Thinking ahead:

The case for a Strategic Clinical Network for Neurology

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The case for a Strategic Clinical Network for Neurology

If the purpose of Strategic Clinical Networks (SCNs) is to tackle the biggest challenges facing the NHS, neurology should be at the top of the list of candidates.

This report summarises the major points arising from interviews with over 30 leaders in the field of neurology services from clinical, commissioning and patient perspectives. Several key concerns were highlighted repeatedly throughout the interview process:

- Need for national clinical leadership and a more effective structure to drive change;
- Lack of neurology specific outcomes indicators to drive performance improvements;
- Unacceptable variation of neurology services across England;
- Rapidly increasing spend on neurological services over the past few years;
- Little associated service improvement with the threat of a serious deterioration as NHS funding is squeezed;
- Lack of coordination/integration of care across primary, secondary, tertiary, and social care;
- Low priority afforded to neurology by commissioners;
- Inadequate GP engagement in neurology;
- Stronger sense of neurological community needed amongst healthcare professionals and other stakeholders;
- Complexity of neurology being largely incompatible with effective ad-hoc local initiatives;
- Failure of the 2005 National Service Framework for Long Term Conditions (NSFLTC) to deliver on its key recommendations.

In the seven years to 2010/11, neurological spending, as recorded by the National Programme Budgeting Database, rose by 174%, five times the rate for cardiovascular problems and over twice the rate for cancer. However, these spend increases point more towards growing demand than improved services.

In fact, our conversations with a number of key stakeholders in the neurological community revealed a widely-held view that neurological outcomes are notably poorer than in other condition areas and that urgent action is required. All were agreed that the imminent squeeze on NHS spending relative to demand presages a serious deterioration in neurological services unless new ways of working are introduced and that this requires national leadership, without which local leadership will also fail to flourish.

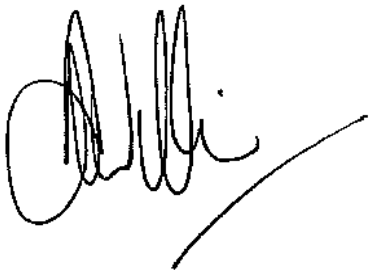
The very nature of neurological services, which encompass a wide range of conditions and complex care pathways, means that a national approach would deliver far superior results than uncoordinated local efforts. There was a great sense of disappointment amongst the stakeholders we approached that the NSFLTC had failed to deliver on its promising recommendations due to a lack of national leadership and mechanisms for monitoring and encouraging progress.

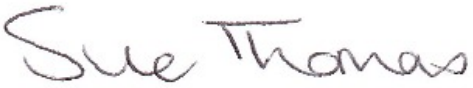
Indeed, despite the notable growth in spend on this category, neurology still seems to have slipped below the outcomes radar and there is not one dedicated neurology indicator included in the NICE proposals for the Commissioning Outcomes Framework (COF). An SCN would answer an urgent call for coordination and play a valuable role in ensuring that benchmarks are set and services are configured to deliver improved outcomes and better value for money.

The current formulation of neurology services in England does not lend itself well to driving change and improvements: practitioners are widely dispersed and collaboration tends to be the exception rather than the norm. In particular, GPs have traditionally shied away from engagement with neurology. Our research showed consensus that the best results would be secured by a dedicated team with a sound understanding of the neurological landscape of the kind which an SCN would provide. In giving general advice on networks drawing on his experience in cancer, Professor Sir Mike Richards saw the creation of a sense of community as perhaps the biggest achievement in his specialty. The development of a more closely linked neurological community would be valuable and would also raise the profile of the therapy area.

A coherent and coordinated national programme of work implemented consistently would inform more effective and comprehensive commissioning of neurological services and deliver immediate and much needed benefits in terms of improved outcomes and wiser, better targeted spending. High quality networks have the potential to usher in a more sophisticated approach to self-management of the kind which will be crucial in neurology. They will also be vital in reshaping the benefits of the latest advances in treatment which should in turn help to arrest rapid growth in NHS spending on social care, up 181% from 2003/04 to 2010/11.

For these reasons and many more adduced in the report, the neurological community is united in calling for the introduction of a Strategic Clinical Network.





Arlene Wilkie
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The Neurological Alliance and Neurological Commissioning Support undertook this piece of work with funding support from Abbott, Genzyme and Novartis to develop a case for a Strategic Clinical Network (SCN) for neurology services. Over the past six weeks we have engaged in conversations with over 30 stakeholders and opinion leaders to explore the current state of neurology services and develop a case for how an SCN for neurology might improve neurology services.

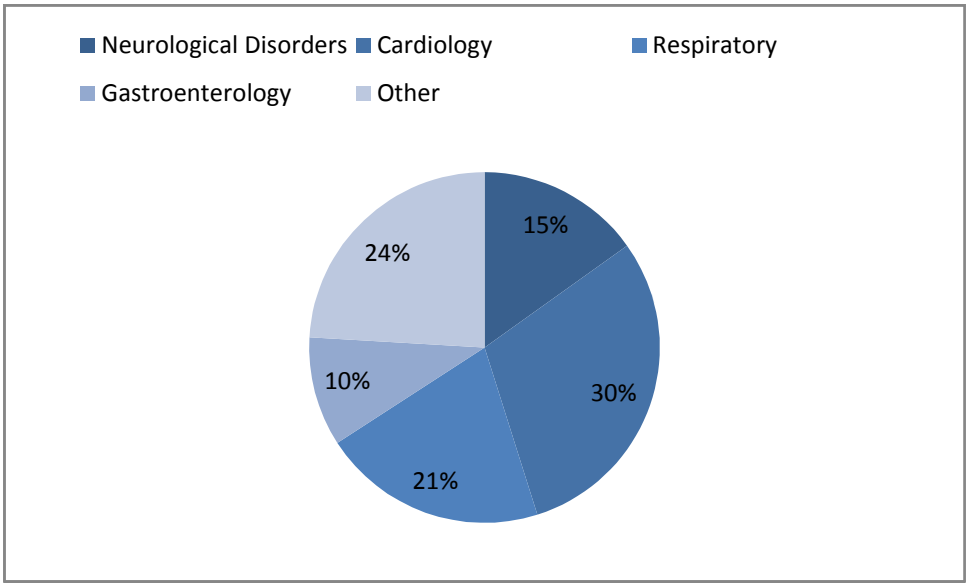
1.1 Overview

There are 10 million people in the UK living with a neurological condition which has a significant impact on their lives.[1] Neurological conditions range from the very common such as migraine and epilepsy, to the very rare such as Progressive Supranuclear Palsy (PSP) and Huntington's disease.

Neurological conditions are the most common cause of physical disability. Of the 10 million people living with a neurological condition in the UK, 1 million are likely to be out of full time employment and approximately 350,000 people require help for most of their daily activities. This latter group will include people with motor neurone disease (MND), forms of multiple sclerosis (MS), those with advanced dementia, severe stroke and people with serious brain injury.[2]

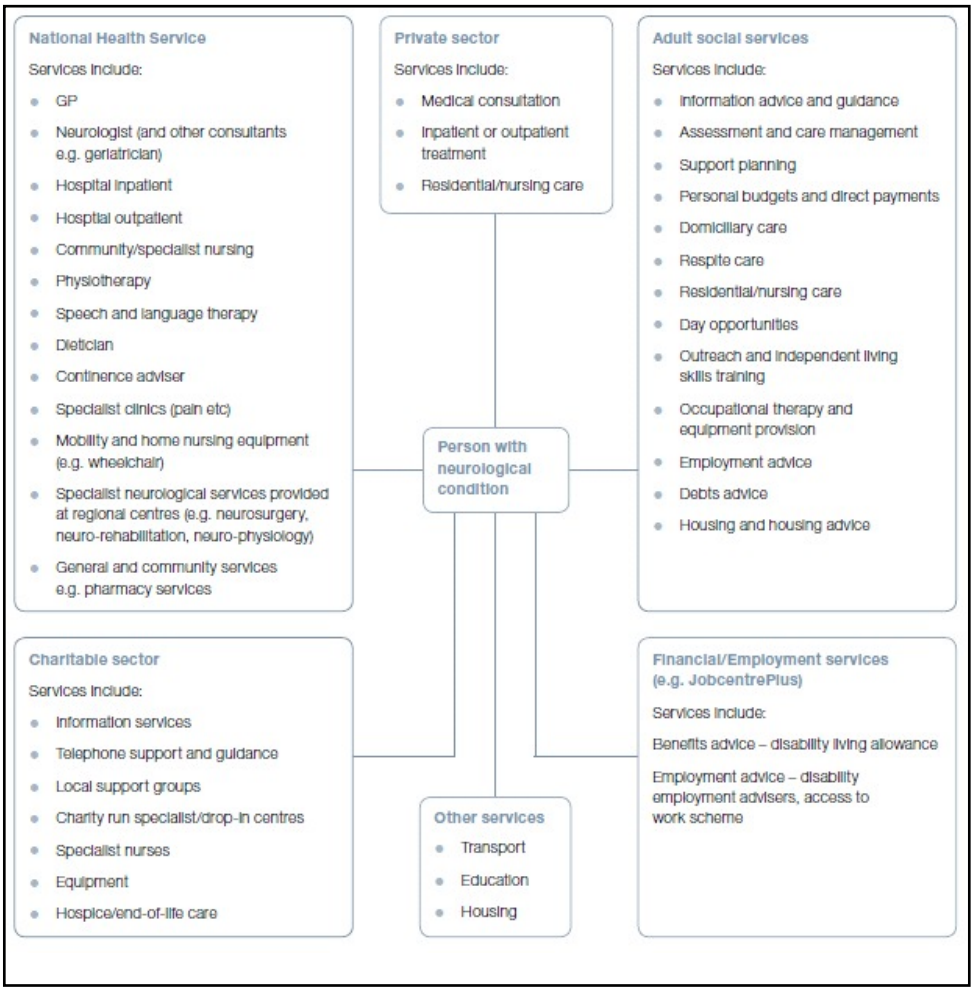
As shown in Figure 1.1, a study of 1,197 medical emergencies in a District General Hospital (DGH) found that neurological disorders were the third most common reason for presentation. Despite having a neuroscience centre located in the DGH, only one third of these admissions were seen by a neurologist or neurosurgeon and only half were admitted under neurological services.[3] This combination of high demand and poor access to expert care reflects the challenge facing neurology services in microcosm.

Figure 1.1: Reasons for medical emergencies at DGHs



The complexity of services available for people with neurological conditions is indicated in figure 1.2

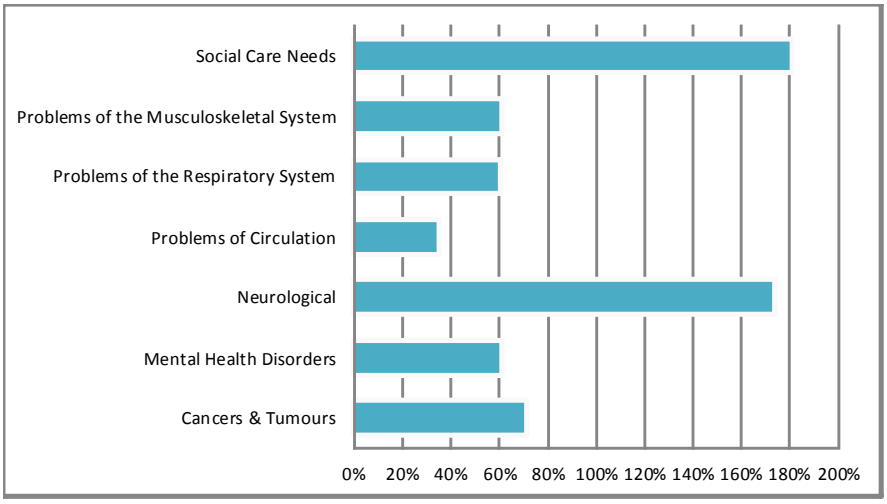
Figure 1.2: Range of services for people with neurological conditions [4]



1.2 Spend

Spend on neurological services has increased 174% in the seven year period since National Programme Budgeting Data began in 2003/4, exceeded only by social care needs (181% growth), which will have a major neurological component (see figure 1.3). Growth in neurological services is from a relatively low base but is rising rapidly with the clear message that neurology needs to be prioritised to avoid a steady deterioration in services or unmanageable costs or both.

Figure 1.3: Programme budgeting gross expenditure % growth, 2003/4 – 2010/11



A crude projection of future spend (see figure 1.4) reinforces this message and emphasises the strong rise in demand for neurological services. Put another way, without the impact of the financial crisis on NHS spending, neurology would have become the second largest service area by 2017/18, behind mental health but ahead of cardiovascular, cancer and musculoskeletal health.

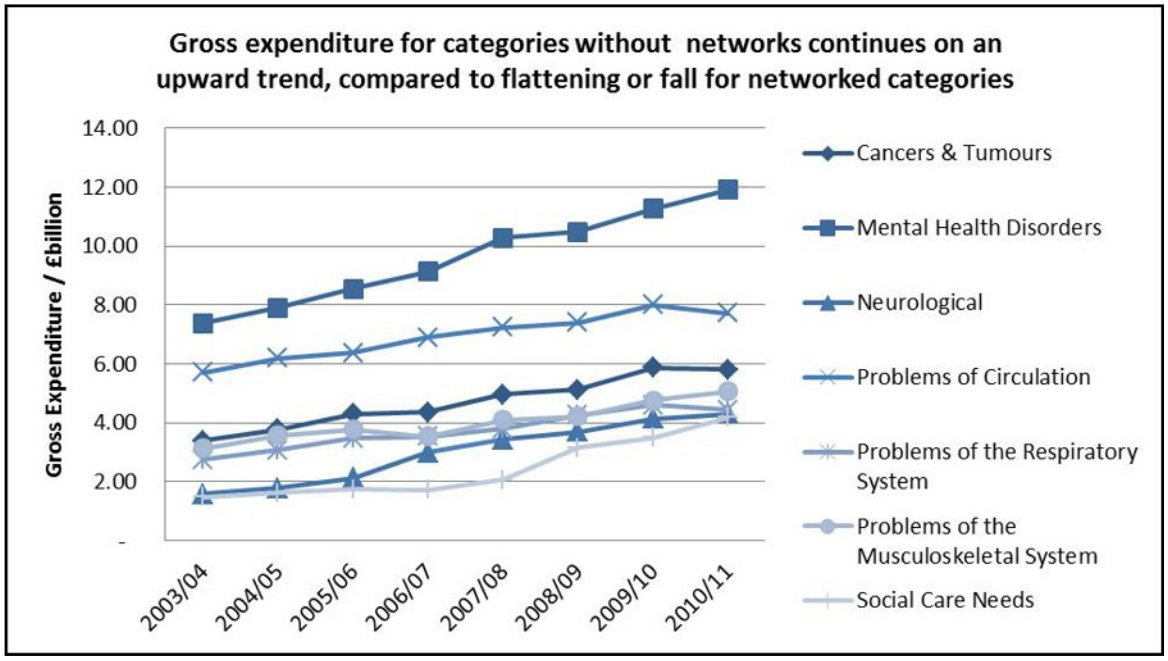
Figure 1.4: Programme budgeting spend, growth and projections

Programme Budgeting Category	Gross Spend / £bn 2003/4	Gross Spend / £bn 2010/11	% Growth 2003/04 - 2010/11	Projected Gross Spend / £bn* 2017/18
Cancers & Tumours	3.39	5.81	72%	9.97
Mental Health Disorders	7.39	11.91	61%	19.19
Neurological	1.57	4.3	174%	11.8
Problems of Circulation	5.72	7.72	35%	10.43
Problems of the Respiratory System	2.75	4.43	61%	7.13
Problems of the Musculoskeletal System	3.14	5.06	61%	8.16
Social Care Needs	1.48	4.18	181%	11.75

**Projection is a crude calculation of growth continuing along historical trends and is only valid as a measure of relative demand*

Closer analysis of the programme budgeting categories shows that, even in times of plenty, effective networks in other services have been consistent with relatively moderate spending growth. Figure 1.5 shows that the cardiovascular networks have combined a major impact on outcomes with the lowest level of service inflation (35%) and in cancer, where there has been strong growth in demand and new treatments have been actively introduced, spending growth (72%) is less than half the level for neurology. In addition, the graph below (figure 1.5) points to flattening or falling trends in spend growth for all areas where networks have been introduced; whilst un-networked categories, most notably neurology, have so far failed the Nicholson challenge.[5]

Figure 1.5: Programme budgeting expenditure trends by category



1.3 Current Service Provision

In June 2011, the Royal College of Physicians and the Association of British Neurologists published a report that made a number of cost neutral recommendations to improve adult neurology services through more efficient working and better use of resources. The report champions an expansion and improvement of local services with a shift in emphasis from scheduled to emergency care. Long-term conditions, it suggests, could be more sustainably and effectively managed through an enhanced role for specialist nurses and special interest general practitioners. It also sees the creation of neurological networks as being key to improving clinical and financial outcomes, by increasing clinical involvement within a commissioner / provider forum.[6]

The December 2011 National Audit Office (NAO) report into health and social care services for adults living with a neurological condition raised significant concerns about the provision of neurological services in the UK.[7] Progress against the 2005 National Service Framework for Long Term Conditions (NSFLTC) was viewed as particularly disappointing, largely due to the lack of levers to support implementation such as: national monitoring, targets and ring-fenced funding for particular work streams.[8] In addition, without the strong national clinical leadership that had accompanied other frameworks, NSFLTC implementation was seen to have been haphazard at best, as evidenced by the NSFLTC midpoint review which revealed a poor response to implementation of the NSFLTC.[9]

Despite reporting some service improvements such as greater access to healthcare services and a reduction in emergency bed days for those living with neurological conditions, the NAO reported that the number of people admitted to hospital as an emergency increased significantly and the variation of emergency admissions across Primary Care Trusts (PCT) was greater than expected.

Following the NAO report the Public Accounts Committee (PAC) heard evidence and produced a report reviewing services for people with neurological conditions. The main conclusions and recommendations included:

- The appointment of a National Clinical Lead for neurology;
- The development of a neurological data set;
- A departmental plan to ensure equitable access to services;
- The Department mandating joint health and social care commissioning;
- More extensive use of care plans in neurological services;
- The development of a generic quality standard for neurological conditions.

The Government's response to the recommendations put forward by the PAC was disappointing, in part because of the imminent transfer of responsibilities from the Department of Health to the NHS Commissioning Board under the Health and Social Care Act 2012. The challenge posed to the quality and cost of NHS services by neurology remains, however, to be addressed.

"There is an opportunity to deliver better care and that has to be the primary purpose. But I can also see an opportunity to create an infrastructure that would deliver a service which is better value for money with public funds. I also see more of an opportunity for the third sector. Creating that awareness around neurology will help to generate third sector funds as well increase the efficiency and value of public funds."

Alasdair McLeish, Acting Chief Executive, MND Association

1.4 Strategic Clinical Networks

In June 2011, the NHS Future Forum published its summary report on proposed changes to the NHS reforms.[10] One of the Forum's key recommendations focused on multi-professional involvement and championed the extended use of clinical and professional networks.

In February 2012 the NHS Commissioning Board (NHSCB) published its draft proposal for Strategic Clinical Networks (SCN) in the NHS. SCNs are intended to bring together primary, secondary and tertiary care clinicians along with partners from social care, the third sector and patients. The SCNs are expected to define evidence-based best practice pathways, which will be implemented through network relationships with commissioners and providers. They should work through England as 'engines' for change and pathway coordination across complex systems of care, maintaining and/or improving quality and outcomes.[11]

The proposal sets out seven criteria which it suggests should form the basis of deliberations about which conditions or patient groups would most benefit from an SCN. Following this advice the Neurological Alliance and Neurological Commissioning Support have been working with the neurological community to build the strongest possible case for an SCN for neurology services. Our evidence centred on interviews with a wide range of stakeholders including neurologists, geriatricians, commissioners, providers and third sector organisations (appendix 1) who have affirmed the need for a national strategic approach to neurology services.

As part of the interview process we asked participants what they thought were some of the most significant challenges facing neurological services. The answers covered a range of issues from diagnosis to end of life care but broadly speaking can be organised into three main themes, which could be considered by an SCN working to identify its key priorities:

1. Low profile and understanding of neurological services across the NHS and social services;
2. Gaps and variation in access to services, starting with diagnosis but particularly rehabilitation and ongoing care;
3. Organisation and delivery of neurological services from acute care to community based services.

We believe that an SCN is vital for improving outcomes across neurology services, providing better value for money and developing a service which inspires confidence in patients and clinicians alike. People living with long term, debilitating neurological conditions and their carers should feel confident that they will be able to lead full and happy lives with appropriate levels of care and support.

Neurology has been overlooked and put into the "too difficult" category for too long and the current opportunity to improve the lives of so many people by developing high quality, integrated neurology services must not be ignored.

1.5 Criteria for a Strategic Clinical Network

Figure 1.6: Summary of how SCN criteria are met by neurology services

#	Criteria	How criteria is met by a neurological network
1	A clear link to a national outcome ambition	Neurological services are addressed by all 5 domains of the NHS Outcomes Framework, in particular, domain 2: Enhancing quality of life for people with long-term conditions.

#	Criteria	How criteria is met by a neurological network
2	The need for a change process and / or co-ordination across complex pathways	• Neurological pathways are unusually complex and require coordination between different settings of care such as primary, secondary, tertiary and social care. • Neurology services interact with a large number of other services making the coordination of care all the more challenging and important.
3	Significant potential for quality improvement through a network model, involving multiple professionals and organisations	• Neurology lacks a sense of community. Neurologists often work alone in DGHs or isolated in other parts of the health service. This is in part due to a shortage of neurologists and the infrastructure in which they work. • People with neurological conditions have complex needs requiring a range of services, the coordination of which would benefit from a network approach.
4	The need for a pan-England approach	• It is widely agreed that neurology needs strong national clinical leadership to drive the service forward. Failure of the NSFLTC to bring about change can be attributed in part to a lack of focus on neurology rather than long term conditions and the absence of strong leadership. • Variation in quality and gaps in services would benefit from a national approach to improvement and organisation. • A pan-England approach would be the most cost effective way of assessing and reconfiguring services and making efficiency savings where possible.
5	Clear rationale for why quality improvement cannot be driven by another means (eg by a Clinical Commissioning Group (CCG))	• Historically neurological conditions have not been prioritised by GPs or commissioners, raising concerns about the position of neurology services in the new NHS. Lack of population data makes informed commissioning for neurological populations at local level very challenging. • Neurology services are spread across different care settings making the integration of all services difficult for CCGs acting alone.
6	An assessment of how the absence of an SCN would result in a lack of continuous quality improvement	• Despite a sharp increase in spending, there was a strong consensus that neurology services often remain poor. • A low base line and sporadic improvements in isolated areas of the service indicates that neurology does not have a precedent of continuous quality improvement to build upon. • Lack of strategic direction, rise in spend and the QIPP agenda raise questions about whether neurology will be able to maintain even current quality in the face of financial constraints.
7	A major part of the pathway will be commissioned by the NHS Commissioning Board	• The NHSCB will be responsible for commissioning specialised services and, through primary care commissioning, in a strong position to encourage greater GP engagement. Specialised neurology includes: Specialised Neurosciences Services (adult); Specialised Rehabilitation Services for Brain Injury and Complex Disability (all ages) and Specialised Spinal Services (all ages).

1. A clear link to a national outcome ambition

1.1 The NHS Outcomes Framework is developed around five domains for monitoring the performance of the NHS:

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

1.2 Across the spectrum of neurological conditions, improvements in neurological services would lead to improved outcomes across these five domains. There is, however, presently a dearth of indicators to help drive necessary change with, for example, neurology almost entirely absent from NICE's recent consultation on the Commissioning Outcomes Framework.

1.3 By contrast, a greater focus on outcome measures in neurology was seen by participants as a conduit to improving standards across the service. The importance of data collection, monitoring and holding people to account was emphasised.

1.4 In particular, improving quality of life for people with neurological conditions was considered to be a key outcome for neurology services. Helping people to stay in work, and providing appropriate levels of care and psychological support were cited as major contributors to achieving this outcome.

1.5 The NSFLTC set out ten quick wins to support its implementation. These could be reviewed, updated and used as a mechanism for performance monitoring, with backing from an SCN this time providing the prospect of success.

1.6 The Department of Health is currently developing the Long Term Conditions Outcomes Strategy, a high level vision that will help drive improvements relative to a range of generic services. However, there was concern that this will not address the full complexity of neurological conditions.

1.7 Participants felt that not enough had been done in the past to understand what outcomes are important to patients and carers and that Patient Related Outcome Measures (PROMs) for neurology should be developed.

1.8 An initial task for an SCN in neurology would be to assess the various national outcomes and agree on a set of criteria specific to neurology which could be addressed through the SCN and its work.

"Lots of the measures are proxy measures. Having access to a specialist nurse doesn't tell us anything about the quality of service. What we really need to know is what is important to the patient. Do they have reduced hospital admissions? Are they happier with their service?"

Sue Woodward, Lecturer, Florence Nightingale School of Nursing and Midwifery, King's College London

"It's very difficult to benchmark deteriorating conditions, whereas quality of life can always be measured."

Ann Bond, Chief Executive, Integrated Neurological Services

"The outcomes [in the commissioning outcomes framework] are too general for neurology. It's very difficult to decide what good outcomes are for someone with Parkinson's or MS. However, we can be clever about mapping ambitions for neurology onto the national outcomes."

David Bateman, Neurologist, Royal College Physicians

2. The need for a change process and / or co-ordination across complex pathways

2.1 Neurological pathways are highly complex. Starting with diagnosis and encompassing acute admissions, outpatient and long-term care, a person living with a neurological condition will require ready access to different parts of the care pathway at different times.

2.2 Neurological conditions are often long term and degenerative meaning that people living with them will often re-enter the system at times of relapse and crisis. This can be through referral from a GP or emergency admissions. Better organised and integrated primary, secondary, tertiary and social care is essential in improving how patients and clinicians navigate services, ensuring better outcomes and reduced costs.

2.3 Neurology pathways interact frequently with other health and social care services such as geriatrics, palliative care, pain management, respiratory and physiotherapy. It is crucial to develop cohesive pathways which work across this matrix and which are transparent, enabling clinicians, social workers and patients to identify what services they need to access and where.

2.4 England suffers from a well-recognised shortage of neurologists combined with a threefold variation across the country. Where Londoners can expect one full time equivalent neurologist per 51,395 of population the average across England is one FTE per 117,526. [12] The knock-on effects include a lack of presence in acute services and growing pressure on outpatient services. Financial pressures mean that the supply of neurologists to the NHS is unlikely to change significantly, while demographics mean that demand will continue to grow. It is therefore essential that services are configured to develop the capacity of primary care while providing optimal access to specialist expertise when required.

2.5 The complexity of neurological services means that people can easily find themselves exiting a care pathway and not receiving required levels of support such as on-going rehabilitation. Developing the role of specialist nurses, key workers and improving the use of care plans is essential to ensure that people transition into appropriate support networks in a smooth and timely manner.

2.6 The provision of acute care was identified as an area which required urgent reconfiguration to ensure that neurology inpatients receive the same level of care as other conditions, with patients routinely seen and treated by a neurologist. There was also serious concern expressed about the shortage and quality of rehabilitation services and the reliance on private rehabilitation which can cost as much as £250,000 a week.

"The pathway for brain injuries must be better. In complex cases, 6 months in a neuro rehab bed costs about £80k, but commissioning delays mean patients can languish in acute care for as long as 9 months, costing up to £250k. This is not just a waste of money, it prevents rehabilitation starting when it has maximum benefit."

Angus Somerville, Chief Executive, Royal Hospital for Neurodisability

""Where there is a planned local pathway the patient can progress through and complete their rehabilitation journey. However, poor/no communication at certain parts of the pathway means that people end up in crisis and GPs have to refer them back up the chain".

Amanda Swain, Executive Committee, UK Acquired Brain Injury Forum

"Services have grown organically so that things are provided in different ways in different places. Referral practice (and what they think they can manage) varies hugely amongst GPs. There are many more GPs than neurologists so tiny changes in their referral practice has a big impact on neurology services."

Paul Morrish, Neurologist, Association of British Neurologists

"Diagnosis and coordination can be completely haphazard and referral into the more structured and specialist areas such as respiratory management and palliative care can often falter as a result. Almost without exception you'll find that areas of good service or integrated care have had some funding, intervention or influence from the third sector. Being dependant on the third sector to ensure and provide good care is unacceptable. That's very much a statutory responsibility."

Farah Nazeer, Director of External Affairs, MND Association

3. Significant potential for quality improvement through a network model, involving multiple professionals and organisations

3.1 Neurologists are seen to be remote from other parts of the healthcare system, in part because they are based in tertiary centres or work single handedly in DGHs. It is widely agreed that neurology services would benefit from developing a stronger sense of community and more robust relationships between the various disciplines involved in neurological care. Indeed the creation of a clinical community is seen by Professor Sir Mike Richards as perhaps the single most important achievement of cancer networks.

3.2 There is a strong belief held by the neurology community that commissioners and primary care practitioners do not understand or prioritise neurological services. A network would provide the opportunity for neurology to raise awareness and inform more effective commissioning of comprehensive and effective services.

3.3 Participants emphasised the importance of GPs to the future of neurology services, yet there are currently few GPs with a special interest in neurology. Building relationships between primary care and local neurologists would help to raise awareness of neurological conditions, develop appropriate referral patterns and increase GP involvement in longer term care of neurological conditions.

3.4 Few DGHs have on-site neurologists and neurological emergencies are usually managed by DGH physicians or intensive therapy unit staff, sometimes with telephone advice from neurological centres or with infrequent visits from centre-based neurologists.[13] Developing networks which include neurologists is vital for improving neurological care in acute settings.

3.5 Specialist nurses can play a central role in delivering neurological care. Maintaining and building upon such expert coordinating roles within neurological care will be crucial to developing seamless pathways and managing costs. Work carried out by Parkinson's UK found that in Harlow and Pennine Acute Trust, a community based Parkinson's nurse can save on average £80,000 per year in reduced admissions through ensuring that the appropriate support is available and co-ordinated in the community.[14]

3.6 Quality variation across England is unacceptable and coordinated action involving practitioners from different parts of the care pathway is required to bring underperforming areas up to the standard set by those areas demonstrating good practice. The National Audit of Seizure Management in Hospitals (NASH) constitutes the first comprehensive UK wide audit of care delivered to people presenting at emergency departments with seizures. The report noted wide variation of standards and in many areas, standards were not sufficiently high to enable good patient outcomes. However, pockets of good practice were found to exist, demonstrating that good care is possible, especially if neurologists engage effectively with acute care.

3.7 There was concern amongst contributors that in the face of the financial challenges facing the NHS, failure to reorganise services might prevent quality improvement and result in an outright deterioration of services. Epilepsy, one of the more common neurological conditions that affects 1 in 103 people in

"Cancer specialists know their team. Neurologists and Geriatricians tend to work in silos. It needs to be built around certain disorders with the relevant multidisciplinary team."
Dr Chris Clough, Consultant Neurologist and Clinical Neurosciences Adviser, Department of Health

"One of the complexities of MND is that you need so many people to come together so quickly. Unless you have that pathway in place to allow that to happen, the alternative tends to lead to crisis both for the individual and the carer and the services."
Farah Nazeer, Director of External Affairs, MND Association

"There is a problem with health and social care coordination. They don't understand each other's cultures or environments."
Sue Millman, Chief Executive, Ataxia UK

England,[16] is already experiencing worsening mortality outcomes for patients. There are three deaths a day in the UK from epilepsy. The UK SUDEP Research Initiative, a joint venture between Epilepsy Bereaved and King's College London and King's College Hospital NHS Foundation Trust, published research in 2011 which showed that epilepsy mortality is rising (Ridsdale). The General Practice Research Database showed that reported deaths in epilepsy rose by 31% in males and 39% in females between 1995 and 2005.[17]

3.8 Most people with stable neurological conditions will not need ongoing hospital care but will need to be cared for by a network of services in a local setting. It is important that all of the relevant providers are involved at a strategic level so that a more cohesive and coordinated pathway can be developed.

"The funding for the North East Neurosciences Network (NENN) has been provided by contributions from the four PCT clusters in the North East, circa 10k per cluster. The network is seen as having a low priority compared to others and as a result investment levels have been low. Establishing a national and regional strategic steer has been difficult and as a result when an area is seen as having a more pressing need than neurosciences then there is even less engagement in the neurology agenda."

Peter Mercer, Director, North East Neuroscience Network

4. The need for a pan-England approach

4.1 In its review of neurological services in England, the PAC pointed to the lack of strong clinical leadership accompanying the NSFLTC and recommended the appointment of a National Clinical Lead for neurology. The need for strong, proactive leadership was echoed by almost all of the contributors to this report.

4.2 Variation in neurology services across England is significant, both in terms of quality and access, both of which could be addressed by a network. For example the Atlas of Variation states that for 2009/10 reported numbers with dementia on GP registers per PCT as a percentage of estimated prevalence ranged from 26.8% to 58.8% (2.2-fold variation) suggesting significant variations in rates of diagnosis. The Atlas also reports a 5-fold variation in Parkinson's disease drug items prescribed per weighted population in primary care and a 9-fold variation between PCTs in emergency admissions for children with epilepsy aged 0–17 years.[18]

4.3 It was widely considered that although spend in neurology has increased sharply, there is no way to measure the impact on outcomes. There was also a general view that the money in the system could (and indeed had to) be made to work more efficiently. An SCN would enable a detailed audit of how neurological services are delivered across England and how these services can be delivered in a more strategic and cost effective way.

4.4 The NAO and PAC reports noted the lack of data collection across neurological services, which was acknowledged by the Treasury in its response. A pan-England approach would allow a network to identify specific outcomes and take responsibility for the collation and analysis of data surrounding these outcomes to identify areas for improvement and to raise standards.

4.5 There is a certain amount of innovative work going on across England to improve services for people living with neurological conditions. Unfortunately, there is little coordination and good practice is rarely transferred to other parts of the system. Neurology would benefit from a national network which facilitates the sharing of successful innovations and good practice.

4.6 Contributors to this report felt that neurologists and other related specialists worked in silos and that local level services weren't incentivised to look at the bigger picture.

4.7 The Treasury's response to the PAC report stated that neurology did have local networks although it conceded that there was not full coverage. Participants in this review were aware of few such networks and those most commonly described were informal meetings at a very local level, or care networks funded and organised by the third sector.

"Neurology services haven't achieved their full potential in this country, and it's not for want of trying."
Professor Graham Venables, Consultant Neurologist, Chair, Neurosciences Clinical Reference Group, Past President ABN

"Networks need to have a role of surveillance, identifying black holes, going to those geographic regions and offering them support to bring up standards and develop services."
Dr Chris Clough, Consultant Neurologist and Clinical Neurosciences Adviser, Department of Health

"If I were to rate neurology services, traumatic brain injury at a regional specialised trauma hospital would have the potential of achieving 9/10 for the first lifesaving hours and weeks. This quickly drops down to a 2/10 according to whether there is a neurological clinical pathway for acquired brain injury in the patient's home region as they will be transferred back there as soon as they are stable."
Amanda Swain, Executive Committee, UK Acquired Brain Injury Forum

5. Clear rationale for why quality improvement cannot be driven by another means (eg by a Clinical Commissioning Group)

5.1 Despite the National Service Framework for Long Term Conditions being published in 2005 and a rapid increase in spend; there has not been a step change in delivering high quality neurological services across the board.

5.2 The majority of participants felt that CCGs would not be well positioned to lead the necessary improvements required for neurology services. Reasons for this included: a perception of apathy in primary care and commissioning about neurology, insufficient knowledge of neurology conditions, pathways and services; as well as a strong feeling that CCGs will have too much on their plates to take on the longstanding but essential challenge of neurology services.

5.3 Many neurological conditions are rarely seen by GPs. Where conditions are more common, GPs are quick to refer to neurologists for diagnosis and treatment. While GPs are seen to be crucial in improving neurological services, support and education needs to be scaled up before they can be expected to drive change.

5.4 An absence of population data makes it difficult for commissioners in both health and social care to understand the neurological need in a particular population. Representation of these conditions at a local level through health and wellbeing strategies and Joint Strategic Needs Assessment would therefore be limited.

5.5 Neurology services are organised across primary, secondary and tertiary care. Specialised and local commissioners will face a real challenge in commissioning comprehensive care pathways which are properly integrated without strategic leadership. For example, a person living with motor neurone disease might require non-invasive ventilation, which would be commissioned by the NHSCB at a tertiary level but supported at a community level. Linking two such aspects of provision into a seamless service will prove challenging without strategic direction.

5.6 Targets have helped to reduce waits for new appointments. However, the increase in outpatient appointments has swamped consultants. This has had the effect of disadvantaging acute inpatient and long term care as resources are diverted elsewhere. Neurology services must be strategically planned and reconfigured looking at the whole system to mitigate some services benefiting at the expense of others.[19]

"I wouldn't rule out local level forever but at the moment there needs to be national leadership. Five years during transition would help to inform data and outcomes and infrastructure."
Ann Bond, Chief Executive, Integrated Neurological Services

"SCNs could demonstrate cost effectiveness to persuade CCGs of the importance of doing things in a particular way."
Dr. Chris Gordon, Consultant Geriatrician and Programme Director, NHS Top Leaders

"It's easy to forget primary care but their involvement is essential. An SCN would help them manage neurology in the community and to structure services that work well for them and their patients."
Paul Morrish, Neurologist, ABN

"My sister died 19 months after being diagnosed with motor neurone disease. The GP had never seen a case before and had no idea what to do. At the end, I asked if he would like to become a neurology specialist GP so that he could share what he had learned, but he refused. It had been so traumatic he said that he hoped he'd never see another case again!"
Glenys Marriott, Recent Chair, North East Neuroscience Network

6. An assessment of how the absence of an SCN would result in a lack of continuous quality improvement

6.1 The NAO report on neurological services published in December 2011 reported a 31% increase in neurological inpatient admissions between 2004/05 and 2009/10, compared to 20% for the NHS as a whole.[20] There was also a 32% increase in emergency neurological admissions to hospital between 2004/05 and 2009/10, compared to 17% for the NHS as a whole. Set against the backdrop of sharply increasing spend there are important questions which need to be answered about whether neurological services are delivering value for money and if the increase in spend is leading to quality improvements. Above all, such increased spending is no longer sustainable.

6.2 The RCP/ABN report[21] raised concerns last year about acute services, which were also highlighted in the 1996 RCP report,[22] calling for the appointment of neurologists in every DGH. This has not been achieved having been overlooked due to spiralling outpatient demand.

6.3 Increasing demand on neurologists' time and concerns about the availability of specialist nurses makes it important that neurology services are looked at as a whole and in a coordinated manner, so as not to disadvantage some areas of the service by improving others. For example, the reduction of outpatient waiting times may lead to reduced capacity in care for people with long-term conditions because of reduced follow up capacity, rushed consultations and a lack of continuity in care.[23]

A respondent to the MS Society's *Access to Healthcare 2011* reported "I lost my nurse in November 2010 with no replacement. My GP is fantastic but I miss my nurse!" Another respondent reported "The MS nurse and physiotherapist are very good but they both have a high work load, especially since the consultant no longer has time for check-ups."

6.4 Despite a significant increase in neurology spend the efficiency drive is affecting front line services. Participants reported specialist nurses being downgraded and roles not being filled once they are vacated. Others have reported the scaling back of services such as outpatient migraine clinics and key worker roles. While all services will need to manage the effects of the QIPP agenda, the lack of neurologists and the long term nature of many neurological conditions make the service particularly vulnerable to lapses in quality.

An SCN is needed to prevent short-termism and slash and burn as the squeeze on NHS services begins to bite. Elements of care delivery could completely disappear if there is no SCN to provide advice to commissioners on how to spend the budget in more efficient ways while still preserving quality."
Bev Castleton, Geriatrician, Royal Surrey County Hospital

"There was no national leadership linked to the NSF, which is probably why most people did nothing about setting up networks. As opposed to stroke that had Roger Boyle as a key lead and clinical champion nationally…then the stroke strategy was developed, which was very effective. There is none of that in neurology. The NSF was a 10 year document with no targets, so most PCTs didn't prioritise it."
Julie Rigby, Network Director, Greater Manchester Neuroscience Network

"Chronic neurological disability is coming from a low base line. I am worried we may lose even more due to the new commissioning arrangements. If these things are commissioned by CCGs they will have a lot of priorities and neurological services have not traditionally been one of them."
Professor Mike Barnes, Chair UK Acquired Brain Injury Forum

7. A major part of the pathway will be commissioned by the NHS Commissioning Board

The NHSCB will be responsible for commissioning primary care services, providing levers for greater GP engagement in neurology. Most services in the Specialised Services National Definitions Set will also be commissioned by the Board directly, as set out in the list below.

#	Definition	Description
No. 8	Specialised Neurosciences Services (adult)	• New drugs, surgical procedures and investigative techniques have changed the relationships between specialties, the use of facilities and the site at which treatment takes place. • Sub-specialisation is now well advanced within neurosurgery, neurology, neuroradiology, neurophysiology and neuropathology and there is increasing involvement with rehabilitation, neuropsychology and neuropsychiatry services in assessment and care. • In parallel with these developments stroke medicine has developed and includes practitioners from elderly care medicine, clinical pharmacology and neurology. Neurosurgery and neuroradiology services for stroke patients are specialised and therefore that aspect of stroke care is included in this definition. • Because of the interrelationships it is important to plan neurosciences services as a whole; a strategic plan for neurosurgery services will take into account plans for neurology services and consider the whole care pathway, including neuro-rehabilitation and key support services such as neuroradiology, neurophysiology and other cognate disciplines.
No. 7	Specialised Rehabilitation Services for Brain Injury and Complex Disability (all ages)	• Specialised rehabilitation services support patients with complex disability whose rehabilitation needs are beyond the scope of their local rehabilitation services. • Specialised rehabilitation services (i.e. Level 1 services) are high-cost, low-volume services catering for patients with injury or illness which has resulted in complex disability. • Complex disability includes a subgroup of people with 'profound disability'; these are more severely affected patients who have help with all their basic care and will often require additional interventions such as spasticity management and postural support programmes, and/or be reliant on highly specialist equipment.
No. 5	Assessment and Provision of Equipment for People with Complex Physical Disabilities	• This definition describes services that provide bespoke/customised equipment to enable adults and children with profound physical disabilities to live as independently as possible in their community or residential environment.

#	Definition	Description
No. 6	Specialised Spinal Services (all ages)	• Specialised spinal cord injuries encompass any traumatic insult to the spinal column at cervical (neck), thoracic (chest), thoracolumbar, lumbar, lumbo-sacral (lower back) or multiple levels which causes complete or partial interruption of spinal cord function. • Such injuries will usually lead to some degree of neurological deficit such as loss of motor function (weakness or paralysis), bowel and bladder function, and sensory or autonomic function (control of blood pressure, etc.). In general the higher up the spine the trauma is inflicted the more serious the degree of SCI. The resultant damage may be permanent, temporary or delayed. • SCI care incorporates the core components of acute care, restorative rehabilitation, reintegration into the community and long term follow-up into a seamless clinical service. The SCI service also includes the surgical and non-surgical stabilisation and rehabilitation of patients with non-progressive spinal cord dysfunction arising from spinal cord pathology or disease.
No. 23	Specialised Services for Children	• Section 23.13 sets out a wide range of specialised paediatric neuroscience services, largely reflecting the equivalent coverage in adult services.
No. 31	Specialised Pain Management Services (adult)	• The management of pain is a requirement of all healthcare professionals. Pain management services are found in most local hospitals and community healthcare services and have been recognised as a distinct form of care for the purpose of health statistics since 1996 when pain management was assigned its own treatment function code (191). • Specialised pain management services diagnose and treat highly complex chronic pain that local pain management services are unable to manage. In some parts of the country the specialist pain centre has the expertise to deliver only one particular treatment from the range included in specialised pain management services (e.g. cognitive behavioural therapy or spinal cord stimulation). For this reason specialised pain management services tend to be provided as part of a clinical network.

Appendix 1

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Appendix 2: References and Footnotes

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