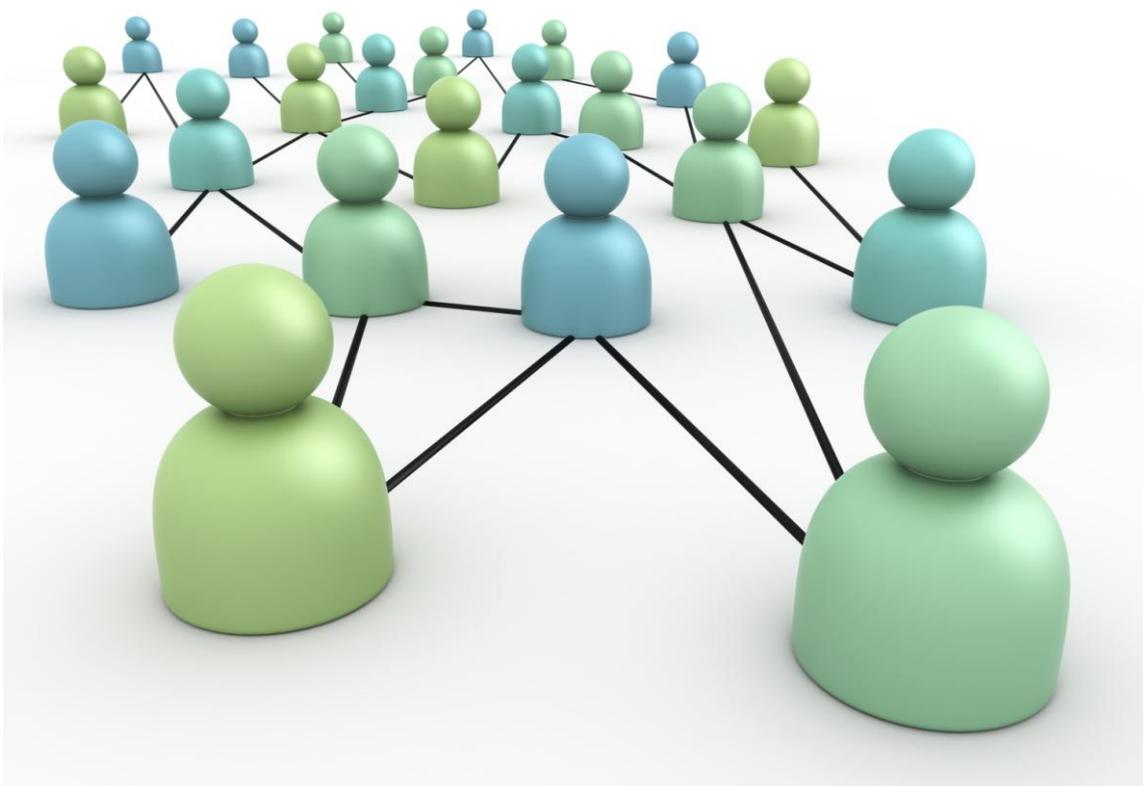


Navigating neurology services: helping strategic clinical networks to be a success story

September 2013



Foreword

Neurology is at last on the map! NHS England has made improvements in the care of neurological conditions a priority by including them in the first wave of conditions to benefit from strategic clinical networks (SCNs). This is a unique opportunity to bring together the expertise of health providers, commissioners and management to redesign neurological care in the interests of patients and the NHS.

SCNs are based on the very successful cancer networks. They can help us bring together innovative ideas and approaches to managing neurological conditions and learn from each other's experience. They are particularly appropriate when a coordinated approach involving many professional groups and organisations is needed to deliver large scale change across complex pathways of care.

Neurological conditions are therefore ideally suited to a SCN approach. So often in the past, improvements in care have failed because of inability to develop successful care pathways across health divides. We now have an opportunity to get this right.

The challenge for us is to use them effectively to make sustained improvements in neurological care. This report from the Neurological Alliance helps to focus minds on some of the challenges ahead, what the SCN's immediate priorities could be and what existing work we can draw on.

I am very much looking forward to working with those involved in setting up SCNs, together with patients and clinicians, to make them a success. It is only by working together that we will be able to tackle the big challenges currently facing neurological services and really make a difference to the patients and families affected by these conditions. Hopefully we can establish permanent clinical networks to achieve continuing and lasting improvement in services for all patients with neurological conditions.

Dr David Bateman
National Clinical Director for Neurological Conditions

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Executive summary

Introduction

Neurological services have often been poorly prioritised by health and social care decision-makers. This is despite the fact that around 10 million people in England – more than one in six – have a neurological condition. It is therefore welcome news that neurological conditions are at the forefront of a new national initiative to set up a small number of large networks to improve health services for particular patient groups or conditions¹.

These strategic clinical networks (SCNs) are intended to make improvements in areas where there are currently major challenges to delivering the best possible care for patients. NHS England, the organisation responsible for setting up and funding these networks, has assigned one of them to focus on mental health, dementia and neurological conditions. The Neurological Alliance wants to work with those involved in setting up this SCN to provide expertise and guidance to help ensure that it delivers real improvements for all people with neurological conditions.

Understanding the challenge

The scale of the challenge faced by the SCN in relation to improving neurological services should not be underestimated. Neurological services have consistently ended up at the bottom of the pile when it comes to political and clinical prioritisation and, as a result of a lack of accountability and leadership within the system, have been shown not to provide value for money².

The Neurological Alliance warned last year that the NHS reforms were failing to put in place the type of turnaround programme that is needed for neurological services³. The responses to our survey for this blueprint highlight a number of recurrent and all too familiar themes, including disjointed neurological care, poor understanding of neurological conditions and delays in accessing care and treatment.

In this early period of operation for the reformed NHS, the SCN is the key opportunity to lead on and deliver substantive neurological service improvements. The SCN has a limited lifespan in which to deliver long-term and meaningful changes and it is therefore vital that this opportunity is capitalised upon from the outset. The Neurological Alliance is optimistic about the SCN's ability to succeed in delivering these improvements. We are hopeful that this blueprint makes a constructive contribution towards helping the SCN to identify some of the challenges ahead, setting its priorities and devising practical solutions.

This report is designed to provide a blueprint for the SCN – it highlights eight priority areas that we believe the SCN should focus on when setting its objectives for neurological conditions and starting to implement them over the coming months. Our recommendations have been informed by a recent meeting of leading stakeholders and a survey of almost 900 people affected by neurological conditions.

Priority areas and key recommendations

Gathering data and intelligence

The SCN should:

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

Involving and empowering patients and carers

The SCN should:

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

Delivering high quality community services

The SCN should:

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

Raising awareness of neurological conditions in primary and community care

The SCN should:

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

Supporting the implementation of national guidance

The SCN should:

- support the translation and implementation of national guidance relating to neurological conditions, for example National Institute for Health and Care Excellence (NICE) guidance, at a local level and lead on measuring progress in achieving the aspirations set out in guidance documents.

Delivering integrated care

The SCN should:

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

Encouraging innovation

The SCN should:

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

Measuring success

The SCN should:

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

NHS England should:

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

Priority area 1: Gathering data and intelligence

Why is this a priority?

The Department of Health (DH) has historically lacked the necessary data to measure the effectiveness of services for people with neurological conditions. Unlike other major condition areas, data on incidence, service provision and patient outcomes relating to neurological conditions are not routinely collated, published or analysed. This makes it very difficult to establish a baseline from which progress can be measured and to understand what types of activities result in the best outcomes. The DH committed in May 2012 to developing a neurological dataset covering resources, services and outcomes by 2014, but disappointingly no progress in its development has been made to date.

In the absence of a neurological dataset, the challenge for the SCN, locally and nationally, will be to quickly establish processes and procedures for assessing the needs of people with neurological conditions and measuring outcomes. Without carrying out an initial needs assessment and establishing a baseline from which to measure improvement, it will be very difficult for the SCN to meet those needs and to demonstrate progress. Accurate and regular data collection is therefore crucial. It is also important that the data collected capture the care of the individual across the totality of services that they come into contact with, rather than providing a snapshot of a person's interaction with one service. There may be value in exploring patient reported outcome measures.

What should the SCN focus on?

One of the key areas of focus should be on measuring emergency admissions and readmissions for people with neurological conditions by collating and analysing hospital episode statistics (HES) relating to neurological admissions. This needs to look specifically at both the primary and secondary causes of admission, as hospitalisation is often prompted by secondary causes such as falls or urinary tract infections, which are in most cases preventable.

In some areas of the country, more than 50% of expenditure on neurological services is being taken up by emergency care⁴. There is also significant variation across the country in the proportion of spending on emergency care⁵. Gathering data to understand the reasons for this variation and the measures that can be taken to reduce emergency admissions where necessary should be a priority for the SCN, both nationally and in each of the 12 regional areas in which the SCN will operate. Appropriate pathways can then be developed to address the common causes for high rates of emergency admissions.

There is also a need to ensure that the data being collected are as accurate and consistent as possible. There are currently variations in the way that neurological admissions are coded, which need to be addressed in order for the data to help inform clinicians' and commissioners' understanding of service performance and outcomes.

The SCN should look to inform the development of a national neurological dataset by submitting data on neurological services and outcomes to NHS England on a regular basis. This will help to highlight where there are gaps in the available data that need to be addressed, and will allow for initial analysis of trends and variations to be carried out.

While building a national picture of the needs of people with neurological conditions is vital, it is also essential to understand local needs and ensure that these are being taken into account by local health and social care decision makers, including clinical commissioning groups (CCGs) and local authorities. The SCN should be a champion for people with neurological conditions locally. It should seek to inform the work of Health and Wellbeing Boards in developing Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) to ensure that the needs of people with neurological conditions are being accurately represented and appropriately prioritised.

As explored above, accurate and regular data collection will help the SCN to assess needs and measure outcomes. These data can then be used to inform JSNAs and JHWSs to ensure neurological need is reflected in these key documents, which will provide the vital incentive for CCGs to seek the tailored support and expertise of the SCN on the commissioning of high quality neurological services.

As well as engaging with setting the local health agenda in this way, the SCN also needs to understand local priorities so it can develop a targeted approach and allocate resources where they are most needed. The SCN will need to target its resources towards projects that guarantee fundamental and long term differences to neurological care – not on narrowly-focused projects that will only benefit a small number of patients. It is only by addressing the whole breadth of neurological conditions, rather than just the most prevalent, that the SCN will make progress where previous policy initiatives have failed.

What existing work can the SCN draw on?

The Neurological Alliance has undertaken work to identify the outcomes which matter most to people with neurological conditions and how these can be translated into outcome measures under the five domains of the NHS Outcomes Framework. Our report setting out these measures, *Intelligent outcomes: applying the health and social care reforms to improve outcomes for people with neurological conditions*⁶, provides a useful starting point for the SCN when considering how it will measure outcomes.

The SCN can also draw on key learning and established best practice from other condition areas, such as cancer and cardiovascular disease. Tools such as patient experience surveys, disease registries and clinical audit tools have all been tried and tested and have helped to drive progress for a number of different patient groups. The SCN should consider how such tools can be developed and used to establish a better understanding of neurological conditions and how they can inform service improvement to deliver better outcomes for patients.

Key recommendations

The SCN should:

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

Priority area 2: Involving and empowering patients and carers

Why is this a priority?

Closely linked to the previous priority area is the need to involve patients and carers in informing local commissioning priorities and empowering them to do so. Supporting people with neurological conditions to voice their concerns and ideas about improving care locally must be a central part of the SCN's remit. It is only by involving patients and carers, including those from hard to reach groups, that the SCN will accurately understand the challenges it faces and what the most appropriate solutions to these challenges are. There are likely to be some challenges around establishing meaningful patient involvement in the SCN but these will not be insurmountable.

It is also vital that patients have a clear understanding of the options of care available to them and the standards they should expect from local services. There is currently too much unwarranted variation in the quality of neurological services and a lack of agreed standards which means that many patients are at a loss when it comes to navigating complex care pathways and knowing where they can access advice and support.

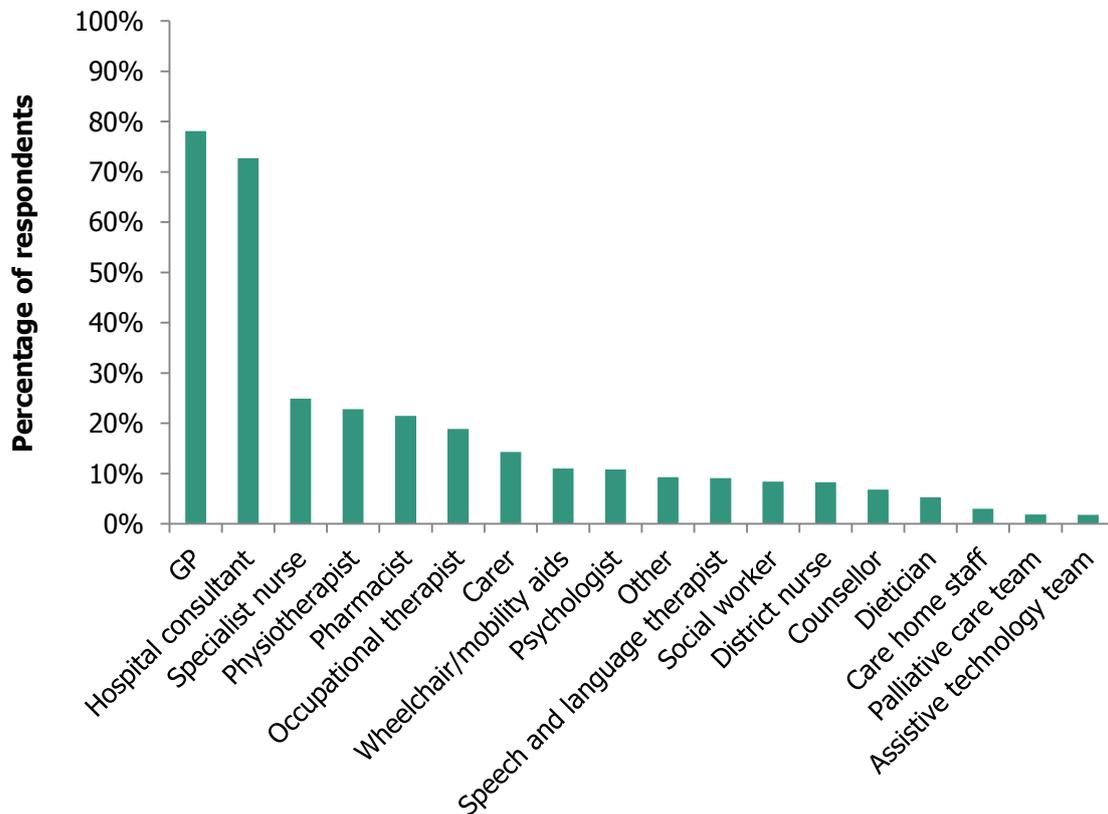
What does the SCN need to focus on?

The SCN should play a key role in helping patients to navigate services through the development and communication of clear written pathways and information about local services. Patients must be involved in the development of these tools so they are accessible and something that patients will actually use. The SCN could develop template pathways at a national level which are then tailored to each of the 12 SCN regions, signposting to local sources of advice and support.

The pathways should focus not only on the different services a person may access, for example primary, community, and specialised services, but also on the cross-over points between services. This will help to ensure that services are as integrated as possible and will help to prevent patients from falling through the gaps between services.

The graph below helps to illustrate the different types of services that are included in the often very complex neurological pathway. People with neurological conditions rely on a wide range of different services for care and treatment and it can be difficult to navigate these services and manage the transition between them.

Which of the following health/social care professionals do you/the person you care for have contact with to help manage your/their condition?

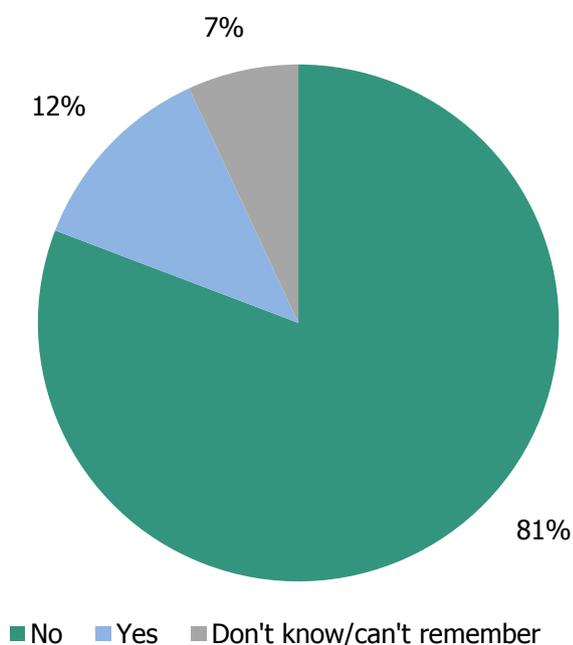


Health/social care professionals

Effective care planning plays an extremely important role in helping people to navigate services. Worryingly, only around one in ten respondents to our survey noted having been offered a written assessment and care plan setting out the different aspects of care involved in managing their condition. Ensuring that people with neurological conditions are offered a care plan and that this is developed in such a way that it supports them to navigate services should be a key priority for the SCN.

"[It is] impossible to even find out all the care available or what is available..."

Have you/the person you care for been offered a written assessment and care plan which sets out the different aspects of care that are involved in managing your condition?



What existing work can the SCN draw on?

The SCN should look to organisations such as the Neurological Alliance and its members to support patient involvement through their networks and existing channels to seek insights from people with neurological conditions. With its limited resources, it will be important for the SCN not to duplicate work that is already underway that can be used to help establish the SCN's priorities.

Our network of Regional Neurological Alliances (RNAs) could, for example, provide a useful conduit for feeding insights and ideas from patients into SCN processes. It is essential that the breadth of neurological conditions are represented, including rarer neurological conditions, rather than focusing only on those that are more prevalent and better understood.

RNAs involve people with neurological conditions and carers in developing resources and tools that can be used by those who need information and support. **Tees Valley Durham and North Yorkshire Neurological Alliance** has, for example, developed a directory which signposts people to information about neurological conditions and services in the region. **West Berkshire Neurological Alliance** has held local focus groups, bringing together people with different neurological conditions, to inform a number of reports on issues such as experience of diagnosis, wheelchair services, and incontinence.

The SCN should draw on examples of best practice such as the work that went into developing the ***Dudley Joint Commissioning Strategy for Long Term Neurological Conditions 2009-2014***⁷. The strategy was prepared jointly by a multi-agency group consisting of representatives from the Primary Care Trust (PCT), the borough council, local hospitals, voluntary organisations, service users and carers. It was informed by ongoing input from service users and carers, including through workshops and the publication of a consultation document. These activities helped to ascertain the lived experience of carers, service users and frontline staff so that real issues were identified and addressed in developing improved services.

The SCN could support the navigation of complex pathways by working with CCGs to support and promote a care navigator scheme. There are existing examples of best practice relating to this, for example in **Islington**, where Age UK has been commissioned by the CCG to provide care navigators. These new posts are designed to promote close working between GP practices and patients in order to share information about local services and to promote independent living. The aim is to provide additional support and guidance that improves patients' access to local services provided by non-traditional provider organisations. This project forms part of Islington's multidisciplinary approach to patient care.

Another excellent example is the work carried out by Neurological Commissioning Support, which was commissioned by **NHS Gloucestershire**, the county council and local patients to kick start development of a commissioning framework and pathway design for neurology. As a result of the project, patients had improved access to information and healthcare professionals had a better understanding of patients' needs⁸.

Key recommendations

The SCN should:

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

Priority area 3: Delivering high quality community services

Why is this a priority?

One of the biggest challenges in neurological services is the need to reduce the high rate of unplanned and avoidable acute neurological admissions. Emergency hospital admissions, in particular, can be extremely distressing for patients and are very costly for the NHS. Better management of neurological conditions in the community would help to prevent unnecessary admissions to acute care and allow resources to be used more efficiently and effectively.

What does the SCN need to focus on?

The SCN should address the lack of focus on community-based neurological services and explore how they can be supported and promoted to deliver high quality care that helps people manage their conditions better and stay out of hospital where possible.

"The NHS Community Care team are understaffed and no longer have physio premises."

This could involve assisting the development of **'neuro-care teams'** in the community to provide an avenue for inter-referral and patient support, and to allow outreach services that support those with complex needs. The teams could be developed at CCG level and would help commissioners to provide neurological services in a way that makes the best

use of the limited resources available to them. It is important that generalists are upskilled to know when they should refer on to specialist teams throughout the patient journey.

What existing work can the SCN draw on?

There are a number of examples of effective community neurological teams across the country that could potentially share best practice. These include the case studies below, which have all been highlighted as examples of best practice by the West Midlands Quality Review Service (a collaborative venture by NHS organisations to help improve the quality of health services in the West Midlands)⁹.

"[I am] not able to get care locally and was sent 250 miles away for over six months...as a young child away from parents it was very upsetting."

The **Walsall Healthcare NHS Trust Community Neurological Rehabilitation Team** provides holistic assessment and care for people with neurological conditions across a range of disciplines including occupational therapy, physiotherapy, speech and language therapy, psychology and rehabilitation services. People with a confirmed diagnosis are able to self-refer to the service¹⁰.

The **Staffordshire and Stoke on Trent Partnership NHS Trust Adult Ability Team** works together to deliver a coordinated and high quality service for people with

"[I would like to see] better community based services to support people to manage their condition."

progressive neurological conditions living in the community. People who use the service are regularly reviewed and their care plans agreed, with the main aim of assisting people to reach their desired or maximum health potential, to enhance their quality of life. The team offers rehabilitation, strategic education and group programmes, a formal monthly multidisciplinary clinical review, telephone support and respite care¹¹.

The **Dudley NHS Foundation Trust Community Neurology Team** provides a single point of contact for people with neurological conditions. It includes specialist nurses, physiotherapists, occupational therapists, speech and language therapists, dietitians, psychologists and specialist pharmacists. The service provides assessment, advice, medication review, rehabilitation, self-management programmes, emotional and psychological support and sign-posting and referral to other professionals and services¹².

Key recommendation

The SCN should:

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

Priority area 4: Raising awareness of neurological conditions in primary and community care

Why is this a priority?

There is often limited awareness and understanding of neurological conditions among non-specialist health and social care professionals. This can lead to delays for patients in accessing the right care and treatment.

What does the SCN need to focus on?

The SCN should play a leading role in supporting awareness-raising activities and understanding of neurological conditions, in particular among primary care clinicians, who are most often the gatekeepers to more specialist care and treatment. The new role of GPs in commissioning services makes the need for them to understand neurological conditions even more pressing.

Informed decision-making regarding the commissioning of neurological services will be dependent on GPs having a sufficient level of awareness and understanding of neurological conditions.

"[I would like to see] better understanding of my condition...as my local hospital seems to not have a clue...and neither do my doctors...I always have to explain what it is to everyone I meet."

78% of respondents to our survey listed their GP as one of the health professionals they, or the person they care for, come into contact with to help them manage their neurological condition. It is therefore vital that GPs are supported to understand neurological conditions and know how best to refer patients on for diagnosis and treatment. The SCN should prioritise education and support for primary care clinicians and draw on existing examples of best practice in this area.

What existing work can the SCN draw on?

"[I would like to see] GPs better educated regarding these illnesses"

Sandwell PCT recently led an initiative to enhance and build up GPs' understanding of neurological conditions. The PCT worked with Sandwell and West Birmingham Hospitals NHS Trust to develop 'Neuro Knowhow' training for GPs. The MND Association, MS Society and Parkinson's UK were involved in the planning and delivery of the project.

The **East Kent Primary Care Epilepsy Service** utilises a network of GPs with a special interest in epilepsy. The service aims to provide community support for people with epilepsy and raise the standards of healthcare locally. The scheme was developed with the collaboration of patients, and primary and secondary care professionals. It offers a new point of referral for people with epilepsy into a network of GPs with a special interest in their condition. Having a locally-based service helps to ensure better care for all patients and is more easily accessible for those who have previously found it difficult to access the right services.

Key recommendation

The SCN should:

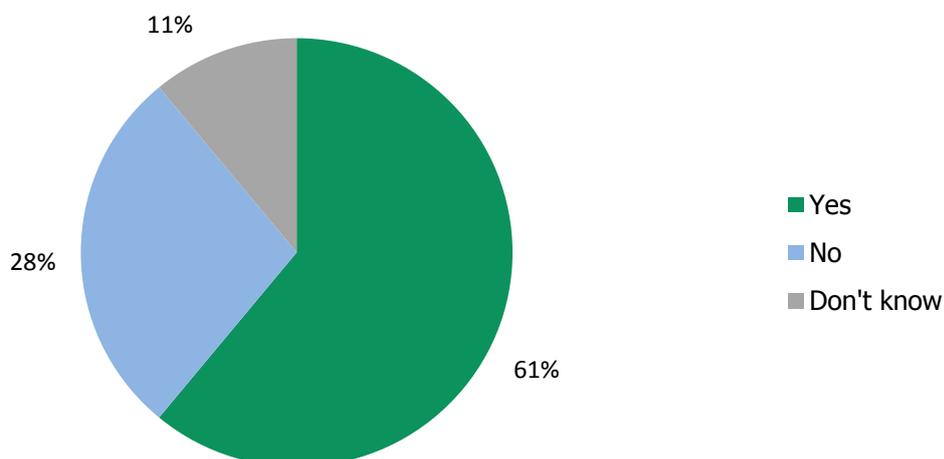
- prioritise education and support to raise awareness and understanding of neurological conditions among non-specialist professionals, in particular primary care clinicians.

Priority area 5: Supporting the implementation of national guidance

Why is this a priority?

If national guidance is not implemented locally, this may result in delays in accessing the services or treatment to which people are entitled. As illustrated below, 61% of respondents to our survey reported that they, or the person they care for, have experienced problems or delays in accessing services or treatment to help them manage their condition.

Have you/the person you care for experienced any problems or delays in accessing services or treatment to help manage your/their condition?



What does the SCN need to focus on?

The SCN should support the translation and implementation of national guidance relating to neurological conditions at a local level and lead on measuring progress in achieving the aspirations set out in guidance documents. This could include guidance from the National Institute for Health and Care Excellence (NICE), for example clinical guidelines and quality standards, but also agreed standards from professional groups such as the Association of British Neurologists. An overview of relevant NICE guidance is included in annex 3.

To date, there are a limited number of published NICE quality standards for neurological conditions. For those that do exist, and for those that will be developed in the future, the SCN should ensure there are procedures in place for raising awareness of the existence of these NICE quality standards and monitoring progress in their implementation locally. CCGs will be held accountable for how the services they commission meet the requirements set out in NICE quality standards. The SCN can therefore support CCGs by

highlighting areas that need attention and supporting them to meet the standards that have been set.

What existing work can the SCN draw on?

The SCN could learn from initiatives such as the **West Midlands Quality Review Service**. This was set up as a collaborative venture by NHS organisations in the area to help improve the quality of health services by reporting on services, outlining what is working well and what merits further attention. The service uses a standards framework drawn from NICE as well as other guidance and methods such as peer review to shine a spotlight on services across the region.

Key recommendation

The SCN should:

- support the translation and implementation of national guidance relating to neurological conditions, for example National Institute for Health and Care Excellence (NICE) guidance, at a local level and lead on measuring progress in achieving the aspirations set out in guidance documents

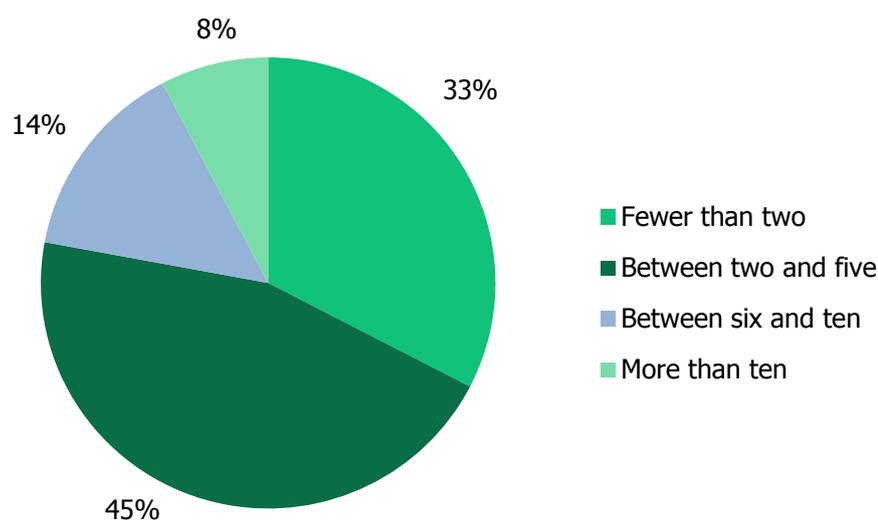
Priority area 6: Delivering integrated care

Why is this a priority?

The original criteria used by NHS England to identify the patient groups that should be covered by the first SCNs included a requirement for “large scale change across very complex pathways of care involving many professional groups and organisations”¹³. Neurological pathways are often very complex and rely on effective coordination between health and social care professionals from across a number of different care settings, including GP services, community care and specialised services.

As illustrated below, more than one in five people who responded to our survey reported that they come into contact with six or more health and social care professionals to help them manage their condition in the course of an average year.

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

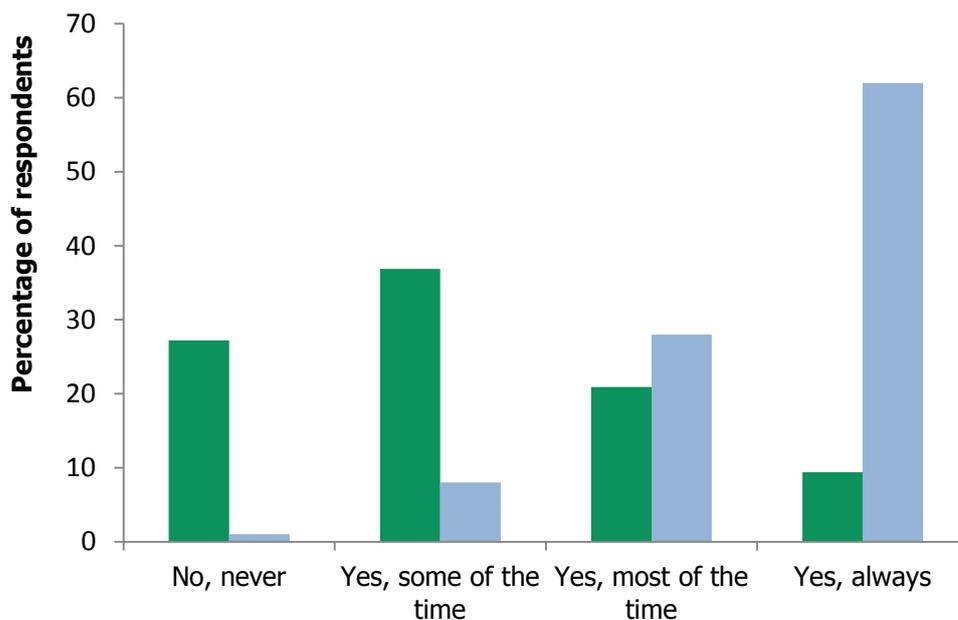


Our survey highlighted significant levels of poor experience for people with neurological conditions in relation to the coordination of care between these different professionals. Over a quarter of respondents reported that the different people treating and caring for them did not work well together to provide the best possible care. Only one in five respondents stated that their care was always well coordinated.

These findings are presented in the graph below. Although our survey results were from a far smaller sample size, it is interesting to see how these results compare with the findings of the Cancer Patient Experience Survey in 2011/12. There is a stark difference in the percentage of people reporting good coordination of care between the two condition areas. 90% of cancer patients stated that their care was well coordinated

always or most of the time, compared to only 30% of people with neurological conditions¹⁴.

Do you feel that the different people treating and caring for you/the person you care for work well together to give you the best possible care, and are well co-ordinated?



Level of effective working between health professionals

- Figures from Neurological Alliance survey
- Figures from Cancer Patient Experience Survey 2011/12

What does the SCN need to focus on?

The SCN should seek to promote continuity of care through engagement with the different agencies involved in supporting people with neurological conditions, including specialised services (both children and adults), social care services and housing authorities. This could be supported through the mapping and communication of examples of current best practice.

Joined-up working between the different specialisms that people with neurological conditions may come into contact with should be facilitated and encouraged by the SCN. Innovative approaches to multidisciplinary team working to take into account co-morbidities and fluctuating needs of patients should be highlighted and shared across the SCN.

What existing work can the SCN draw on?

A recent initiative piloted in **Stoke on Trent** has demonstrated how multidisciplinary working can provide enhanced support for people with neurological conditions¹⁵. An independent social work practice was set up in 2012 to provide services to people with MS, Parkinson's and MND. The practice has relied on close working between social workers, nurses and GPs specialising in neurological conditions. The team takes a holistic perspective when conducting assessments or reviews and aims to look at how it can change the package of care to better meet people's needs.

"[I would like] for all doctors involved with a patient to liaise with each other even if it is not their field...if they are all treating you they should know what the others are doing!"

Key recommendation

The SCN should:

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

Priority area 7: Encouraging innovation

Why is this a priority?

It is only through encouraging and sharing effective innovative approaches to service design and delivery that the SCN will achieve significant and lasting improvements to neurological services. One of the founding criteria for SCNs is that their focus must be in an area where previous efforts at large-scale service improvement have failed. The need for new and innovative approaches is therefore part of the core purpose of SCNs.

What does the SCN need to focus on?

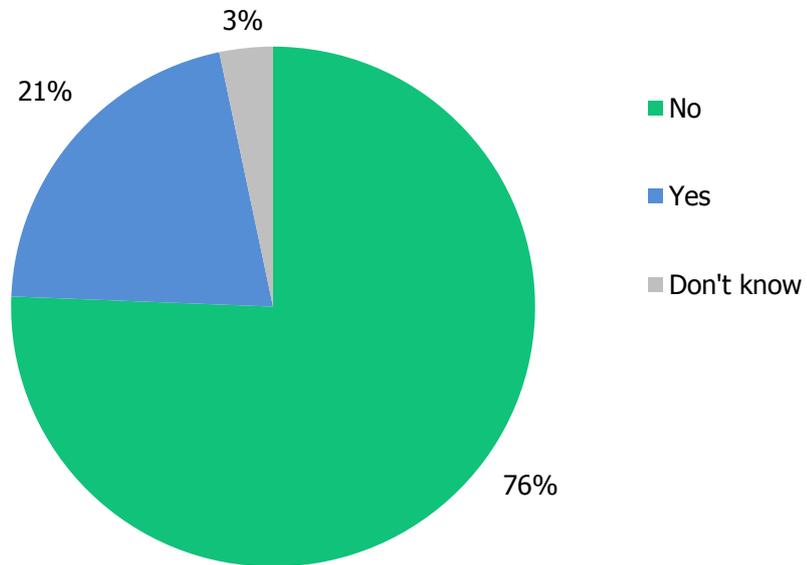
The SCN should identify and share effective innovative practice and ensure that new ideas and approaches to delivering high quality care are encouraged and applied to meet local priorities. Part of this could be through learning from best practice in other condition areas, particularly mental health and dementia, which also come under the SCN's remit. The cross-fertilisation of ideas between these condition areas could be extremely helpful in trying to uncover new successful practices in neurology.

Another simple way of encouraging the spread of best practice will be through bringing together those involved in running SCNs in different condition areas to discuss successes and challenges and to learn from each other. A biannual best practice seminar could be a good vehicle for this type of exercise. Encouraging open dialogue and peer support will be central to this and should be encouraged from the early stages of SCN development.

What existing work can the SCN draw on?

Encouraging innovation could also be facilitated through the SCN engaging with AHSNs to provide neurological expertise and encourage them to allocate some of their resources to focusing on neurology. AHSNs have been tasked with promoting the adoption and spread of innovation with clinical research and trials, informatics, education, and healthcare delivery. There is therefore a clear and significant opportunity here for the SCN to make sure neurological conditions are on the agenda of AHSNs.

Have you/the person you care for ever been offered the opportunity to take part in a clinical/research study?



Furthermore, collaboration with AHSNs presents an opportunity to reverse the historic trend for neurological conditions to lag behind other condition areas in the prioritisation of health research funding, despite their significant economic and societal impact¹⁶. 76% of people who responded to our survey stated that they had never been offered the opportunity to take part in a clinical research trial. This is something that needs to be addressed by the SCN in partnership with AHSNs so that neurological conditions do not continue to lag behind.

Key recommendations

The SCN should:

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

Priority area 8: Measuring success

Why is this a priority?

Although the SCN is a non-statutory body, it will have an annual accountability agreement with NHS England for delivering a programme of quality improvement which has been agreed with NHS England's five domain leads and local partners¹⁷. From very early on in its development, the SCN will need to have a robust plan in place for how it will measure and report its achievements.

SCNs have a number of fixed points for measuring success, including the NHS Outcomes Framework. In addition, NHS England has set out five 'lenses' which provide the guiding principles for SCNs. The recommendations which have been included in this report should help the SCN to achieve successes in each of these areas. The five lenses are:

- Quality - contribution to the NHS Outcomes Framework
- Clinical leadership
- Patient and public voice
- Equality and health inequalities
- Innovation and the NHS change model

What does the SCN need to focus on?

To measure progress accurately, the SCN should look to undertake an annual audit of progress which reflects the priority areas set out in its original strategy and workplan. The findings of the audit should not only be used for reporting progress but also to inform local priorities for the year ahead.

It will be of fundamental importance for the SCN to link up with CCGs and commissioning support units in relation to measuring success and reporting progress. It is vital that CCGs buy in to the SCN and value the support it provides in the commissioning of neurological services. Supporting CCGs to report successes in the commissioning of neurological services and delivering improved outcomes for patients should therefore be a central part of the SCN's role.

The same applies in relation to NHS England's specialised commissioning role. The SCN will need to support NHS England in measuring the success of specialised neurological commissioning across the country and to identify areas where improvements are needed.

What existing work can the SCN draw on?

The examples set out under priority area 1 are also relevant here. Measuring and reporting improvements in the outcomes that matter most to people with neurological conditions will be paramount to showing successes and identifying areas for further improvement. Tools such as patient experience surveys and clinical audits can be used to measure and report success.

In considering how it holds SCNs to account for their progress, NHS England should take into account learning from the experience of cancer networks. Macmillan Cancer Support and The King's Fund have reported that there was considerable variation in the success of cancer networks locally and very few mechanisms by which networks could be held to account for the performance within their locality¹⁸. It is important that this situation is not repeated in relation to SCNs and that they are held fully accountable by NHS England.

There should also be a reciprocal requirement on CCGs to engage with SCNs across all the condition areas they cover to ensure that they are fulfilling their core purpose of quality improvement.

Key recommendations

The SCN should:

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

NHS England should:

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

Annex 1: Overview of survey findings

The Neurological Alliance conducted an online survey of people with neurological conditions and their carers on determining local priorities for neurological care. The survey was disseminated via the Neurological Alliance's member networks and was open for approximately one month between June and July 2013. A total of 876 people responded to the survey.

An overview of the findings is set out below. Free text answers have been omitted from this overview.

1. How did you hear about this survey?		
answered question		850
skipped question		26

2. Which of the following statements most closely describes you?		
answered question		876
I have a neurological condition	73.9%	647
I care for someone with a neurological condition	18.6%	163
Other	7.5%	66

3. In which age bracket are you? If you are a carer, please indicate the age of the person you care for.		
answered question		867
0-15	3.8%	33
16-24	6.5%	56
25-29	6.1%	53
30-39	13.3%	115
40-49	25.6%	222
50-59	25.4%	220
60-69	14.8%	128
70-79	4.2%	36
80-89	0.2%	2
90+	0.2%	2

4. In which part of the UK do you live?		
answered question		849
East Midlands (Derbyshire, Leicestershire, Nottinghamshire, Northamptonshire, Rutland)	6.2%	53
East of England (Bedfordshire, Cambridge, Essex, Hertfordshire, Norfolk, Suffolk)	10.5%	89
Greater London	9.4%	80
North East (County Durham, Northumberland, Teeside, Tyne & Wear)	4.1%	35
North West (Cumbria, Lancashire, Greater Manchester, Cheshire, Merseyside)	13.4%	114
South East (Berkshire, Buckinghamshire, Hampshire, Isle of Wight, Kent, Oxfordshire, Surrey, Sussex)	21.7%	184
South West (Bristol, Cornwall, Devon, Dorset, Gloucestershire, Somerset, Wiltshire)	11.1%	94
West Midlands (Birmingham and West Midlands, Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire)	6.0%	51
Yorkshire and the Humber (North Yorkshire, West Yorkshire, South Yorkshire, East Riding and Humberside)	7.9%	67
Northern Ireland	2.4%	20
Scotland	5.3%	45
Wales	2.0%	17

5. What type of neurological condition do you / the person you care for have?		
answered question		876
Alzheimer's	0.1%	1
Ataxia	1.1%	10
Acquired brain injury	6.1%	53
Acquired spinal injury	0.2%	2
Batten disease	0.2%	2
Brain tumour	1.5%	13
Cavernoma	9.8%	86
Charcot-Marie-Tooth disease	0.2%	2
Chronic pain	6.8%	60
Dystonia	9.2%	81
Encephalitis	0.8%	7
Epilepsy	17.9%	157
Fibromyalgia	6.4%	56
Guillain-Barre syndrome	0.5%	4
Hemiplegia	0.3%	3
Huntington's Disease	1.7%	15
Meningitis	0.2%	2
Migraine	8.2%	72
Motor neurone disease	0.1%	1
Multiple sclerosis	11.4%	100
Multiple system atrophy	4.1%	36
Muscular dystrophy	0.3%	3
Myalgic encephalomyelitis (ME)	16.9%	148
Myasthenia gravis	0.3%	3
Parkinson's disease	6.2%	54
Polio	0.1%	1
Progressive supranuclear palsy	1.6%	14
Stroke	1.9%	17
Syringomyelia	0.3%	3
Tourette's	0.5%	4
Transverse myelitis	3.1%	27
Tremor	2.4%	21
Trigeminal neuralgia	1.1%	10
Tuberous sclerosis	0.0%	0
Other	11.1%	97

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

answered question		859
Less than two	32.6%	280
Between two and five	45.3%	389
Between six and ten	14.4%	124
More than ten	7.7%	66

7. Which of the following health / social care professionals do you / the person you care for come into contact with to help manage your / their condition?

answered question		854
Assistive technology team	1.8%	15
Care home staff	3.0%	26
Carer	14.3%	122
Counsellor	6.8%	58
Dietician	5.3%	45
District nurse	8.3%	71
GP	78.1%	667
Hospital consultant e.g neurologist, surgeon, psychiatrist	72.7%	621
Occupational therapist	18.9%	161
Social worker	8.4%	72
Specialist nurse	24.9%	213
Speech and language therapist	9.1%	78
Palliative care team	1.9%	16
Pharmacist	21.5%	184
Physiotherapist	22.8%	195
Psychologist	10.8%	92
Wheelchair/mobility aids specialist	11.0%	94
Other	9.3%	79

8. Do you feel that the different people treating and caring for you / the person you care for (such as GP, hospital doctors, hospital nurses, specialist nurses) work well together to give you the best possible care, and are well co-ordinated?

answered question		865
Yes, always	9.4%	81
Yes, most of the time	20.9%	181
Yes, some of the time	36.9%	319
No, never	27.2%	235
Don't know	5.7%	49

9. Have you / the person you care for been offered a written care assessment and care plan which sets out the different aspects of care that are involved in managing your condition?

answered question		859
Yes	12.3%	106
No	80.9%	695
Don't know / can't remember	6.8%	58

10. Have you / the person you care for experienced any problems or delays in accessing services or treatment to help manage your / their condition?

answered question		849
Yes	61.0%	518
No	28.0%	238
Don't know	11.0%	93

11. Have you / the person you care for ever been offered the opportunity to take part in a clinical / research study?

answered question		859
Yes	21.1%	181
No	75.7%	650
Don't know	3.3%	28

12. If there could be one priority for health and social care services for people with neurological conditions in your area, what would it be? For example, improved out of hours care or better co-ordination between health and social care services.

answered question		779
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Annex 2: Attendees at roundtable discussion

Dr David Bateman, National Clinical Director for Neurological Conditions, NHS England
Mike Birtwistle, Managing Director, MHP Health
Dr Beverley Castleton, Consultant Physician, Geriatric Medicine
Amanda Cheesley, Long Term Conditions Advisor, Royal College of Nursing
Caroline Dollery, Clinical Director, East of England Strategic Clinical Network for Mental Health, Neurology and Learning Disability
Phil Gray, Chief Executive, Chartered Society of Physiotherapy
Caroline Hacker, Head of Policy and Service Improvement, Parkinson's UK
Rachel Harrison, Vice Chair, Hampshire Neurological Alliance
Pat Haye, Deputy Director Clinical Senates and Clinical Networks, NHS England
Dr John Hughes, Medical Director, Sue Ryder
Joanna Knott, Minutes Secretary, West Berkshire Neurological Alliance
Nick Losseff, Clinical Director, London Neuroscience Network
Dr Wojtek Rakowicz, Council Member, Association of British Neurologists
Charles Rendell, Commissioning Consultant, Neurological Commissioning Support
Dr Greg Rogers, Clinical Champion for Epilepsy, Royal College of General Practitioners
Jonathon Sheppard, Consultant, MHP Health
Angus Sommerville, Chief Executive, Royal Hospital for Neurodisability
Amanda Swain, Trustee and Executive Member, UKABIF
David Walter, National Healthcare Partnership Manager, UCB
Dr David White, Board Member, Cavernoma Alliance
Arlene Wilkie, Chief Executive, Neurological Alliance
Emily Wooster, SCN Sub-Group Chair, Neurological Alliance

Annex 3: Overview of existing NICE guidance relating to neurological conditions

1. Overview

Total number of NICE Quality Standards to be developed by 2019:	177
Total published as of 10.09.13:	44
Number in development as of 10.09.13:	39
Number not yet published or in development:	94

2. Summary of neurological NICE Quality Standards by condition

Quality Standard	Publication date	Review date
Dementia	June 2010	June 2015
Stroke	June 2010	June 2015
Supporting people to live well with dementia	February 2013	February 2018
The epilepsies in adults	February 2013	February 2018
The epilepsies in children and young people	February 2013	February 2018
Headaches in young people and adults	August 2013	August 2018
Autism (children, young people and adults)	January 2014	tbc
Faecal incontinence	February 2014	tbc
Head injury	tbc	tbc
Multiple sclerosis	tbc	tbc
Parkinson's disease	tbc	tbc
Delirium	tbc	tbc
Management of transient loss of consciousness in adults	tbc	tbc
Motor neurone disease	tbc	tbc
Neurological problems (relatively uncommon neurological problems e.g. muscular dystrophy)	tbc	tbc

3. Summary of neurological NICE clinical guidelines by condition

NICE clinical guideline	Publication date	Review date
Head injury	2003	New guideline due Jan 2014
Multiple sclerosis	November 2003	New guideline due in 2014
Brain tumours	June 2006	tbc
Parkinson's disease	June 2006	tbc
Dementia	November 2006	tbc
Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy)	November 2003	tbc
Bacterial meningitis and meningococcal septicaemia	June 2010	tbc
Epilepsy (adults and children)	January 2012	tbc
Autism in adults	June 2012	tbc
Autism in children and young people	June 2012	tbc
Stroke	July 2008	tbc
Stroke rehabilitation	June 2013	tbc
Management of autism in children and young people	August 2013	tbc
Headaches	September 2013	tbc
Neuropathic pain - pharmacological management	October 2013	tbc
Spinal injury assessment	May 2015	tbc
Motor neurone disease	tbc but in development	tbc

Annex 4: Neurological Alliance members

Members	
Action Duchenne	www.actionduchenne.org
Action for Dystonia, Diagnosis, Education and Research	www.actionfordystonia.co.uk
Action for M.E.	www.actionforme.org.uk
Ataxia -Telangiectasia Society	www.atsociety.org.uk
Ataxia UK	www.ataxia.org.uk
Batten Disease Family Association	www.bdfa-uk.org.uk
Brain and Spine Foundation	www.brainandspine.org.uk
Brain Research Trust	www.brt.org.uk
Brain Tumour UK	www.braintumouruk.org.uk
British Acoustic Neuroma Association	www.bana-uk.com
The Ann Conroy Trust	www.annconroytrust.org.uk/
Cavernoma Alliance	www.cavernoma.org.uk
CMT United Kingdom	www.cmt.org.uk
Different Strokes	www.differentstrokes.co.uk
Epilepsy Action	www.epilepsy.org.uk
Epilepsy Bereaved	www.sudep.org
Epilepsy Society	www.epilepsysociety.org.uk
FibroAction	www.fibroaction.org
Fighting Strokes	www.fightingstrokes.org
Guillain-Barré Syndrome Support Group	www.gbs.org.uk
Headway	www.headway.org.uk
Hemihelp	www.hemihelp.org.uk
Joint Epilepsy Council of the UK and Ireland	www.jointepilepsycouncil.org.uk
Motor Neurone Disease Association	www.mndassociation.org
Multiple Sclerosis Society	www.mssociety.org.uk
Multiple Sclerosis Trust	www.mstrust.org.uk
Multiple System Atrophy Trust	www.msatrust.org.uk
Myasthenia Gravis Association	www.mgauk.org
National ME Centre	www.nmec.org.uk
National Tremor Foundation	www.tremor.org.uk
Neurosupport	www.neurosupport.org.uk
Pain Concern	www.painconcern.org.uk
Parkinson's UK	www.parkinsons.org.uk
Polio Survivors Network	www.poliosurvivorsnetwork.org.uk
Royal Hospital for Neuro-disability	www.rhn.org.uk
Sue Ryder	www.sueryder.org
The British Polio Fellowship	www.britishpolio.org.uk
The Cure Parkinson's Trust	www.cureparkinsons.org.uk
The Dystonia Society	www.dystonia.org.uk

The Migraine Trust	www.migrainetrust.org
The Nerve Centre Kirklees	www.thenervecentrekirklees.org.uk
The PSP Association	www.pspeur.org
The Stroke Association	www.stroke.org.uk
The Tuberous Sclerosis Association	www.tuberous-sclerosis.org
Tourettes Action	www.tourettes-action.org.uk
Tranverse Myelitis Society	www.myelitis.org.uk
Trigeminal Neuralgia Association UK	www.tna.org.uk
UK Acquired Brain Injury Forum	www.ukabif.org.uk

Associates	
Association of British Neurologists	www.theabn.org
British Paediatric Neurology Association	www.bpna.org.uk
Chartered Society of Physiotherapists	www.csp.org.uk
Forward M.E.	www.forward-me.org.uk
The Encephalitis Society	www.encephalitis.info
The National Hospital for Neurology and Neurosurgery Development Foundation	www.nationalbrainappeal.org
The Stoke Mandeville Spinal Foundation	www.smsf.org.uk
Glenside Manor	www.glensidemanor.co.uk
Independent Healthcare Advisory Services	www.independenthealthcare.org.uk
PJ Care Limited	www.pjcare.co.uk
South West Alliance of Neurological Organisations	www.swano.org
Yorkshire and Humberside Association of Neurological Organisations	www.yhano.org.uk

Regional Neurological Alliances	
Black Country Neurological Alliance	-
Buckinghamshire Association of Neurological Organisations	www.bucksvoice.net/bano
Cornwall Alliance of Neuro-Domain Organisations	www.candoweb.org
Gloucestershire Neurological Alliance	www.glosna.org.uk
Greater Manchester Neurological Alliance	www.gmneuro.org.uk
Hampshire Neurological Alliance	www.hantsneuroalliance.hampshire.org.uk
Hounslow and Richmond Neurological Partnership	-
Lancashire and South Cumbria Neurological Alliance	www.lascna.co.uk
Lincolnshire Neurological Alliance	www.lincolnshire-neurological-alliance.org.uk
Merseyside and Cheshire Neurological Alliance	www.neurosupport.org.uk
Northern Neurological Alliance	www.na-na.org.uk
Oxfordshire Neurological Alliance	www.oxna.org.uk
Swindon and Wiltshire Neurological Alliance	www.swna.org.uk
Tees Valley, Durham, and North Yorkshire Neurological Alliance	www.na-tvdny.org.uk
West Berkshire Neurological Alliance	www.wbna.org.uk

About us

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

Contact us

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