

Report on specialised neurosciences services and QIPP

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1. Executive summary

This report forms one in a series by the Specialised Healthcare Alliance looking at services prioritised by the National Specialised Commissioning Group in relation to the delivery of quality and productivity at a time of spending constraint, otherwise known as QIPP. It was particularly informed by a stakeholder workshop on specialised neurosciences services organised by the Alliance and the East of England Specialised Commissioning Group in Stansted on 22nd October 2010. A wide range of stakeholders including patients, commissioners, clinicians, other healthcare professionals and representatives from the main patient groups attended the workshop.

The report sets out some background information on QIPP and specialised neuroscience services before seeking to distil the major themes explored during the workshop in relation to diagnosis, commissioning and outcomes, integrating pathways and efficiency.

Among the most important points to emerge, neurology has a particular need for strategic leadership with a view to building consensus around necessary change of the kind seen in London's stroke services. Otherwise, attention is drawn to this report's concluding recommendations and especially:

- The contribution patients can make in helping inform diagnosis and subsequent decisions about treatment and care;
- The need for personal care plans as an essential requirement of integrated care, supported by a nominated keyworker;
- The importance of neuroscience networks as a mechanism to shape services and ensure proper integration within healthcare and between health and social care;
- The importance of registries in benchmarking care and supporting research.

2. Background

2.1 What is "QIPP"?

Quality, Innovation, Productivity and Prevention (QIPP) is the flagship policy being used by the NHS to find the £15-20 billion of savings identified by Sir David Nicholson as necessary in 2011/14 as a result of rapidly rising demand for services and a challenging fiscal climate.¹

The overall aim of the scheme is to combine improvements in quality of care with efficiency savings that can be reinvested in front-line services. Ideally, quality and productivity will go hand-in-hand, providing a better service for the patient, as well as cost savings for the NHS as a whole.²

The National Specialised Commissioning Group (NSCG) has prioritised ten services for taking forward the QIPP agenda, with each Specialised Commissioning Group (SCG) leading on one of the services. In each case, the NSCG has established three main objectives in relation to QIPP as follows:

- Working through the SCG Finance Network, benchmark and demonstrate value for money in the agreed services;

¹ For background on QIPP: The NHS quality, innovation, productivity and prevention challenge: an introduction for clinicians (March 2010), available from [here](#)

² See NHS Improvement's [QIPP site](#) for more background

- Working with the SCG Public Health Network, develop common CQUIN (Commissioning for Quality and Innovation)³ goals for the agreed services;
- Working through the SCG Public Health Network, develop common health outcomes for the agreed services.

The East of England SCG was the lead for specialised neurosciences services. The Specialised Healthcare Alliance worked with SCGs to review these services with the aim of ensuring a balanced discussion between the four strands of QIPP.

QIPP is clearly important in the context of specialised neurosciences services. Given the often high cost and pace of innovation in specialised neuroscience services, the challenge is to retain and increase quality in an environment where there is pressure to deliver significant efficiency gains and savings.

2.2 Specialised neurosciences services

Neurosciences and the National Definitions Set

The clinical neurosciences services have undergone a period of great change. 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. Routine stroke care, including 24 hour access to a stroke specialist, urgent brain imaging (with expert interpretation) and thrombolytic treatment, is not considered a specialised service.

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.⁴

Scale of Neurosciences treatment

The Neurological Alliance estimate that 10 million people in the UK are living with a neurological condition.⁵ Half of neurology outpatient referrals originate in GP practices, but an estimated 30 to 50 per cent of these referrals are inappropriate for specialised care or contain insufficient clinical information to triage patients. An estimated 50 per cent of all referrals are requests for advice on patient management only.⁶

Although there is an endemic problem with over referral, tackling this problem is only part of the solution as the incidence of neurological conditions diagnosed is likely to rise further with demographic changes. Over referral also co-exists with under referral and mis-referral with a recent King's Fund study expressing concern that problems arising from poor

³ The CQUIN payment framework makes a proportion of providers' income conditional on quality and innovation. See [here](#) for more information.

referral management might be exacerbated by the proposed move to GP commissioning.

At present an estimated 350,000 people across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition.⁷

The scale of the problem outlined above means that neurological services are likely to come under pressure to improve efficiency savings, building on the work that is already being done. In addition, the year-on-year growth of the patient population makes these savings, which would be reinvested, essential. At the same time, there are opportunities to drive up the quality of neuroscience services, for example through the agreement of various outcomes to measure quality of care.

Policy framework

Neurological conditions are the central focus of the National Service Framework on Long Term Conditions. Published in 2005 the NSF sets 11 quality requirements which aimed to improve the way health and care services aid people with long-term neurological conditions to live as independently as possible.⁸ These quality requirements are summarised below:

Quality Requirement	Brief description
QR1. A person centred service	People with long term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.
QR2. Early recognition	People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.
QR3. Emergency and acute management	People needing emergency admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.
QR4. Early & specialist rehabilitation	People with long term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation.
QR6. Vocational Rehabilitation	People with long term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

⁴ Specialised Services National Definition Set, Neurosciences. Edition 3, available [here](#).

⁵ Getting the best from neurological services, Neurological Alliance, available [here](#).

⁶ NWSCG Neurosciences report, 2009.

⁷ National Service Framework, Long term conditions, available [here](#).

⁸ National Service Framework, Long term conditions.

QR7. Providing Equipment and accommodation	People with long term neurological conditions are to receive timely, appropriate assistive technology / equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.
QR8. Providing personal care and support	Health and social care work together to provide care and support to enable people with long term neurological conditions to achieve maximum choice about living independently at home.
QR9. Palliative care	People in the later stages of long term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.
QR10. Supporting family and carers	Carers of people with long term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.
QR11. Caring for people with a neurological condition in hospital or other health and social care settings	People with long term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting. ⁹

In December 2009 North West SCG published Analysis of Referrals to Neuroscience Services and Examination of Local Tariffs. The publication investigates the rising service demand and looks for practical actions for the effective use of resources.

In 2006 NICE published guidelines on the diagnosis and management of Parkinson's disease in primary and secondary care settings.¹⁰ NICE also published guidelines for the management of Multiple Sclerosis in 2003.¹¹ An audit by the RCP of the guidelines on MS found poor levels of implementation, particularly in the field of neuro-rehabilitation, while All Party Parliamentary Group reports on Parkinson's and Muscular Dystrophy have found major shortcomings, with life expectancy for the latter more than 50 per cent greater in the North East compared to the South West.

3. Main themes

The workshop combined scene-setting presentations and interactive sessions. The latter aimed to ensure that all those attending had an opportunity to contribute to multi-disciplinary discussion involving clinicians, commissioners, policy makers, patients and their representatives.

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Overall, the workshop was broken down into the following four sessions:

⁹ Neurological Commissioning Support, available [here](#).

¹⁰NICE guidelines for Parkinson's disease available [here](#).

¹¹NICE guidelines for MS available [here](#).

- Diagnosis
- Commissioning and outcomes
- Integrating pathways
- Efficiency

The workgroup sessions were designed to be mutually supportive, and to identify relevant points across the QIPP agenda. For example, improvements in diagnosis and better structured treatment pathways are likely to lead to better health outcomes, higher quality care and improved productivity.

3.1 Diagnosis

Although the importance of early diagnosis has been repeatedly identified as a priority in neurological conditions, a series of presentations showed the sometimes conflicting pressures at work. In particular, neurological conditions were the third most common reason for GP consultations and accounted for a quarter of all hospital medical admissions. Perhaps 50 per cent of such GP consultations concern headaches, with a multiplicity of potential causes. An audit in the North West had concluded that perhaps 30-50 per cent of referrals from GPs to tertiary centres were inappropriate or made with insufficient supporting information to triage patients. For example, Salford Royal NHS Foundation Trust had turned back 85 per cent of referrals for headache in the last year. These pressures were set to grow with an ageing population, intensifying the search for legitimate ways to reduce referrals.

Neurological Commissioning Support was providing support to PCTs and others to improve standards of care and efficiency. As things stood, there was a tenfold difference in outpatient costs across England. No PCTs had yet met a single NSF Quality Requirement and only 13 per cent had met evidence-based quality markers. Neuronavigator was a new commissioning tool enabling, amongst other things, costs to be unbundled for an adult year of care.

The critical importance of GPs in the referral pathway was exemplified by the moving testimony of Norman Starling about his late wife Molly. She had fallen over for no discernible reason and lost control of her left foot. Although Norman had questioned whether there might be a neurological cause such as MS, the GP had referred Molly to a cardiologist. Having been sent back to the GP, Molly had been referred to a podiatrist and then on to a rheumatologist. The rheumatologist ordered an MRI scan prior to her being seen by a spinal surgeon, who referred her to a neurologist, where a diagnosis of Motor Neurone Disease was made – a year after the onset of symptoms and only three months before Molly's death.

Following her diagnosis, Molly did not see another doctor until she lost the ability to swallow. Meanwhile, social services had assessed her position only over the phone and shown very little understanding.

Norman questioned whether Molly's GP had shied away from making a diagnosis because of its gravity. Above all, he regretted that they had not made more had not been made of her remaining months of quality life because of the late diagnosis.

In subsequent discussion, the following points were explored:

- How can GPs be trained to identify patients who need rapid referral?
It was easier to recognise the problem facing GPs in making rapid referrals of the right patient to the right specialty than to resolve it. Attention typically focused on the need for more specialised training but this might not prove realistic in practice given the highly diverse nature of a GP's workload and the small number of rare conditions likely to come before them. A changed mindset making greater use of online diagnostic tools and advice from neurologists might be more productive. This could also extend to the nature of the doctor/patient relationship in making diagnoses – see below.
- Is the current referral pathway the right pathway or does it waste time and money?
The presentations and discussion highlighted the danger of jumping to conclusions about referrals management. There was evidence of patients being referred inappropriately by GPs to tertiary centres. Equally 50 per cent of referrals to centres came from District General Hospitals with extra cost attached, while the sadly far from unique case of Molly Starling demonstrated the huge financial and human costs of multiple, ill-directed referrals. What few seemed to dispute was that for the right patient it made better sense to have a referral pathway direct to a specialist centre, probably as part of a hub and spokes model of care.
- What are the capacity constraints?
The main, well recognised capacity constraint was a shortage of neurologists thought this would be ameliorated by better referrals supported by the requisite information.
- Could informed patients play a more recognised role in the process?
People increasingly had access to high quality information which, allied with direct experience of their own symptoms and personal motivation, put them in a position to inform the process of diagnosis. In the nature of things, such input would not always be well directed but it made sense to bring about a change in attitudes which recognised the patient's potentially constructive role.

3.2 Commissioning and Outcomes

The workshop was briefed on Commissioning for Quality and Innovation (CQUIN) payments as a means of embedding continuous quality improvement across all providers. Clearly, this could have value in supporting clinical and patient outcomes in neurosciences, providing the right CQUIN measures could be identified. The influence of CQUINs might be expected to grow as the percentage of payment (currently 1.5 per cent) dependent on their achievement rose.

In a wide-ranging discussion the desirability of mutually reinforcing outcome measures was noted. For example, the presence of a key worker was important to patients but also tended to enhance standards of clinical care and clinical outcomes. Specific suggestions included:

- Unplanned admissions
The level of unplanned admissions was a good proxy for standards of care and therefore had potential as a CQUIN across specialised neurosciences, with the advantage of allowing more demanding, lower targets from year to year;
- Registries

Registries were an essential component in ensuring access to services, follow-up and ongoing improvement;

- Key workers
Patients found the nomination of a key worker reassuring, improving their experience of care and consequently benefiting outcomes;
- Good care plans
Care plans were still often lacking or perfunctory. They provided an effective way to promote integrated care taking into account co-morbidities and the involvement of social care and other agencies. COQUIN could be helpful in securing more universal uptake;
- Outcome versus process indicators
It was important to distinguish between outcomes and process as in the current White Paper but the latter remained important eg in relation to women on epilepsy drugs taking folic acid;
- Quality of life
There was support for a measure around quality of life but greater uncertainty as to whether this would be achievable in practice.

3.3 Integrating pathways

Neurosciences posed a major challenge in ensuring that patients had prompt access to specialist expertise (eg for diagnosis and key treatment decisions) combined with local services for the majority of care. Rehabilitation and enablement were a crucial part of the care pathway for neurological conditions by decreasing dependence on the health service and potentially delivering savings through alternative pathways. The National Council for Palliative Care had developed care pathways which focused on symptom control.¹²

The advantages of expediting access to the latest specialist care were exemplified by the recent changes to London's stroke services. These had been triggered in particular by the Sentinel Stroke Audit, which had shown that London's services were poor and with little sign of improvement. Furthermore, the greatest availability and need for services had been at odds in Inner and Outer London respectively.

A combination of strategic leadership and clinical support for change had helped forge agreement around the introduction of eight hyper-acute stroke units (HASUs), accessible within a maximum of thirty minutes across the capital and operating as part of wider networks, including local stroke units and community rehabilitation services. The early results showed a dramatic improvement in clinical outcomes (eg a fall in 30 day in-hospital mortality from 13.4% to 6% at the UCLH HASU) allied with a significant reduction in average length of stay (17 to 11 days) and a higher than expected level of discharges direct from HASUs to patients' homes (35% versus 20%).

Apart from London's unusual concentration of Academic Health Science Centres, other important factors in bringing about successful change had been use of cardiac and stroke networks, collaboration, especially with social care, measurement along the whole patient pathway and dissemination of good practice.

Discussion was focused on identifying the strongest ideas for improving integration of neurosciences care more generally, as follows:

¹² [National Centre for Palliative Care](#), available [here](#).

- What are the best ways to ensure fully integrated care pathways and speedy access to rehabilitative care?

The creation of a multidisciplinary neuroscience networks across the country was seen as the best way of promoting and sustaining the integrated care, including social care. There was also interest in professionals working at different points along the care pathway, maybe on a rotational basis, to help break down silos;

- How do we ensure that individuals with complex needs have sufficient and well coordinated care?

There was strong support for every patient to have a care plan and a nominated keyworker, appropriate to their needs. For example, this might be a specialist nurse in many cases or a consultant for someone on complex drug therapy. Parkinsons UK had data on the cost effectiveness of this approach;

- Is the current configuration of providers optimal as between super centres for key diagnostic and treatment decisions and ongoing care at local level?

In conjunction with the development of networks, opinion favoured a hub and spokes model for diagnosis, treatment and care. This would require greater than usual collaboration between spokes pending more uniform levels of expertise.

3.4 Efficiency

The impact of demographic change underlined the importance of achieving greater efficiency in neurosciences. It would, however, be important to avoid unintended consequences. For example, the North West SCG had estimated that a 10 per cent reduction in GP referrals would save £1.5 million pa. Equally, the King's Fund had remarked on the prevalence of under-referral and mistaken referral, either to the wrong specialty or with inadequate supporting information to support a diagnosis.

In seeking to improve efficiency, it might be more productive to concentrate on helping GPs make accurate referrals in neurology rather than expecting them to be conversant in what are often rare conditions. This might be assisted by a defined opportunity for patients who wished to share their own thinking about diagnosis, which would be consistent with greater patient involvement in decisions about treatment and the delivery of care.

GPs might also be assisted by greater use of the phone and email to seek advice from neurologists prior to a referral. The absence of any mechanism for payment presently militated against such communication, except between professional acquaintances.

As exemplified in the case of London's stroke services, the tendency in tertiary care was towards a smaller number of larger neuroscience centres. The advent of more elective care in areas such as neuro-oncology had led to significant reductions in length of stay. There was a concomitant need to split tariffs between acute care and rehabilitation eg for brain injury.

In seeking to develop proposals which would deliver better quality of care at an unchanged or lower price, the interface between hospital and home attracted overwhelming attention. Variations on a theme included mobile rehab teams operating out of hospitals and specialist teams going out of hospitals to prevent emergency

admissions. However achieved, better transition from hospital to home was seen as essential, with the full involvement of social services.

3.5 Recommendations

In the light of the workshop, the following recommendations are made:

- The contribution patients can make in helping inform diagnosis and subsequent decisions about treatment and care should be recognised and enlisted;
- Referral direct to an expert centre needs to be available for appropriate patients to speed diagnosis and spare patients from prolonged limbo;
- Personal care plans should be universally introduced as an essential requirement of integrated care, supported by a nominated keyworker;
- Multidisciplinary neuroscience networks should be developed across the country to shape services and ensure proper integration within healthcare and between health and social care;
- The hub and spokes model has the potential to expedite key decisions about diagnosis and care, consistent with most delivery at a local level;
- Registries should be more widely used to benchmark care and support research.