

Neurological Commissioning Support



Supporting local commissioners
to get the right services in the right place
at the right time for neurology

Dr Paul Zollinger-Read, Director of GP commissioning NHS East of England and medical adviser at The King's Fund says:

'Through commissioning we must strive to improve the outcomes of care that our patients receive. Two of the mechanisms to achieve this are clinically-led commissioning and involving patients in decisions about their care. However, to achieve these ambitions requires a fundamentally different approach to commissioning; one that unlocks the power of patient experience and knowledge.

One of the exciting opportunities that the current reforms provide is to involve those who know best about care to help commission that care. NCS has a deep understanding of patient need which it has demonstrated through experience and delivery. This knowledge and involvement of patients in the commissioning process has enabled them to increase the value of local services. Value encompasses quality, cost effectiveness and improved patient experience; these are the three pillars that commissioners must base their plans on.

How do we truly involve patients in decisions about their care? This is an immensely important challenge as we know that involvement not only delivers better outcomes for patients but is highly efficient in terms of the use of resources. NCS have demonstrated a clear ability to rise to this challenge and this has been shown through many of their local projects outlined in this document. In the words of Don Berwick, "If we continue to do things the way we always have, we will have the same results". Commissioning needs to rise to the challenge of improving patient outcomes in a resource-tight environment. Involvement of groups such as NCS is crucial to that success.'

Getting to Grips with Neurology Commissioning Support for Clinical Commissioning Groups

In the midst of the current reform of the NHS, and with commissioning practice for both health and social care being revolutionised, it has never been more important to centre commissioning decisions around value, both financial value and the values service users place on the health and social care services they receive. It is all too easy to overlook the understanding and insight that those affected by a long-term neurological condition can add to the commissioning process, particularly in light of the financial savings that must be made at present.

Formed by three leading neurological charities, Neurological Commissioning Support (NCS) combines the experience each has of working in service development, alongside expertise in neurology and a proven history of working effectively with those affected by a long-term neurological condition (LTNC).

The Department of Health's Innovation, Excellence and Service Development Fund has awarded NCS a three year grant to work with Clinical Commissioning Groups (CCGs) in England between 2011 and 2013. Each year will see DH-supported projects developing in new areas, as well as individual CCGs working with NCS independently.

Our focus with this work is to support clinical commissioners in better understanding how they can provide greater value and increased quality in the planning and delivery of neurology services. As with all of our work, these projects will look to actively involve service users and carers from start to finish.

What we do

Working for the past three years with health and social care commissioners, and understanding their challenges and constraints, NCS is ideally placed to continue this supporting role for CCGs, helping them to understand neurology commissioning, and enabling them to meet the needs of those living with a long-term neurological condition (LTNC).



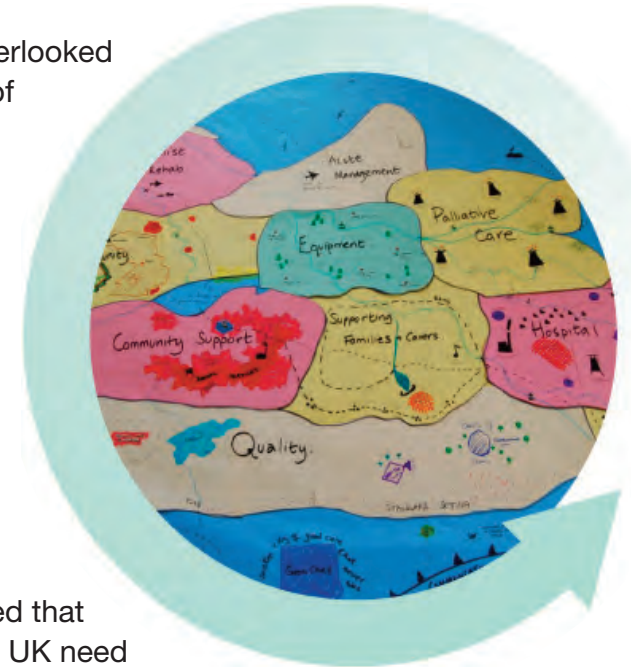
We do this through a range of services:

- Service modelling, strategising and redesign
- Metrics and data analysis
- Unbundling spend
- Engaging and involving service users, carers and stakeholders
- Local network stimulation
- Understanding populations
- Commissioning masterclasses

In addition to these core areas of work, we offer short-term facilitation locally, supporting the first steps of integration and coordinated working. We embrace partnership-working across all sectors as well as across different areas of health and social care. We also offer a range of tools to inform, support, and enable commissioners to get to grips with the needs of their local population, and to meet those needs in a cost-effective yet responsive way, delivering quality services to enable people to remain as independent as possible.

Why Neurology?

Neurology is often overlooked and the implications of doing so are underestimated. Approximately **8 million** people across England, and **10 million** across the UK, have a LTNC, which includes conditions such as multiple sclerosis, Parkinson's, motor neurone disease, and epilepsy. It is estimated that **350,000** people in the UK need help with the activities of daily living because of a neurological condition, and **850,000** people will be acting as a carer.



This map was created by stakeholders showing how services 'feel' at present: Cornwall 16th February 2011

These people, living with a neurological condition, account for **20%** of acute hospital admissions and are the third most common reason for seeing a GP. Neurology also ranks as the **8th** highest cost to the NHS by programme budget spend but with effective informed commissioning, a huge amount of unnecessary spend could be avoided, enabling individuals to have control of their condition, and a better quality of life.

Service modelling, strategising and redesign

'Doing the same thing twice doesn't mean the first time was right'

NCS have a proven track record in modelling the provision of services within an area, identifying innovative solutions for service delivery and implementing them to best effect.

Our 'tried and tested' model of reviewing services is adaptable to any locality, and there are any number of different ways in which we operate. One unchanging aspect of our work, however, is to involve and widely consult with service users, carers, clinicians, social care professionals and other stakeholders. Our aim is always to listen, assimilate what is said, and to facilitate shared visions for outcomes, utilising shared decision-making for short, medium and longer-term activities to achieve those outcomes.

New ways of thinking

Over £4,000,000 was being spent in non-elective admittances for epilepsy in one area. NCS intervention outlined an A&E triage system and ambulance triage to reduce admissions overall.

Maximising service potential

One site was spending £100,000.00 annually on a day case facility that benefited only a small number of people with Acquired Brain Injury. NCS intervention suggested a stratification of patients for severity, designed to target greater numbers with more complex needs, resulting in a greater net benefit.

Metrics and data analysis

'We can't know what we have yet to learn'

NCS understands the huge benefit that data can bring to understanding current performance and areas for improvement for commissioning plans. However, it is important to use data in the right way, drawing on more than one type of data, and examining it alongside qualitative research and lived experience.

Often data can highlight simple, easy changes that can be made which will streamline care pathways and increase quality of life for people as well as saving unnecessary expenditure. It can highlight problems in the wider system, such as coding, or draw attention to a higher than average level of need for a specific group of people. Learning to use it effectively is an essential commissioning skill.

"NCS provided skilled and expert support and became a valued part of the team"

Steve Hams, Former Associate Director of Clinical Change.
NHS Gloucestershire



Neurology Tariffs

Examination of data in various sites has found huge discrepancies between locally negotiated neurology tariffs due to the lack of a national tariff. In one area, 5 different acute providers were contracted at differing rates for first and follow-up consultations. Utilising information of tariff costs³ highlighted that the cost to a PCT for a first neurology consultant outpatient appointment (England) varies from £67.00 to £592.00, (average £249.00 standard deviation £90.00) the cost of a follow-up appointment ranged between £64.00 to £416.00 (average £153.00 standard deviation £56.00).

Awareness of these discrepancies allows contracts to be renegotiated in an informed way, as well as raising competition amongst providers. It allows primary care commissioners to re-evaluate the services being received for the amount agreed, and to use this to ensure that the best financial value for patients is being achieved.

NCS utilise data from Dr Foster Intelligence which, combined with local HES and SUS data, and qualitative data from our own service audit tool, 'Quality Neurology', allows us a clear and rounded picture of localised services to work from.



Quality Neurology is an audit and evaluation tool designed by the MS Society, Parkinson's UK, MND Association and Ataxia UK. It measures how the health and social care services in any given area meet the needs of people affected by a long term neurological condition against the Quality Requirements of the National Service Framework (NSF) for LTNC.

Following analysis, the two aspects of the tool give services an evidenced 'score' from consensus agreement by professionals, and qualitative feedback from service users and carers, and provide an overall service picture from which recommendations can be given.

In 2010 we used the tool to conduct a mid-point review of the NSF for Long Term Neurological Conditions⁴, which can be found on our website.



³Morrish P, What is happening to English neurology: an update. Clinical Medicine 1101:3-4 (Royal College of Physicians London), 2010

⁴Halfway through: are we halfway there? A midpoint review of the National Service Framework for Long Term Conditions', (NCS:London), 2010

Unbundling spend to highlight cost-savings

'You can't save money you don't know you're spending'

Finding out the true cost of any service, piece of equipment or dose of medication has always been a hard task for commissioners. Using our Neuronavigator tool, NCS are able to identify costs for MS, MND and Parkinson's.

Maximising service potential

One area had high SARs (Standardised Admission/Attendance Ratios) of £4,500,000 for non elective admitted tariff for Parkinson's disease, mainly for urinary tract and respiratory infections, and falls. NCS intervention introduced a triage system to residential care homes which dramatically reduced admissions within 3 months.

neuronavigator is a unique web-based tool designed to help commissioners understand the complexity of support, services, and associated costs, that are needed by those living with MS, Parkinson's and MND. It provides an overall 'neurology' budget based on the needs of people affected by these three conditions within any defined population size.

Funded by BUPA Giving, Neuronavigator is based on the 'Year of Care' concept (describing the ongoing support and services that a person should receive, looking at a cyclical picture as opposed to a linear care pathway), breaking down conditions into phases.

The tool, populated with national data and informed by consensus expert opinion, can be used in myriad ways, from simply understanding what services for your population should look like from a best-practice viewpoint, to trialling alternative and innovative service delivery models and comparing the financial implications. The fully referenced tool contains best practice and cost-saving, quality-increasing suggestions, as well as flagging adherence to policy such as NICE and opening the door to new ways of providing the right services in the right place at the right time.



Early intervention prevents crisis – and saves money

Two people with MND were admitted to an Intensive Care Unit for ventilation via A&E following respiratory crisis. This unplanned emergency care cost £45,000.00 per month for the ICU admission alone. NCS has outlined how, with respiratory assessment and intervention to prevent crisis, using reusable, non-invasive ventilation (NIPPV), the cost of earlier intervention could have been only £12,000.00 – £44,000.00 per month less than the ICU. This equates to a saving of £528,000.00 per annum – for one person.

Engaging and involving service users and carers

‘People who don’t just know it, but live it daily – these are the real experts’

At NCS, we believe that people who are affected by a long-term neurological condition, living with the implications of that daily, are true experts in their needs and in the best ways to manage their condition, and as such should be at the heart of the commissioning process. We have found that giving service users choice and control over their own treatments and consulting them in decision making leads to improved outcomes.

Involvement of service users and carers in work around end of life in Bath and Northeast Somerset resulted in empowerment to individuals, training to local staff, and what one service user referred to as ‘breaking the taboo of death’ locally.

“It felt good to share my views... to be listened to”

A person living with MS,
speaking about an NCS focus group on end of life care

Message in a Bottle

In one area, a higher than expected number of people with MND were being admitted to hospital in the last 2 days of their life, and dying there. A ‘Message in a Bottle’ intervention for ambulance crews detailed patients’ preferred place to die and resulted in the launch of Advanced Decisions documentation across the whole area, which has reduced hospital deaths.

IV steroid treatment at home

Treating people living with MS for a relapse by administering intravenous steroids at home, as opposed to within a day care hospital setting, delivers an average cost saving of £1,797.00 per patient. Studies have proved home delivery to be superior to the outpatient experience, safer to administer and cheaper. Key findings include better coordination of care, more convenient and timely treatment, and improved mental wellness of people living with MS, who found the calmness of their home environment comforting and reassuring⁵.

In NHS Gloucestershire, a full-scale review of neurological services, encompassing MS, Parkinson’s and MND actively involved people across a multitude of professions, sectors, and lived experiences.

Throughout the review, in addition to the consultation of over 1,300 service users and carers, a user and carer Reference Group worked in direct partnership with the Steering Group, chaired by the commissioner. This group has set itself up as a Regional Neurological Alliance, to continue to support and influence service development locally.

“I was elated with the work done and really appreciate NCS’ valuable input in getting the Gloucestershire Neurological Alliance running.”

Glyn Price, Interim Chair,
Gloucestershire Neurological Alliance

⁵ Porter, B; Matheson, F and Chataway, J (2007), p40, ‘Key steps to delivery of a person centred relapse service’, The National. Hospital for Neurology and Neurosurgery and the Multiple Sclerosis Trust

Local network stimulation

'None of us is as smart as all of us'

Across the projects NCS has participated in, we have learned that more is achieved when people are encouraged to work together, share information and peer review. Our work in assisting the formation and maintenance of neurology networks ensures that all parties have a voice and that decisions made about service changes are representative.



To involve all necessary stakeholders – service users, carers, clinicians across primary, secondary and tertiary care, commissioners, members of adult social care, the pharmaceutical industry – is often so much easier to say than to do. However, we believe that only through creating strong local networks, sharing understanding and expertise, and each bringing their own specialisms, can clear visions be made, and more powerful outcomes achieved.

Development, or support and inclusion, of existing clinical networks for neurology is essential. NCS's founding organisations all have locally-based service development staff, many of whom are strongly involved in local networks, and are often instrumental in supporting wider engagement.

Team working to gain a fuller understanding

In Surrey, NCS have been supporting adult social care and the NHS to work together to understand their current services, the needs of their population, the implications for it in the future, and to gain control over their planning to deliver better outcomes for service users and their carers going forward.

Public Health has supported the gathering and interpretation of data, whilst the use of our audit tool and support from the wider voluntary sector has seen service user and carer engagement. This has allowed us to gain a clear picture of services from both a user and clinical viewpoint, and to involve any personally-held data that individuals may have gathered. The wide range of information gathered allowed for a detailed Joint Strategic Needs Assessment, and the use of NCS's Neuronavigator budgeting tool supported financial planning and implications for the future, and enabled the creation of detailed business plans.



Additionally, owing to the support of pharmaceutical partners both financially and in local staff time, neurology clinical networks are being set up to better inform and advise the ongoing commissioning process.

David Colin Thomé, former National Clinical Director for Primary Care, Department of Health, says:

'I see the changes to the NHS as an opportunity for the growth of new local partnerships and networks to deliver better services, and NCS can play a strong role in these partnerships, bringing clarity to the neurological commissioning process.'

I have had the pleasure of seeing NCS grow in experience and understanding, and noted the successful outcomes they have brought in localised projects. I have every confidence that they, as a not-for-profit organisation with pedigree in the delivery of quality outcomes, are excellently positioned to aid commissioners in the allocation of resources to achieve both better value and better care.'

Understanding populations

'You can't plan to support people if you don't know they're there'

Understanding your population is essential, and there is a wealth of information and data surrounding population management at your disposal – but it means nothing if you do not then translate this information into what the needs of the population are. Coupling national and local data with lived experiences, analysing services with a consideration for the varying needs of your population, means informed planning to create quality services to benefit the local population.

The Cornwall Alliance of Neural-Domain Organisations (CAN-DO), a volunteer patient/carer led organisational, in partnership with Cornwall and Isles of Scilly PCT and Local Authority, commissioned NCS to support them in reviewing the neurological services across the county and to recommend areas for improvement.

Our engagement of people locally had to be tailored to the area. Over 12 focus groups were run due to the rurality of the county, including 2 groups on the Isles of Scilly. Social networking sites and local press were used, in addition to surveys, telephone discussions, letters, emails, one-to-one interviews, and stakeholder meetings.

Using a shared decision-making process, the priorities for action were developed and services redesigned. The geography of the area, the placement of professional staff, and the needs of the population were all combined in creating an action plan. Key outcomes such as equality of access to services, coordination and integration of care, and clear access to information and support being among the top priorities.

Actions have included a 'one stop shop' for advice from two newly appointed neurology care advisers to streamline support, a NeuroResponse telecare service for people with MS utilising video support for patients and advice for GPs, and a MyClinic swipe IT neurology support service for those living in rural areas. Programmes empowering people to set up their own local exercise classes for maintenance exercise, and the outline of health and social care Hubs to further communication between professionals are longer-term goals.

"NCS provided both superb administration and also, due to NCS staffs' experiences of working at the 'front-line', a real understanding of the issues for patients. Their approach was dynamic and, when the Health Authority adopts the recommendations, I'm sure we will see both economic and efficiency improvements... Top marks across the board."

Roger Weatherly. Chair, CAN-DO



Partners & Affiliates

We believe that our work can only be successful when we go beyond the traditional parameters of commissioning. We embrace partnership and believe it to be an incredibly powerful tool for change, facilitating communication between the various aspects of health care, between health and social care, and between statutory and other bodies.



Our affiliate scheme allows for other voluntary organisations to add their expertise and support to commissioning groups, and to partner on key pieces of work. Additionally, our 'Pharmaceutical Neurological Partnership' or 'PNP' exchanges mutual support with industry and seeks partnership opportunities from them locally whilst providing commissioning and policy updates and workshops, and offering mutually beneficial secondments.

The Department of Health has provided funding to NCS through the 'providing better value' project, which aims to put service users and carers at the heart of neurology commissioning.

Our Founding Organisations

The MS Society

The MS Society is the UK's largest charity for people affected by multiple sclerosis (MS) - about 100,000 people in the UK.

www.mssociety.org.uk

The Motor Neurone Disease (MND) Association

The MND Association is the only national charity in England, Wales and Northern Ireland that funds and promotes global research into the disease and provides support for people affected by MND.

www.mndassociation.org

Parkinson's UK

Parkinson's UK is a Parkinson's support and research charity that has been working to find a cure and improve life for everyone affected by Parkinson's for over 40 years.

www.parkinsons.org.uk

Affiliate Partner

Epilepsy Society

Epilepsy Society is the leading national epilepsy medical charity working for everyone affected by epilepsy, through cutting edge research, awareness campaigns and expert care.

www.epilepsysociety.org.uk



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