of new quality incentive schemes<sup>28</sup>.

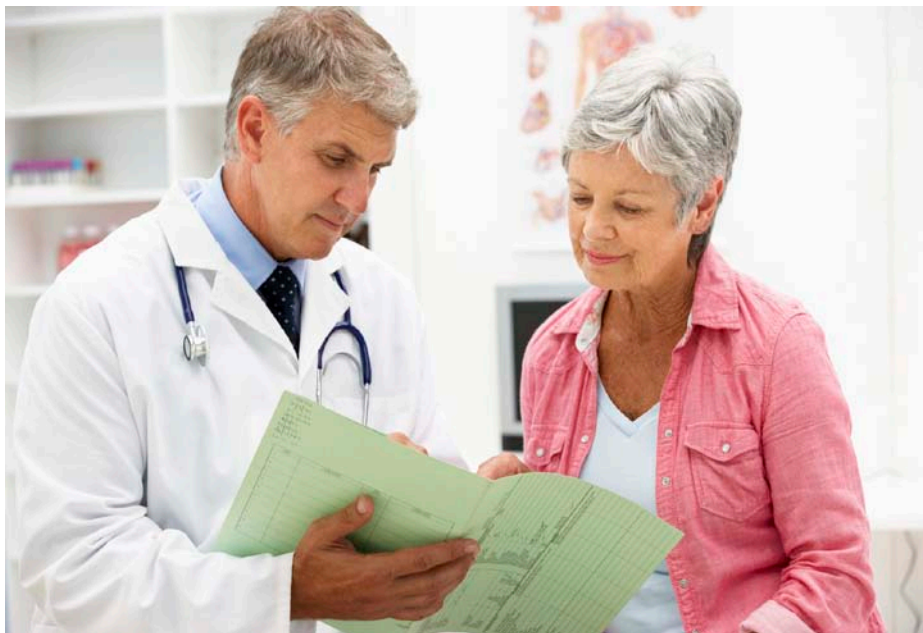
Recognition of neurological services also falls short when it comes to rewarding the delivery of quality improvements through financial payments such as the Commissioning for Quality and Innovation (CQUIN) framework. The appropriate use of financial incentives has the potential to significantly influence health service delivery, focusing attention in areas of need and encouraging the necessary changes in practice which commissioners have deemed to be important. It is therefore disappointing that less than 1% of the CQUIN indicators utilised by trusts in 2010/11 were in the area of neurology. Just 22 of the 4,794 indicators listed for that period were within the neurology category and all of these related specifically to neurological rehabilitation<sup>29</sup>.

**“It is disappointing that less than 1% of the CQUIN indicators utilised by trusts in 2010/11 were in the area of neurology.”**

## The long-term conditions agenda

There is an indication that long-term conditions, more broadly, are being given a collective focus by the Government, signalled by its intention to develop a new cross-departmental Long-Term Conditions Outcomes Strategy. An effective outcomes strategy for long-term conditions with clear recommendations and a properly resourced plan for implementation would indeed be welcome news and have an important role to play in improving outcomes for patients. It would have the potential to benefit some people with neurological conditions, particularly those with co-morbidities. Alone, however, it will not be enough to deliver urgent improvements in outcomes for all people with long-term conditions, given that it will be unable to go to the level of detail that is required to deliver large-scale improvements within a specific disease area.

In light of the legacy of underprioritisation of neurological services, a condition-specific focus is needed in addition to this broad strategy. The failings within neurology care that have persisted to date will continue to do so unless targeted action is taken by the Department of Health and NHS Commissioning Board to use the policy levers that are available to drive improvements to neurological services. This targeted approach could potentially take the form of a neurological outcomes strategy. The PAC recommended in its report that the NAO should undertake a follow-up review of progress against the PAC's recommendations in 2014. Given this is only 18 months away, there is additional pressure on the Department of Health and NHS Commissioning Board to ensure that urgent action is taken.



## Defining the outcomes that matter for people with neurological conditions

### Defining outcome measures for neurological services

Evidence suggests that the NHS is effective at delivering improvements on issues that it has prioritised and that it tends to prioritise those issues on which it can easily measure progress. However, it has in the past not been possible to identify appropriate quality metrics for neurological services, which have been largely overlooked, contributing to their underrepresentation in the current NHS quality improvement framework.

This must change. As the NHS shifts its focus to outcomes, so the neurological community must identify the outcomes which matter most to patients. This will enable a set of outcome measures to be devised for incorporation into the current NHS quality assurance framework.

The NHS Outcomes Framework is the bedrock of the new NHS quality assurance architecture. As such, it should be the starting point in devising outcome measures that are capable of delivering the step-change in the quality of neurological services that is needed. The NHS Outcomes Framework will be used to hold the NHS Commissioning Board to account for the outcomes it delivers through NHS services. The Board itself will be structured around the five domains of the NHS Outcomes Framework, with national professional leads for each of the five outcome areas reporting to the Medical Director (for Domains 1,2 and 3) and Chief Nursing Officer (for Domains 4 and 5). The five domains of the NHS Outcomes Framework and their relevance to neurological conditions are set out in Figure 5 below.

**Figure 5: NHS Outcomes Framework domains and their relevance to neurological conditions**

NHS Outcomes Framework domain	Relevance to neurological conditions
<b>Domain 1: Preventing people from dying prematurely</b>	<ul style="list-style-type: none"> <li>- Reducing premature mortality due to poor management of symptoms</li> </ul>
<b>Domain 2: Enhancing quality of life for people with long-term conditions</b>	<ul style="list-style-type: none"> <li>- Quick and accurate diagnosis</li> <li>- Prompt and equitable access to appropriate specialists and treatment</li> <li>- Access to high quality information</li> <li>- Support to self-manage the condition</li> <li>- Maintaining functional ability</li> <li>- Coordinated health and social care support</li> <li>- Enhancing quality of life for carers</li> </ul>
<b>Domain 3: Helping people to recover from episodes of ill health or following injury</b>	<ul style="list-style-type: none"> <li>- Helping people to recover their independence and functional ability</li> <li>- Reducing emergency admissions and length of stay</li> <li>- Helping people to return to work</li> </ul>
<b>Domain 4: Ensuring that people have a positive experience of care</b>	<ul style="list-style-type: none"> <li>- Improving people's experience of care across all care settings</li> <li>- Access to a clinical nurse specialist or specialist coordinator</li> <li>- Provision of a personal care plan</li> <li>- Dying well</li> </ul>
<b>Domain 5: Treating and caring for people in a safe environment; and protecting them from avoidable harm</b>	<ul style="list-style-type: none"> <li>- Getting the right medicines at the right time</li> <li>- Timely access to assistive equipment (including wheelchairs)</li> </ul>

## What types of outcome measures are needed?

There are a number of indicators within the existing framework that are of relevance to the services provided for people with neurological conditions. However, NHS Outcomes Framework measures are necessarily high level and may be of limited use in performance management. It is therefore important that outcome measures are disaggregated according to geography, demography and disease. Only this way can progress in particular disease areas really be measured and, where necessary, improved.

In terms of measuring progress on meeting the needs of people with neurological conditions, three different forms of outcome measures will be needed:

- **Overarching measures** – these cross-cutting measures cover the outcomes that are expected for all NHS patients, regardless of their condition or specific health needs (eg waiting time measures)
- **Overarching measures, disaggregated for neurological conditions** – these measures, which are also cross-cutting, can relate to specific aspects of care, such as the provision of personal care plans, but require specific measurement for different cohorts of patients (eg people with neurological conditions)
- **Neurology-specific measures** – these measures relate to the outcomes that are required specifically for people with neurological conditions (eg time taken to reach a stable neurological diagnosis)

It is important to remember that the full spectrum of broad overarching measures right through to very specific measures will be needed in order for the quality of neurological services to be raised to the level at which they can and need to be.

## What are the outcomes that matter most to people with neurological conditions?

For each of the domains of the NHS Outcomes Framework, we have below identified both the high-level outcomes and the quality indicators which could be used to measure progress in neurological conditions for each particular area.



## Domain 1: Preventing people from dying prematurely

Figure 6: Summary of recommended outcome measures under Domain 1

Domain 1: Preventing people from dying prematurely	
NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
- 1a: Potential years of life lost from causes considered amenable to healthcare	- Under 75 mortality rate for people with neurological conditions

### Why is this domain important for people with neurological conditions?

Some neurological conditions can be life-threatening and others can shorten life expectancy, whilst many people with neurological conditions will live a completely normal life-span. Some neurological conditions, such as epilepsy, may be a direct cause of premature death whereas others, such as multiple sclerosis, may cause premature death indirectly due to the symptoms of the condition. For example, it may be that the primary cause of a premature death is a respiratory problem but this problem has arisen due to a person's neurological condition. Had this problem or set of symptoms been better managed, it might not have resulted in premature death.

It is crucial that efforts are made to devise suitable indicators so that premature death due to neurological conditions can be measured. An appropriate indicator would be to look at premature mortality that occurs due to poor management of the symptoms of neurological conditions.

### Which overarching measures need to be disaggregated for neurological conditions?

- Indicator 1a: *“Potential years of life lost from causes considered amenable to healthcare”*

The proposed list of causes considered amenable to healthcare, set out in the current framework, includes only epilepsy in the neurological disorders category. As explained above, causes considered amenable to healthcare should include the symptoms of neurological conditions, for example respiratory infections, so that the number of avoidable deaths in neurological conditions can be measured. It is vital that neurological conditions are recorded on death certificates even if the primary cause of death is due to respiratory problems, for instance, so that providers are held to account for poor management of neurological conditions that results in premature death.

### What specific measures are needed for neurological conditions?

The exact number of people with a neurological condition, and of those who die with, or as a result of, their neurological condition is currently unknown. It is suspected that there are a significant number of avoidable deaths due to poor management of neurological conditions. An additional indicator is therefore needed to measure mortality rates in neurological conditions specifically. Similar to the measures that are currently included for under 75 mortality rate from cardiovascular, respiratory, and liver disease, cancer and serious mental illness, the healthcare contributions that can be made to bring down mortality rates for neurological conditions include early and accurate diagnosis, optimal pharmacotherapy, and prompt access to specialist care. To fall in line with the other indicators included in the framework, we suggest the following additional measure:

- Under 75 mortality rate for people with neurological conditions



## Domain 2: Enhancing quality of life for people with long-term conditions

Figure 7: Summary of recommended outcome measures under Domain 2

Domain 2: Enhancing quality of life for people with long-term conditions	
NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
<ul style="list-style-type: none"> <li>- 2: Health related quality of life for people with long-term conditions,</li> <li>- 2.1: Proportion of people feeling supported to manage their condition</li> <li>- 2.2: Employment of people with long-term conditions</li> <li>- 2.4: Health-related quality of life for carers</li> </ul>	<ul style="list-style-type: none"> <li>- Time taken to reach a stable neurological diagnosis following first consultation due to symptoms</li> <li>- Unplanned hospitalisation for people with long-term neurological conditions</li> <li>- Attendances at A&amp;E for people with long-term neurological conditions</li> <li>- Proportion of patients with a neurological condition who see a specialist who understands their condition within 24 hours of being admitted to hospital</li> <li>- Proportion of people with a neurological condition who have a personal care plan</li> <li>- Proportion of people with a neurological condition who have access to a clinical nurse specialist</li> <li>- Proportion of people with a neurological condition given access to counselling/psychological support</li> </ul>

### Why is this domain important for people with neurological conditions?

The large majority of neurological conditions can significantly affect a person's quality of life. This domain, therefore, is of the utmost importance. Research conducted by the Neurological Alliance revealed a number of key outcomes that have been identified by people with neurological conditions, and those that care for them, as the most important in relation to their quality of life<sup>30</sup>. These include the following:

- **Quick and accurate diagnosis** – ensuring that individuals with suspected neurological disease are referred quickly to a specialist team with expertise in the differential diagnosis of the condition, that they have rapid access to test results, and rapid referral to appropriate care and treatment
- **Prompt and equitable access to appropriate specialists and treatment** – ensuring that people are referred to a multi-disciplinary team including, for example, a consultant neurologist, clinical nurse specialist, movement specialist, physiotherapist, counsellor, and a specialist palliative care team representative, and that they are given rapid access to treatment. This may also include ensuring that young people with neurological conditions have a smooth and supported transition from paediatric to adult services
- **Access to high quality information** – ensuring that people are provided with high quality verbal and written information from diagnosis onwards. This should include information about the condition itself, the range of treatments available (and any side effects), where they can access additional information and support, including relevant patient support and patient representative groups. They should have a named individual (for example, a specialist nurse) who they can contact for support, advice and further signposting

- **Supporting management of the condition** – ensuring that people are able to self-manage their condition and maintain their independence through ongoing assessment and treatment, provision of a personal care plan and named care coordinator, social care support, information on direct payments and benefits, and timely access to assistive equipment and adaptations tailored to individual needs
- **Maintaining functional ability** – providing people with the necessary support to be able to retain independence at home, in the community and in the workplace
- **Coordinated health and social care support** – good communication across disciplines and between health and social care to deliver a consistent, coordinated service at the point of need
- **Enhancing quality of life for carers** – it is vital that carers and family members receive adequate support, including a carer’s assessment, access to respite care, and tailored information about the condition and sources of support and advice

### Which overarching measures need to be disaggregated for neurological conditions?

- Indicator 2: *“Health related quality of life for people with long-term conditions”*
- Indicator 2.1: *“Proportion of people feeling supported to manage their condition”*
- Indicator 2.2: *“Employment of people with long-term conditions”*
- Indicator 2.4: *“Health-related quality of life for carers”*

The basis for Indicator 2 on the EQ-5D is problematic, as it fails to take into account some of the debilitating symptoms of neurological conditions, such as fatigue. This measure will therefore only go some way in helping to understand whether quality of life for people with neurological conditions is improving. The Department should develop neurology-specific PROMs to reach beyond EQ-5D in measuring quality of life.

Similarly, indicators 2.1, 2.2 and 2.4 are all appropriate indicators but must be disaggregated for neurological conditions so that the specific impact of neurological conditions can be measured.

The rate of unplanned hospitalisation is a good proxy indicator for whether conditions are being well-managed. Emergency admissions are extremely distressing for patients and carers and, therefore, have a major impact on a person’s quality of life. There are currently two measures in Domain 2 relating to emergency admissions: 2.3.i – *“Unplanned hospitalisation for chronic ambulatory care sensitive conditions”* and 2.3.ii – *“Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s”*. The definition of chronic ambulatory care sensitive conditions used relates to chronic conditions that are usually managed in primary care and the only neurological condition that is included in the list is epilepsy. By limiting this indicator to a small number of conditions, there is a danger that the rate of unplanned hospitalisation for other neurological conditions will be overlooked. As explored earlier, we know that emergency admissions for neurological conditions are at an unacceptably high level and there are currently no indicators in place to address this, to the detriment of patient care and outcomes and NHS finances.

### What specific measures are needed for neurological conditions?

A number of additional specific measures are needed to drive the vital improvements to neurological services and to deliver the desired outcomes (listed above) that have been identified by people with neurological conditions and those that care for them. The additional measures that are required include the following:

- Time taken to reach a stable neurological diagnosis following first consultation due to symptoms
- Unplanned hospitalisation for people with long-term neurological conditions

- Attendances at A&E for people with long-term neurological conditions
- Proportion of patients with a neurological condition who see a specialist who understands their condition within 24 hours of being admitted to hospital
- Proportion of people with a neurological condition who have a personal care plan
- Proportion of people with a neurological condition who have access to a clinical nurse specialist
- Proportion of people with a neurological condition given access to counselling/psychological support

A number of the desired outcomes identified by people with neurological conditions are also relevant to Domains 3 and 4 and there are a number of additional specific measures suggested later that relate to the desired outcomes set out above.



### Domain 3: Helping people to recover from episodes of ill health or following injury

Figure 8: Summary of recommended outcome measures under Domain 3

Domain 3: Helping people to recover from episodes of ill health or following injury	
NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
<ul style="list-style-type: none"> <li>- 3a: Emergency admissions for acute conditions that should not usually require hospital admission</li> <li>- 3b: Emergency readmissions within 30 days of discharge from hospital</li> <li>- 3.6: Proportion of older people who were still at home 91 days after discharge from hospital into reablement/rehabilitation services</li> </ul>	<ul style="list-style-type: none"> <li>- Hospital bed days for people with neurological conditions, following emergency and elective admissions</li> <li>- Proportion of people with a neurological condition given access to rehabilitation services within two weeks of referral</li> <li>- Time taken to return to a near-baseline level of functional ability for people with neurological conditions</li> <li>- Proportion of people with a neurological condition able to remain in employment</li> </ul>

#### Why is this domain important for people with neurological conditions?

Maintaining personal independence, functional capability and ability to work have all been identified as key desired outcomes by people with neurological conditions. Neurological conditions can have a wide range of effects on a person's ability to maintain a 'normal' life. Some people may need certain adaptations or flexible working hours to be able to remain in work. Others may experience severe disability which prevents them from working and makes them reliant on others to carry out day-to-day tasks. It is therefore important that 'recovery' is understood in flexible terms so that it can be applied to the context of the full spectrum of neurological conditions, where a baseline level of 'good' health may be different from the wider population.

#### Which overarching measures need to be disaggregated for neurological conditions?

- Indicator 3a: *"Emergency admissions for acute conditions that should not usually require hospital admission"*
- Indicator 3b: *"Emergency readmissions within 30 days of discharge from hospital"*
- Indicator 3.6: *"Proportion of older people who were still at home 91 days after discharge from hospital into reablement/rehabilitation services"*

The primary cause for a hospital admission may be an acute infection, but this may have occurred due to a person's underlying neurological condition. It is crucial that neurological conditions are recorded as a secondary diagnosis and this information is taken into account as well as the primary diagnosis so that providers are held to account for poor management of neurological conditions that results in emergency admissions.

### What specific measures are needed for neurological conditions?

A number of specific measures could be included that address the desired outcomes outlined by people with neurological conditions and their carers, and to capture the rate of 'recovery' from episodes of illness in those with neurological conditions. These include the following:

- Hospital bed days for people with neurological conditions, following emergency and elective admissions
- Proportion of people with a neurological condition given access to rehabilitation services within two weeks of referral
- Time taken to return to a near-baseline level of functional ability for people with neurological conditions
- Proportion of people with a neurological condition able to remain in employment



**Domain 4: Ensuring that people have a positive experience of care**

**Figure 9: Summary of recommended outcome measures under Domain 4**

Domain 4: Ensuring that people have a positive experience of care	
NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
<ul style="list-style-type: none"> <li>- 4a: Patient experience of primary care - i GP services and ii GP out of hours services</li> <li>- 4b: Patient experience of hospital care</li> <li>- 4.1: Patient experience of outpatient services</li> <li>- 4.2: Responsiveness to in-patients’ personal needs</li> <li>- 4.3: Patient experience of accident and emergency services</li> <li>- 4.4.i: Access to GP services</li> <li>- 4.6: An indicator to be derived from the survey of bereaved carers (to address improving the experience of care for people at the end of their lives)</li> <li>- 4.8: An indicator to be derived from a children’s patient experience questionnaire (to address improving children and young people’s experience of healthcare)</li> </ul>	<ul style="list-style-type: none"> <li>- Additional measures to be derived from national neurology patient survey</li> </ul>

**Why is this domain important for people with neurological conditions?**

This domain is closely linked to Domain 2 and the desired outcomes that were listed earlier, as identified by organisations representing people with neurological conditions and their carers. Having a positive experience of care should be the underlying feature that cuts across all aspects of treatment and all care settings. In addition to this, it is important that measures are in place relating to people’s experience of end of life care services.

**Which overarching measures need to be disaggregated for neurological conditions?**

- *4a Patient experience of primary care – i) GP services and ii) GP out of hours services*
- *4b Patient experience of hospital care*
- *4.1 Patient experience of outpatient services*
- *4.2 Responsiveness to in-patients’ personal needs*
- *4.3 Patient experience of accident and emergency services*
- *4.4.i Access to GP services*
- *4.6 An indicator to be derived from the survey of bereaved carers*
- *4.8 An indicator to be derived from a Children’s Patient Experience Questionnaire*

**What specific measures are needed for neurological conditions?**

The patient experience surveys currently in use do not, unfortunately, have the level of granularity that is required to gather information about the specific experiences of people with neurological conditions. A solution to this could be to develop a national survey for people with neurological conditions, similar to the National Cancer Patient Experience Survey, to gather insights into the care experienced by people with neurological conditions. Through this, a better understanding of the current variations in experience of the neurological patient pathway could be achieved and patient experience measures identified for inclusion in future iterations of the NHS Outcomes Framework.

## Domain 5: Treating and caring for people in a safe environment; and protecting them from avoidable harm

Figure 10: Summary of recommended outcome measures under Domain 5

Domain 5: Treating and caring for people in a safe environment; and protecting them from avoidable harm	
NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
<ul style="list-style-type: none"> <li>- 5a: Patient safety incidents reported</li> <li>- 5b: Safety incidents involving severe harm or death</li> <li>- 5.1: Incidence of hospital-related venous thromboembolism (VTE)</li> <li>- 5.2: Incidence of healthcare associated infection (HCAI) - i MRSA and ii C. difficile</li> <li>- 5.3: Incidence of newly-acquired category 2, 3 and 4 pressure ulcers</li> <li>- 5.4: Incidence of medication errors causing serious harm</li> <li>- 5.6: Incidence of harm to children due to 'failure to monitor'</li> </ul>	<ul style="list-style-type: none"> <li>- Proportion of people with a neurological condition who receive information about the side effects and potential adverse effects of their treatment</li> <li>- Proportion of people with a neurological condition admitted to a hospital or care home who are given their medication on time</li> <li>- Time taken between referral and being provided with appropriate assistive technology (including wheelchairs) or adaptations for people with a neurological condition</li> </ul>

### Why is this domain important for people with neurological conditions?

Similarly to positive patient experience, keeping people safe and protecting them from harm should be a cross-cutting feature of all health and social care services. There are, however, a number of areas of specific relevance for people with neurological conditions. It is particularly important, for example, that people with neurological conditions who are admitted to hospital or care homes are given their medication at the right time, and that all people with neurological conditions receive helpful information about the side effects and potential adverse effects of their medication. It is also essential that individuals have timely access to appropriate equipment and adaptations so they can live safely and independently.

### Which overarching measures work for neurological conditions?

The following indicators are all relevant for people with neurological conditions, some more so than for the general population due to the increased likelihood of someone with a neurological condition having to spend time in hospital. These indicators all need to be disaggregated for neurological conditions:

- *5a Patient safety incidents reported*
- *5b Safety incidents involving severe harm or death*
- *5.1 Incidence of hospital-related venous thromboembolism (VTE)*
- *5.2 Incidence of healthcare associated infection (HCAI) - i MRSA and ii C. difficile*
- *5.3 Incidence of newly-acquired category 2, 3 and 4 pressure ulcers*
- *5.4 Incidence of medication errors causing serious harm*
- *5.6 Incidence of harm to children due to 'failure to monitor'*

### What specific measures are needed for neurological conditions?

A number of specific measures could be included that address the particular problems that may be faced by people with neurological conditions:

- Proportion of people with a neurological condition who receive information about the side effects and potential adverse effects of their treatment
- Proportion of people with a neurological condition admitted to a hospital or care home who are given their medication on time
- Time taken between referral and being provided with appropriate assistive technology (including wheelchairs) or adaptations for people with a neurological condition

**Recommendation: The Department of Health and NHS Commissioning Board should work with the neurological community to develop outcome measures that can be used to drive improvements to services for people with neurological conditions**

**Recommendation: The NHS Information Centre for Health and Social Care should disaggregate the outcome measures in the NHS Outcomes Framework according to geography, demography and disease so that progress in specific disease areas, such as neurological conditions, can be measured and prioritised**

**Recommendation: The Department of Health and NHS Commissioning Board should commission the development of a national survey for people with neurological conditions to gather insights into the care experienced by this group of people and to be used as the basis for patient experience measures for inclusion in future iterations of the NHS and Adult Social Care Outcomes Frameworks**

The diagram below summarises how the additional recommended outcomes measures should be mapped to the NHS quality improvement system. Further work will be needed to refine and test this model.



Figure 11: Mapping neurological outcome measures to the NHS quality improvement system

Level	Additional outcome measures required
<b>NHS Outcomes Framework</b>	<ul style="list-style-type: none"> <li>- Unplanned hospitalisation for people with neurological conditions</li> <li>- Attendances at A&amp;E for people with neurological conditions</li> </ul>
<b>NHS Mandate</b>	<ul style="list-style-type: none"> <li>- Proportion of people with a neurological condition who have a personal care plan</li> </ul>
<b>Commissioning Outcomes Framework</b>	<ul style="list-style-type: none"> <li>- Under 75 mortality rate for people with neurological conditions</li> <li>- Hospital bed days for people with neurological conditions, following emergency and elective admissions</li> <li>- Proportion of people with a neurological condition able to remain in employment</li> </ul>
<b>Provider and service measurement frameworks</b>	<ul style="list-style-type: none"> <li>- Time taken to reach a stable neurological diagnosis following first consultation due to symptoms</li> <li>- Proportion of patients with a neurological condition who see a specialist who understands their condition within 24 hours of being admitted to hospital</li> <li>- Proportion of people with a neurological condition who have access to a clinical nurse specialist or specialist coordinator</li> <li>- Proportion of people with a neurological condition given access to counselling/psychological support</li> <li>- Proportion of people with a neurological condition given access to rehabilitation services within two weeks of referral</li> <li>- Time taken to return to a near-baseline level of functional ability for people with neurological conditions</li> <li>- Proportion of people with a neurological condition who receive information about the side effects and potential adverse effects of their treatment</li> <li>- Proportion of people with a neurological condition admitted to a hospital or care home who are given their medication on time</li> <li>- Time taken between referral and being provided with appropriate assistive technology (including wheelchairs) or adaptations for people with a neurological condition</li> <li>- Further measures derived from a national neurology patient experience survey</li> </ul>

## Taking action to improve outcomes for people with neurological conditions

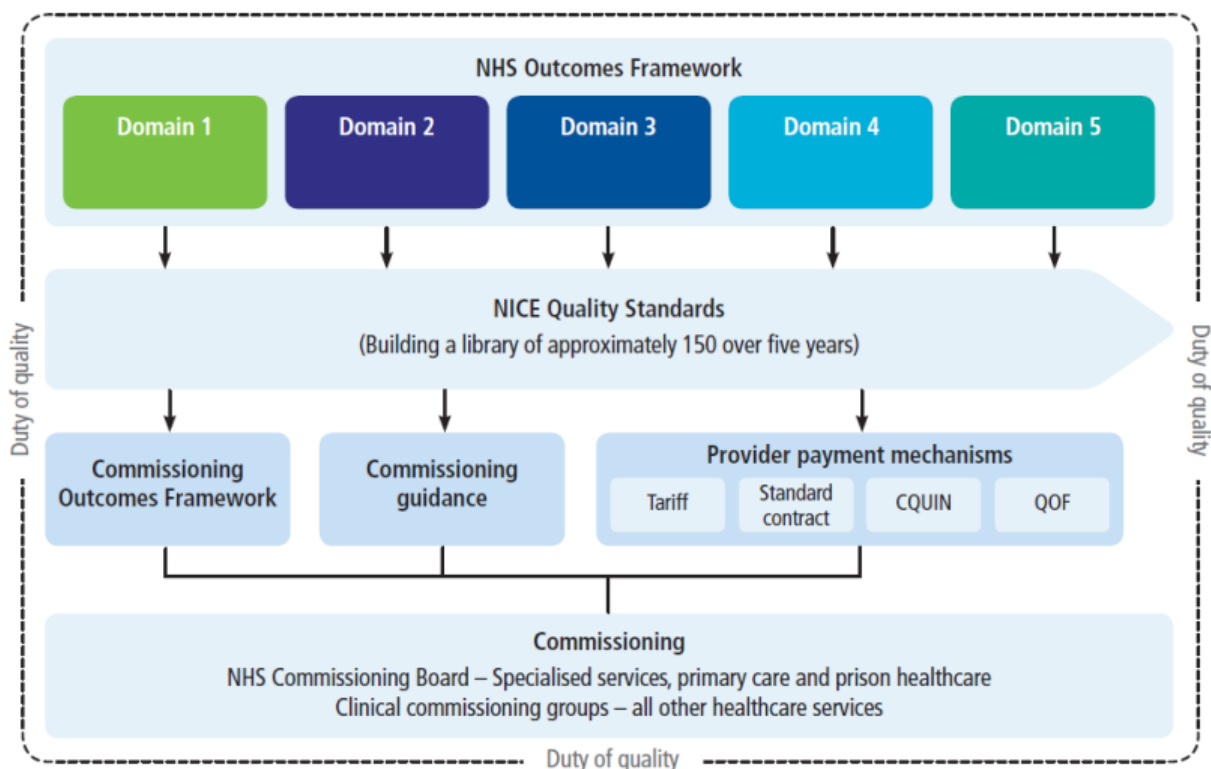
### Translating outcome measures into policy levers

The first step in focusing efforts to improve services is to identify the outcomes that really matter, as set out in the previous chapter. High level outcome measures can be of limited utility, however, and will not in themselves provide the necessary information for performance management, service improvement or accountability, for the following key reasons:

- Macro-level outcomes can mask variations in performance
- There is most often a time-lag in the manifestation of outcomes – it is therefore very difficult to use outcome measures as a real-time measure of improvement
- There is difficulty in attributing a particular outcome to a specific health intervention or service

It is therefore necessary to translate outcome measures into policy levers which can be used to truly effect change. The measures we identified in the previous chapter will need to be incorporated at every stage of the NHS quality improvement system, from the NHS Outcomes Framework right through to provider payment mechanisms, such as the CQUIN scheme, as set out in Figure 12 below. This will be essential if these outcome measures are to be truly effective in holding to account all those involved in the delivery of neurological services.

Figure 12: The NHS quality improvement system<sup>31</sup>



There are three main types of policy lever that could be utilised to deliver improvements to neurological services:

1. **Quality metrics** – to inform strong commissioning and accountability. These metrics could be utilised, for example, in the NHS Outcomes Framework, the COF, or NICE quality standards. An example of a metric that could be used is as follows:

- *Proportion of people with a neurological condition who have access to a clinical nurse specialist or specialist co-ordinator*
- 2. Quality incentives** – to encourage provider improvement. These incentives could, for example, be included as part of the CQUIN scheme or the QOF. An example of a CQUIN that could be used is as follows:
- *Number of patients with a diagnosed neurological condition admitted to hospital who saw a specialist with expertise in their condition within 24 hours of being admitted.*

Year-of-care tariffs, currently being piloted by the Department, are also likely to be a vital quality incentive mechanism to improve services for people with neurological conditions. Significant progress has already been made in this area through the use of the year-of-care ‘Neuronavigator’ tool, developed by Neurological Commissioning Support, which helps commissioners to cost one year of best practice for people with motor neurone disease, multiple sclerosis and Parkinson’s disease. Further work needs to be done to expand this to cover other conditions.

- 3. Quality accountability tools** – to address inequalities and empower patients. Quality accounts are one such mechanism, requiring providers to report on the quality of their services. An example of the way in which this mechanism can be used would be for the following statement to be included in a provider’s quality priorities for the year, as set out in its annual quality account:

- *“[Name of provider] will be taking the following actions to improve data collection in relation to patient experience of people with neurological conditions...”*

**Recommendation: The Department of Health and NHS Commissioning Board should incorporate a range of quality metrics relating to neurological conditions into the NHS Outcomes Framework, NICE quality standards and the Commissioning Outcomes Framework**

**Recommendation: Commissioners should make use of quality incentives, such as the Commissioning for Quality and Innovation (CQUIN) scheme and year-of-care tariffs to drive improvements to neurological services**

**Recommendation: Health and social care providers should utilise quality accountability tools, such as quality accounts, to drive local improvements to neurological services and to demonstrate the action they are taking to raise the quality of services**

## Gathering intelligence

The underpinning enabler for these policy levers is intelligence. The NAO and PAC reports clarified that the Department of Health lacks the necessary data to measure the effectiveness of services for people with neurological conditions. The PAC recommended that the Department should develop a neurological dataset covering resources, services and outcomes and that key indicators from the dataset should be included in the NHS and Adult Social Care Outcomes Frameworks. This recommendation was accepted by the Government with a target implementation date of April 2014<sup>32</sup>. In order for the Government to succeed in meeting its own commitment, it will need to undertake a number of targeted activities.

**Recommendation: Public Health England should appoint a lead public health observatory for neurology to lead the way in gathering information about the outcomes that matter in neurology**

**Recommendation: The Department of Health and NHS Commissioning Board should work with the lead public health observatory for neurology to develop key indicators relating to neurological services that can be included in the NHS and Adult Social Care Outcomes Frameworks**

**Recommendation: The Department of Health and NHS Commissioning Board should develop neurology-specific PROMs that can reach beyond current provisions in measuring the quality of life of people with neurological conditions**

### The need for strong leadership

The success of utilising these policy levers is dependent upon strong leadership. There is a need for focused improvement driven by clinical leaders at a national and local level. The legacy of neglect that has hampered progress in driving up the quality of neurological services must now be turned around with a move to high quality, clinically-led and patient-centred services.

**Recommendation: The Department of Health and NHS Commissioning Board should adopt a targeted approach to drive improvements to neurological services, potentially in the form of a national neurological outcomes strategy and commissioning support pack setting out how each policy lever should be applied in practice**

A targeted approach, potentially in the form of a neurological outcomes strategy, is needed to:

- Show what action needs to be taken to improve outcomes in neurological services and to ensure that all people with neurological conditions, and their carers and families, are able to access high quality services
- Explain what support, information and choices will be given to people with neurological conditions, and their carers and families, so that they can make best use of services and become partners in their care
- Describe how neurological services will be held accountable for the outcomes they deliver
- Set out what support the Government will provide to help neurological services deliver high quality outcomes
- Demonstrate how the Government will work with the charity sector to help shape neurological services to meet the needs of people with neurological conditions and their carers and families
- Help to address variations in service provision and quality, ensure that money is being spent appropriately and send a clear signal that neurological services must be seen as a priority

The Department of Health's intention to develop a Long-Term Conditions Strategy will not, on its own, be sufficient to deliver the desired improvement in outcomes for people with neurological conditions. It is only by developing a more focused approach to neurological conditions to supplement the Long-Term Conditions Strategy that sustained and significant improvements in outcomes will be delivered. Given the PAC's recommendation for the NAO to follow up on the progress against the PAC's recommendations in 2014, there is an additional motivation for the Department to ensure that urgent action is taken.

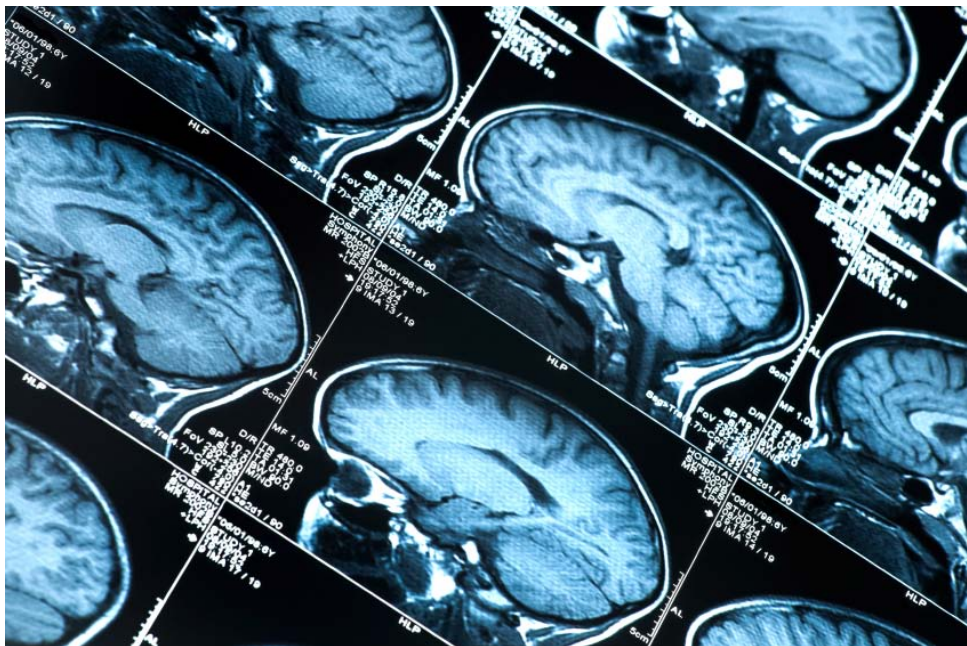
This new approach should not be about spending more money or setting top-down targets. Instead, it is about ensuring that the limited resources that are available across health and social care services are used in the best way possible to ensure that people with neurological conditions have access to high quality services and have better outcomes as a result.

A targeted strategy will need to be driven by clinical leaders at national level and, at local level, through the establishment of the strategic clinical network for neurological conditions (alongside mental health and dementia), the plans for which were recently announced by the NHS Commissioning Board Authority<sup>33</sup>. The strategic clinical network for neurological conditions will have an important role to play in supporting

national leadership by providing the necessary neurological expertise to inform each stage of the commissioning process. It should also take the lead in identifying gaps in service provision, promoting best practice, supporting the integration of services, advising clinical commissioning groups on collaborative commissioning, and addressing variations in care at regional and local level.

**Recommendation: The Department of Health and NHS Commissioning Board should ensure that there is dedicated clinical leadership and full accountability for the quality of neurological services at a national level to drive much-needed improvements to neurological services**

**Recommendation: The NHS Commissioning Board should ensure that the planned strategic clinical network for neurological conditions provides the necessary neurological expertise to inform each stage of the commissioning process on an equitable basis across the country and supports the delivery of integrated, cost effective care, and that it is sufficiently resourced to do so**



## Conclusion

We are hopeful that, by working closely with health and social care professionals, people with neurological conditions, and their carers and families, the Department of Health, NHS Commissioning Board and wider NHS will be able to devise a way forward for neurological services that is truly capable of delivering the quality improvements that are so urgently needed.

Meeting the needs of the eight million people with a neurological condition in England will be a crucial test case for the success of the Government's health and social care reforms. Neurological services have for too long not been given due focus and attention. This has resulted in unacceptable variation in outcomes and unacceptably high costs for the NHS. There are currently worrying signals that this pattern could be repeated in the new NHS landscape.

Rather than going down the same path, the Government should work with NHS commissioners and providers, and the wider neurological community, to harness the opportunity presented by the health and social care reforms to deliver much-needed improvements to neurological services and to gain greater control over costs. Ensuring the delivery of high quality neurology services will be vital in meeting the Government's vision for an NHS that is focused on improving outcomes and supporting greater integration of services.

Responding to the shift in the focus of the NHS to improving outcomes, this report has sought to articulate the outcomes which matter most to people with neurological conditions and to suggest how these can be translated into quality indicators for NHS and social care services. Our recommendations are intended to ensure that NHS resources are directed towards investing in quality and not paying for the cost of failure, as has happened in the past.

## Annex 1: Summary of Public Accounts Committee recommendations and Government response

Public Accounts Committee recommendation	Government response
<p>The proposed NHS Commissioning Board should appoint a dedicated National Clinical Lead for neurology to provide leadership on the commissioning and design of neurological services. It should also establish local neurological networks, coordinated by the NHS, with clearly responsible and accountable local leadership.</p>	<p>The Government disagrees with the Committee's recommendation.</p>
<p>The Department should develop a neurological data set covering resources, services and outcomes, which should include linking existing health and social care data using the patient's NHS number. Key indicators from the data set, including emergency admissions and readmissions for neurological conditions, should be included in the NHS and Adult Social Care Outcomes Frameworks with appropriate targets for reduction.</p>	<p>The Government agrees with the Committee's recommendation. <b>Target date:</b> <b>April 2014</b></p>
<p>The Department should set out in its reply to the Committee how it will ensure all people with neurological conditions have appropriate access to services. The Committee would expect this to include how the Department will drive improvements through the quality section of the NHS Standard Contract, the Commissioning Outcomes Framework, the joint strategic needs assessments and the health and wellbeing boards.</p>	<p>The Government agrees with the Committee's recommendation. <b>Target date:</b> <b>April 2013</b></p>
<p>In its Commissioning Outcomes Framework, the Department should mandate joint health and social care commissioning of neurological services, supported by health and wellbeing boards through the joint strategic needs assessment.</p>	<p>The Government disagrees with the Committee's recommendation.</p>
<p>The Department should set out in its Commissioning Outcomes Framework that every person with a neurological condition should be offered a personal care plan, covering both health and social care. The evidence suggests that this is best done by a single professional, for example a specialist nurse or care coordinator.</p>	<p>The Government agrees with the Committee's recommendation. <b>Target date:</b> <b>April 2012</b></p>
<p>The Committee welcomes the announcement at the hearing that NICE will be developing quality standards for Parkinson's disease, multiple sclerosis and motor neurone disease. However, these will not cover other neurological conditions. In addition to the three Quality Standards announced, the Department should instruct NICE to develop a generic Quality Standard covering other neurological conditions.</p>	<p>The Government agrees with the Committee's recommendation. <b>Target date:</b> <b>April 2012</b></p>

## Annex 2: Summary of recommended neurological outcome measures

NHS Outcomes Framework domain	Relevance to neurological conditions	NHS Outcomes Framework indicators that need to be disaggregated for neurological conditions	Additional outcome measures that need to be incorporated into the NHS quality improvement system
<b>Domain 1: Preventing people from dying prematurely</b>	<ul style="list-style-type: none"> <li>- Reducing premature mortality due to poor management of symptoms</li> </ul>	<ul style="list-style-type: none"> <li>- 1a: Potential years of life lost from causes considered amenable to healthcare</li> </ul>	<ul style="list-style-type: none"> <li>- Under 75 mortality rate for people with neurological conditions</li> </ul>
<b>Domain 2: Enhancing quality of life for people with long-term conditions</b>	<ul style="list-style-type: none"> <li>- Quick and accurate diagnosis</li> <li>- Prompt and equitable access to appropriate specialists and treatment</li> <li>- Access to high quality information</li> <li>- Support to self-manage the condition</li> <li>- Maintaining functional ability</li> <li>- Coordinated health and social care support</li> <li>- Enhancing quality of life for carers</li> </ul>	<ul style="list-style-type: none"> <li>- 2: Health related quality of life for people with long-term conditions,</li> <li>- 2.1: Proportion of people feeling supported to manage their condition</li> <li>- 2.2: Employment of people with long-term conditions</li> <li>- 2.4: Health-related quality of life for carers</li> </ul>	<ul style="list-style-type: none"> <li>- Time taken to reach a stable neurological diagnosis following first consultation due to symptoms</li> <li>- Unplanned hospitalisation for people with long-term neurological conditions</li> <li>- Attendances at A&amp;E for people with long-term neurological conditions</li> <li>- Proportion of patients with a neurological condition who see a specialist who understands their condition within 24 hours of being admitted to hospital</li> <li>- Proportion of people with a neurological condition who have a personal care plan</li> <li>- Proportion of people with a neurological condition who have access to a clinical nurse specialist</li> <li>- Proportion of people with a neurological condition given access to counselling/psychological support</li> </ul>
<b>Domain 3: Helping people to recover from episodes of ill health or following injury</b>	<ul style="list-style-type: none"> <li>- Helping people to recover their independence and functional ability</li> <li>- Reducing emergency admissions and length of stay</li> <li>- Helping people to return to work</li> </ul>	<ul style="list-style-type: none"> <li>- 3a: Emergency admissions for acute conditions that should not usually require hospital admission</li> <li>- 3b: Emergency readmissions within 30 days of discharge from hospital</li> </ul>	<ul style="list-style-type: none"> <li>- Hospital bed days for people with long-term neurological conditions, following emergency and elective admissions</li> <li>- Proportion of people with a neurological condition given access to rehabilitation services within two weeks of referral</li> </ul>



		<ul style="list-style-type: none"> <li>- 3.6: Proportion of older people who were still at home 91 days after discharge from hospital into reablement/ rehabilitation services</li> </ul>	<ul style="list-style-type: none"> <li>- Time taken to return to a near-baseline level of functional ability for people with neurological conditions</li> <li>- Proportion of people with a neurological condition able to remain in employment</li> </ul>
<b>Domain 4: Ensuring that people have a positive experience of care</b>	<ul style="list-style-type: none"> <li>- Improving people's experience of care across all care settings</li> <li>- Access to a clinical nurse specialist</li> <li>- Provision of personal care plan</li> <li>- Dying well</li> </ul>	<ul style="list-style-type: none"> <li>- 4a: Patient experience of primary care - i GP services and ii GP out of hours services</li> <li>- 4b: Patient experience of hospital care</li> <li>- 4.1: Patient experience of outpatient services</li> <li>- 4.2: Responsiveness to in-patients' personal needs</li> <li>- 4.3: Patient experience of accident and emergency services</li> <li>- 4.4.i: Access to GP services</li> <li>- 4.6: An indicator to be derived from the survey of bereaved carers (to address improving the experience of care for people at the end of their lives)</li> <li>- 4.8: An indicator to be derived from a Children's Patient Experience Questionnaire (to address improving children and young people's experience of healthcare)</li> </ul>	<ul style="list-style-type: none"> <li>- Additional measures to be derived from national neurology patient survey</li> </ul>
<b>Domain 5: Treating and caring for people in a safe environment; and protecting them from avoidable harm</b>	<ul style="list-style-type: none"> <li>- Getting the right medicines at the right time</li> <li>- Timely access to assistive equipment (including wheelchairs)</li> </ul>	<ul style="list-style-type: none"> <li>- 5a: Patient safety incidents reported</li> <li>- 5b: Safety incidents involving severe harm or death</li> <li>- 5.1: Incidence of hospital-related venous thromboembolism (VTE)</li> <li>- 5.2: Incidence of healthcare associated infection (HCAI) - i MRSA and ii C. difficile</li> </ul>	<ul style="list-style-type: none"> <li>- Proportion of people with a neurological condition who receive information about the side effects and potential adverse effects of their treatment</li> <li>- Proportion of people with a neurological condition admitted to a hospital or care home who are given their medication on time</li> <li>- Time taken between referral</li> </ul>

		<ul style="list-style-type: none"><li>- 5.3: Incidence of newly-acquired category 2, 3 and 4 pressure ulcers</li><li>- 5.4: Incidence of medication errors causing serious harm</li><li>- 5.6: Incidence of harm to children due to 'failure to monitor'</li></ul>	and being provided with appropriate assistive technology (including wheelchairs) or adaptations for people with a neurological condition
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### Annex 3: List of attendees at policy roundtable

Name	Position	Organisation
Professor Colin Blakemore	Professor of Neurosciences	University of Oxford
Mike Birtwistle	Managing Director	MHP Health Mandate
Dr Chris Clough	Co-Chair Clinical Neurosciences Advisor	National Leadership Group Department of Health
Steve Ford	Co-Chair Chair	National Leadership Group Neurological Alliance
Isabel Lawicka	Account Manager	MHP Health Mandate
Sally Light	Director of Rehabilitation	Royal Hospital for Neurodisability
Sue Millman	Chief Executive	Ataxia UK
Farah Nazeer	Director of External Affairs	MND Association
Sally Percy	Policy and Public Affairs Officer	Neurological Alliance
Dr Diane Playford	Consultant in Rehabilitation Medicine	British Society of Rehabilitation Medicine
Professor Martin Rossor	President	Association of British Neurologists
Michael Speer	Consultant	MHP Health Mandate
Professor Tim Stokes	Consultant Clinical Adviser, Centre for Clinical Practice	NICE
Sue Thomas	Chief Executive	Neurological Commissioning Support
Hannah Verghese	Advocacy and Policy Manager	The Migraine Trust
Arlene Wilkie	Chief Executive	Neurological Alliance
Sue Woodward	Lecturer, Florence Nightingale School of Nursing and Midwifery	King's College London
Dr Paul Zollinger-Read	Director of Commissioning Development	NHS Midlands and East

## References

- <sup>1</sup> The Neurological Alliance, *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, April 2003
- <sup>2</sup> Department of Health, *National Service Framework for Long-term Conditions*, March 2005
- <sup>3</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>4</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>5</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>6</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>7</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>8</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>9</sup> NHS Institute for Innovation and Improvement, *Commissioning for Quality and Innovation (CQUIN) payment framework, 2010/11 Summary of indicators*, accessed on 12 June 2012 via: [http://www.institute.nhs.uk/commissioning/pct\\_portal/cquin.html](http://www.institute.nhs.uk/commissioning/pct_portal/cquin.html)
- <sup>10</sup> Department of Health, *National Service Framework for Long-term Conditions*, March 2005
- <sup>11</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>12</sup> Public Accounts Committee, *Seventy-Second Report: Services for people with neurological conditions*, February 2012
- <sup>13</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>14</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>15</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>16</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>17</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>18</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>19</sup> National Audit Office, *Services for people with neurological conditions*, December 2012
- <sup>20</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>21</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>22</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>23</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>24</sup> Department of Health, *2010-11 Programme Budgeting PCT Benchmarking Tool*, updated February 2012
- <sup>25</sup> HM Treasury, *Treasury Minutes: Government responses on the Sixty Eighth, the Seventieth, the Seventy Second and the Seventy Fourth Reports from the Committee of Public Accounts – Session 2010-12*, April 2012
- <sup>26</sup> National Institute for Health and Clinical Excellence, *NICE quality standards topic library*, accessed on 10 April 2012 via: <http://www.nice.org.uk/guidance/qualitystandards/QualityStandardsLibrary.jsp>
- <sup>27</sup> National Institute for Health and Clinical Excellence, *Consultation on potential COF indicators*, February 2012
- <sup>28</sup> MHP Health Mandate, *COF up? What does the commissioning outcomes framework say about NHS prioritisation?* March 2012, accessed on 10 April 2012 via: <http://www.mhpc.com/blog/cof-what-does-commissioning-outcomes-framework-consultation-say-about-nhs-prioritisation>
- <sup>29</sup> NHS Institute for Innovation and Improvement, *Commissioning for Quality and Innovation (CQUIN) payment framework, 2010/11 Summary of indicators*, accessed on 12 June 2012 via: [http://www.institute.nhs.uk/commissioning/pct\\_portal/cquin.html](http://www.institute.nhs.uk/commissioning/pct_portal/cquin.html)
- <sup>30</sup> The Neurological Alliance, data on file
- <sup>31</sup> Department of Health, *Developing the NHS Commissioning Board*, July 2011
- <sup>32</sup> HM Treasury, *Treasury Minutes: Government responses on the Sixty Eighth, the Seventieth, the Seventy Second and the Seventy Fourth Reports from the Committee of Public Accounts – Session 2010-12*, April 2012
- <sup>33</sup> NHS Commissioning Board Authority, *The Way Forward: Strategic clinical networks*, July 2012