North East
Neurosciences
Network

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Dear Jon

North East Neurosciences Network Report to Middlesbrough Health Scrutiny Panel

Many thanks for asking me to report on the work of the NE Neurosciences Network to the Scrutiny Panel.

This is the first time that any Scrutiny Panel in the North East has considered neurosciences services and I hope that out of this review will come a sustained partnership with the incoming Health and Well Being Boards.

In this report I have outlined the history of the work of the Network and some of the achievements and challenges we still face. This is a complex area of work, covering many conditions and different life experiences for patients. Included within our work are some extremely rare diseases such as neurofibromatosis to the more common multiple sclerosis. What each person requires though is an appropriate, timely and personal care pathway to enable them to achieve their best outcomes.

Neurosciences services have traditionally been lacking in the kind of investment seen in other areas. In particular, specialist and life long rehabilitation provision has not seen the same investment as that in the Newcastle area.

Much work remains to be done, for example, contracts for step-forward provision are still needed and there are major imperatives to ensure that the South Tees Hospitals NHS Foundation Trust retains and is supported to sustain its full trauma centre services and all major specialties.

I look forward to meeting members on 24th August, but if you require further information please let me know.

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Introduction. Background to neurosciences services.

Introduction. Background to clinical neurosciences services. [1]

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 the definition of a 'specialist' service. Definitions are to be found in the appendices. 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 these 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. In the North East, specialist services are commissioned by the NE Specialist Commissioning team, together with out-patient clinics. Community provision and long term rehabilitation are currently commissioned by PCTs.

Scale of Neurosciences treatment

The Neurological Alliance estimate that 10 million people in the UK are living with a neurological condition.[2] Half of neurology outpatient referrals originate in GP practices, but an estimated 30 to50 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. Although there is a perception of a 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 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.[3] 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 should 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.

Integrating pathways

Neurosciences poses a major challenge in ensuring that patients have prompt access to specialist expertise (e.g. for diagnosis and key treatment decisions) combined with local services for the majority of their care. Rehabilitation and enablement are 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, for example, have developed care pathways which focus on symptom control.

In 2006 NICE published guidelines on the diagnosis and management of Parkinson's disease in primary and secondary care settings. NICE also published guidelines for the management of Multiple Sclerosis in

[1] http://www.shca.info/PDF%20files/Final%20Neurosciences%20Services%20and%20QIPP%20report.pdf Report on specialised neurosciences services and QIPP.
[2] Getting the best from neurological services, Neurological Alliance
[3] National Service Framework, Long term conditions.

2003. 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.

The main provider of neurosciences services for Middlesbrough is the South Tees NHS Hospitals Foundation Trust.

1. The History and Aims of the NE Neurosciences Network [4]

For the past five or six years, the planning & development of Neurological Services has been guided by the National Service Framework for Long-term neurological conditions (NSF LTnC).

The NSF was published in March 2005. It was introduced with no financial allocation or ring-fenced monies, nor any targets for PCTs, provider trusts or GPs. Instead of national targets, the NSF provided quality requirements for the inspection authorities – at that time the Healthcare Commission and the Commission for Social Care Inspection - to use in measuring local progress. This NSF was intended to be used by both patients and professionals.

PCTs in the North East were slow to adopt and implement the NSF and it was not until April 2008 that the NE Neurosciences Network was established under the umbrella of Middlesbrough PCT with a remit to co-ordinate a NE approach. Lynne Barr, well known locally and nationally for her work in rehabilitation, was appointed as the Network leader, on a half time basis, and the remainder of her time was spent as the Long Term Conditions lead for Yorkshire and the Humber at the Department of Health. Because of my long-standing special interest in neurological conditions I was asked by the PCT, on behalf of all the PCT commissioners in the North East, to chair the Network in November 2008 after I retired as chairman of the South Tees NHS Hospitals Trust.

The NSF LTnC focused on the needs of people with neurological conditions and brain or spinal injuries, calling for joint working across all agencies, including providers of transport, housing, employment, education, benefits and pensions, to support people to live independently. It also addressed issues relevant to a wide range of people with long-term conditions and disabilities.

The NSF LTnC set 11 quality requirements to transform the way health and social care services support people with long term conditions to live as independently as possible. (See appendix 1.)

Local NHS and Social Services were responsible for reviewing their services to see if they already met the Quality Requirements in this NSF. They had to get the views of local people with long-term neurological conditions and their families and carers, as well as the views of voluntary organisations and professionals to help them to decide their local priorities for making changes and improvements, to meet the Quality Requirements in full over the ten years. How quickly this would be achieved would depend upon local priorities. The establishment of the Network enabled this to be done across traditional health and social care commissioning boundaries, with individual PCTs taking the lead and sharing their outcomes, to develop a single standard.

The key areas focussed on during implementation were:

a. making progress in delivering each quality requirement;
b. building capacity in staffing, facilities, equipment and range of service providers to ensure access to appropriate services for people with long term neurological conditions;
c. developing a more integrated approach to delivering services with an increase in working with a range of agencies and using joint budgets.

[4] The Network's website can be viewed at http://www.nenp.org.uk/nenn.aspx

The Network was set up with the principle aims through commissioning to:

- Develop agreed standards and support local collaborative developments to meet the Quality Requirements in the National Service Framework for Long-term neurological conditions (NSF LTnC).
- Link service standards and required developments to national and local policy initiatives across the North East of England, the northern third of North Yorkshire (Hambleton, Richmondshire and Ryedale) and North Cumbria. This ensured that patients attending tertiary services either in Newcastle or Middlesbrough were included in the commissioning plans. However, neither Cumbria PCT nor North Yorkshire and York PCT contributed to the running costs of the Network.
- Redesign regional and local services, targeting resources to improve equality of access and standards of service, resulting in sustainable outcomes for users of the services and their carers.
- Develop and enhance resources, knowledge and skills across the North East to improve access to information and standards of care, appropriate rehabilitation and support for users of the service and their carers.

2. The unique features and profile of the Network.

The Network is unique in England as it is the only commissioner-led neuroscience network supported by key agency representatives and Neurological Alliances.

- The membership reflects the stakeholders required to deliver the requirements of the NSF, whilst building 4 separate local forums and appropriate relationships with existing providers to support future commissioning requirements.
- It enlists the support and advice of users of the services, housing and social care commissioners and, through each local forum, local clinicians.
- The Network has been highly regarded by the Department of Health Long Term Conditions Team and features in department promotional material as offering best practice in Commissioning.[5]
- The strength of the Network reflects the members' contributions and expertise as well as key relationships with other major work streams like the stroke strategy, to align the direction and effort with other major endeavours and to avoid duplication of work.

i. The profile of the Network was further developed during years one and two by regular attendance at the NE NHS Director of Commissioning meetings quarterly, where the Network was recognized for:

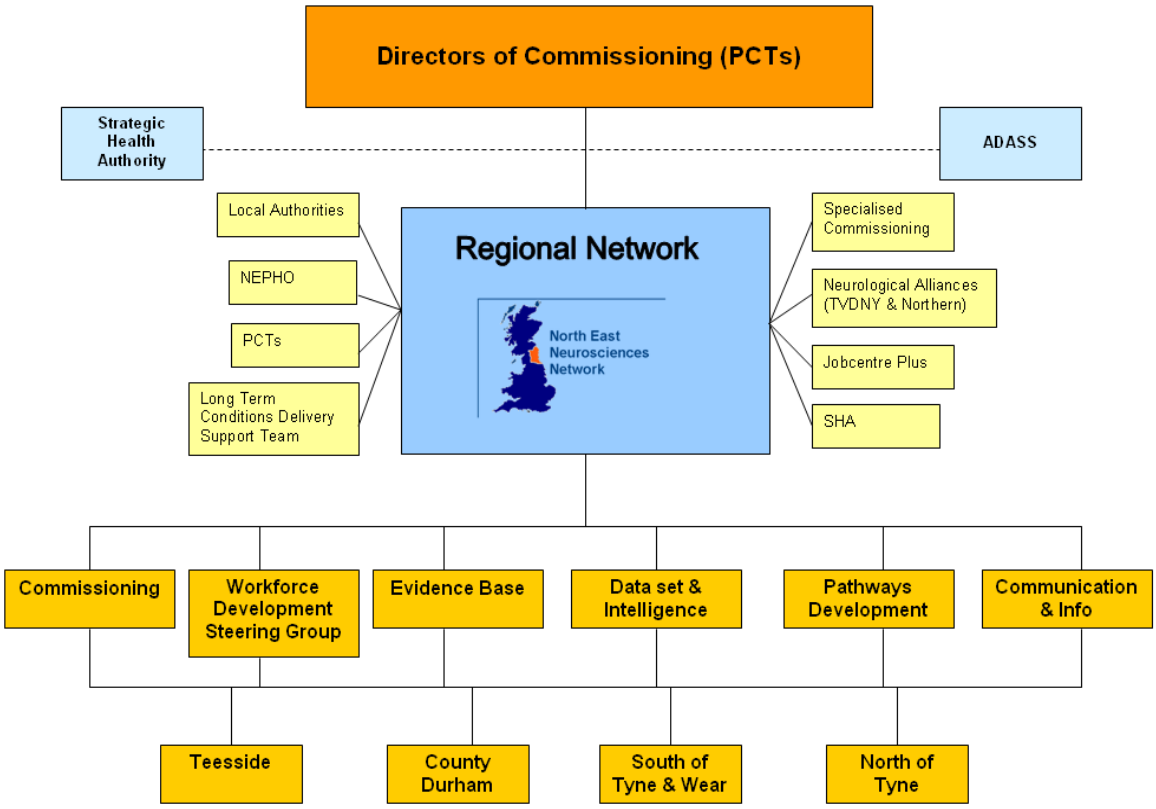
- Uniqueness of the commissioning approach
- Value for money and effectiveness
- Recognising the need for infrastructure at a community level, access to support and continuity

ii. Furthermore, its National Profile was enhanced by:

- Regional workforce development recognition and publicity
- Network representatives presenting at LTnC conferences in London and the National OT Conference together with presentations for other SHAs.
- National long term conditions delivery support team: including the north east development as best practice
- Representatives from DH attending and supporting Network events locally

[5] The Department of Health LTC team was disbanded in March 2011

- Recognition by the SHA in its Health and Social Care Awards for excellence in commissioning (October 2010)
- Retention and commitment of an independent chair person, adding value of her external network and commitment to this role



The structure of the Neurosciences Network

The Network is a commissioner-led group with a 5 Year Commissioning Strategy. It does not however commission any services directly. Through the joint strategy local PCT commissioners develop their community services, whilst the in-patient and acute outpatient services are commissioned by the NE Specialised Commissioning Team (NESCT).

The Network achieves strong representation of the views of patients and the neurological charities by the membership of both Neurological Alliances covering the whole of the NE. The Tees Valley Durham and North Yorkshire Alliance (TVDNY) has been in place since I started it in 2004 and for some years it has been a registered charity. It has had constant support from Middlesbrough Council with Phil Dyson being one of its Trustees. Since his retirement he has taken over as chairman of the Alliance.

The Northern Alliance is of more recent development, but it too has now gained charitable status. Both organisations play a key part in the development of neurosciences but are dependent upon external strategic funding which has become harder to find in the current climate.

The Network also has the following sub groups that report directly to its board:

2a. Joint Commissioning

Building on the significant working relationship developed between the Network and the regional disability group, in year one a joint commissioning strategy across the region was developed:

- Linking the Neurosciences agenda and local implementation through physical disability strategies in Local Authorities.
- Support for the development of a Regional workforce plan to include social workers, working towards accreditation in disability (neurosciences) and working towards the establishment of appropriate specialist posts/skills across viable geographical areas.
- Local Authorities to have representatives from several/all Local Authorities for Dataset Group and membership of PHINE (Public Health Information North East) to establish a Regional informatics group/exchange network for neurosciences.
- Information for people living with Neurological Conditions, provided by the two Neurological Alliances and delivered directly through local information services provided by the Local Authorities, independent and voluntary sectors.
- Support developments/trials for the national Personalisation agenda.
- Motor Neurone Disease: Year of Care. National Pilot rollout for Teesside.
- Mapping of Continuing Care funding for people with neurological conditions.
- Development of specific self management programmes to include social care, access to local authority services, self assessment and individual budgets, housing, adaptations and Disability Facilities Grants, welfare rights and advocacy.
- Future reporting and consultation arrangements between the North East ADASS and the North East Neurosciences Network.

2b. Workforce Development

Following a successful bid to the SHA during the first year (2008/2009) for the Workforce Innovations Programme (WIP), to improve skills standards and services regionally, a WIP Bid Steering Group was established and a WIP Co-coordinator was appointed in the summer of 2009. She managed, promoted and developed the programme over the two years. The Network produced a full WIP Programme review report at the end of the programme in March 2011.

The Network established four local forums in Primary Care patches, directly linking commissioners to consumers working on regional and local priorities. The establishment of the local forums was part of the WIP bid and a project manager was recruited on a short term basis to support local commissioners develop the forums and promote membership. Three of the four forums have locally elected Chairs and Vice Chairs and the Durham / Darlington forum is about to recruit for a second time to these posts. NHS reorganisation led to this forum losing its lead commissioner and stalled activity. Currently across the NE there is a mailing list of 300 names with 100 – 120 people meeting quarterly disseminating circa 35 pieces of work through the Network.

2c. Dataset and Intelligence

The purpose of this group was to establish a consistent approach to collation and use of appropriate data to inform future commissioning and evaluation of neurosciences services.

- To establish a baseline dataset that can be agreed and used across the region to inform the development and implementation of clinical pathways
- To identify additional data sources to supplement the information we require to commission

- To use the dataset to produce a health needs analysis (produced in June 2009). Hard copies have been provided for members of the Scrutiny Panel. Some elements of this analysis are being updated.

The DH Long Term Conditions Delivery Support Team enlisted the support of the Network through local commissioners and the Data Set Working Group to contribute and share experiences and knowledge to enable them to establish a compendium of resources. These were to support the commissioning of Long Term Neurological Conditions, during the next stage of health and social care delivery. The Neurology Collection 2010 Compendium for Commissioners, edited by Lynne Barr, was published in autumn 2010 and provides a useful resource for PCTs and clinical commissioning groups (CCGs).

2d. Pathways Task Group

This group worked on recommending approaches to the development of pathways across the Region. It was agreed that three high level pathways be addressed with a PCT commissioner and local forum taking a lead on each of the pathways:

- Acquired Brain Injury (ABI) – South of Tyne and South of Tees. A Network bid was successful to appoint a project co-coordinator for the South Tees Hospitals NHS Foundation Trust to look at the needs of those with ABI. This post has been unsuccessfully advertised twice and is out to advert again with a revised job description. This is a key post which will give further insight into the long-lasting impact of ABI, especially in Middlesbrough where there is a higher incidence than in other areas in the north east.
- Progressive neurological conditions – Tees
- Epilepsy/headaches – County Durham and Darlington

2e. Information and communication

During 2008 – 2009 PCTs set up service level agreements with Tees Valley Durham & North Yorkshire (TVDNY) and the North East Neurological Alliances to

- Improve quality and accessibility of information and signposting for patients
- Improve communication across and between agencies
- Improve the knowledge and understanding of professionals

Working in partnership with the Network a website was developed in 2008 and in April 2010 the new North East Neurological Partnership website was launched. The partnership consists of the Network and the two regional Neurological Alliances. The site address is www.nenn.org.uk The site attracts over 100,000 hits per year offering access to users, carers and professionals. This was extended in March 2011 by launching an Evidence Portal with over 90 pieces of evidence generated regionally to improve neurological practice and research. It also includes clients' stories. Members of the Scrutiny Panel have been provided with DVDs produced after examining the lives of those with different neurological conditions, at workshops in Middlesbrough.

2f. Evidence Based Practice Sub Group

The Evidence Based Practice Sub Group started work in late 2009 and comprises clinicians, commissioners and academics with an interest in Patient Reported Outcome Measures (PROMS). PROMs are measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patient's health status or health related quality of life at a single point in time. The health status information collected from patients by way of PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to NHS Patients.

At this point there was no British tool available to help commissioners measure and compare the experience which patients with neurological conditions had received during their complex care pathway. Following an extensive literature search, a previously developed Canadian tool was considered the best option and the fact it was already established meant it could be used without having to go through the ethics approval process. The method for collecting the patient information and timelines were agreed. Middlesbrough was selected as the social care organisation to contribute to this review but like other providers found the experience complex and without dedicated funding for advocacy support, difficult to engage with.

Unfortunately, response rates were low and it was considered by the group that the information gathered was not sufficient to quantify robust outcome evidence. There were a number of reasons for this:

- The needs of people to have independent advocacy to assist in the completion of the questionnaire
- The complex care pathways they followed meant identifying individual service contributions was difficult
- It was rare to complete an isolated package of care as the majority of these people had continuing health and social care needs.

Whilst failing to produce a commissioning toolkit was disappointing for commissioners, a number of vital lessons were learned, resulting in further work with the Department of Health, the Network and the University of Northumbria to explore the measuring of outcomes in this specialist field of rehabilitation.

The lack of such a tool is of key importance when considering the way in which individual clients spend personal health and social care budgets in the future. Members will know that the Tees area is piloting personal health and social care budgets.

3. Budget

The Network operates on a tight budget with a total resource of £40,000 annually awarded through the NE PCOs (£10k each) to March 2012.

Middlesbrough PCT initially contributed an additional £30,000 towards the salary of the Network lead but this was withdrawn in March 2011.

The Network has been active in securing additional resources to invest in local service developments but without targets and ring fenced budgets this is an ongoing challenge. Nationally, neurosciences rehabilitation is rarely seen as a commissioning priority

PCT Locality	**Topic**	**Amount Y1 2008-2009**	**Amount Y2 2009-2010**	**Amount Y3 2010-2011**
Durham & Darlington	Research Information service from Neuro Alliance (TVDNY) Epilepsy. Community rehabilitation Self management ABI Co-ordinator South Durham	£96k	£130k	£130k
South of Tyne & Wear	Vocational rehab Information and support for Neuro Alliance North Community development worker for	£38k	£33k	£75k

PCT Locality	Topic	Amount Y1 2008-2009	Amount Y2 2009-2010	Amount Y3 2010-2011
	ABI Community Neuro Rehab			
North of Tyne	Pathways development Research Neuro rehab scoping exercise	£45k £15k	£45k £15k £5k	£45k £15k
Tees	Information service TVDNY Self management programmes Pathways development ABI Co-coordinator	£16k £120k	£16k	£16k £60k. Bidding cycle ended 22 July 2011. 3 bids approved To be appointed summer 2011.
Regional Resource	Workforce development bid		£366,504	£327.00

4. Performance

The process for monitoring the progress and performance of the Network was never established through formal performance indicators, however, in Year 1 it was agreed that the Network would report to the North East NHS Directors of Commissioning. The outputs of the Network include the resources identified and investments gained, the roles and relationships established and the level of stakeholder engagement. The NSF standards were adopted as the legitimate focus for the Network.

The following table demonstrates the performance achieved to date.

4a Achievements and Highlights	
Workforce Innovations Programme	• Impact and profile of neuroscience services and needs of patients and clients • Mentor and mentee recruitment, status and professional recognition • High calibre of recruits and leadership development • The only national programme addressing this area of work
South Tees Forum	• Established forum with agreement on rotational chair and vice chair which has since been successfully elected from the membership. • Agreed priorities and actions linked to QIPP and Reablement agenda • Pilot site for Map of Medicine for motor neurone disease. Goes live at the end of August. • Currently working with Map of Medicine to develop local pathways for epilepsy, Parkinson's and MS • Led region wide service model and specification for community neuro rehab teams. Shared with social care colleagues with a view to linking to the Tees Reablement Plan • Developed evidence base to justify additional epilepsy specialist nurse via 2 Middlesbrough based Mind of Information workshop days. • Education programme for GPs on the management of headaches
Durham & Darlington Forum	• Establishment of forum originally with PCT commissioner as chair. This development stalled when she was made redundant late 2010. A new commissioner with a far extended set of commissioning responsibilities has now been appointed and a new chairman has come forward to restart the

4a Achievements and Highlights	
	group. • Agreed priorities linked to QIPP • Established self management programmes for people with progressive conditions • Developed local access to outpatients and specialist neuro rehab usually accessed out of area • Developed evidence base to justify epilepsy and headache services onto QIPP agenda • Led on region-wide scoping of epilepsy services and development of pathway
North of Tyne Forum	• Establishment of forum with independent chair (Chair of Northumbria LINKs and living with a neurological condition) • Agreed priorities • Successful bid to resource development of an audit tool. Worked with service user focus groups to gather an evidence base to inform future commissioning decisions
South of Tyne Forum	• Establishment of forum with dedicated chair (consultant neurologist) and vice chair • Formal link established with LTC Programme Board through chair on both groups • Development, procurement and implementation of a neuro self management programme • Led on region-wide Brain Injury pathway which included a listening event with users and carers, mapped current pathway and worked in collaboration with Walkergate Park to include outcomes of their scoping exercise to ensure future pathways of care have Core Standards including a Key Worker, an information vessel and raising awareness in DGHs • Commissioned dedicated specialist resource to develop a business case for a model for inpatient and community based specialist rehabilitation for individuals with Acquired Brain Injury (ABI), ensuring quality of service throughout the care pathway. • Developed information and engagement strategy
Partnership with voluntary sector – Tees Valley area	A Mind of Information – Neurological Conditions Explained 2 full-day events each attended by 80 participants. An opportunity for health and social care professionals in the private and public sector to share experiences, enhance their knowledge, listen to real life stories and consider what individuals and professional teams can change to improve working practices. The first event in November 2009 was overwhelmed with registrations. This led to a follow up event in November 2010 with commitment from the organisers to make it an annual event. Funding is yet to be sourced for a follow-up event. At present there are over 70 people registered as wanting to attend the next session. A request has been made to NHS Tees to fund a further session.

4a Achievements and Highlights	
Service Level Agreements with the Tees Valley, Durham & North Yorkshire (TVDNY) and the Northern Neurological Alliance	This list is by no means exhaustive but reflects the length of partnership and energy contributed by the Alliances to neuroscience service development. • Attendance at all four local forums and involved in Network sub groups • Developed Network User and Carer Strategy • Contributed to the content management on website activity • Monthly bulletin produced circulated to key stakeholders and posted on website • Established Bishop Auckland Peer Support Network, the first peer support network under the neuro banner in England. This acts as an information service for newly diagnosed individuals. • Survey on services for people with neurological conditions 'Appreciative Enquiry Report' published July 2011
Health and Social Care Awards 2010	**Excellence in Commissioning** The Network was runner up in the Regional Awards in October 2010 for its unique approach to commissioning, designed to meet the challenges in the NSF for LTnC. Ironically, this award coincided with the retirement and redundancies of some of the key players in the Network. It was a period of great unrest for staff, who were enduring competitive rounds of interviews. Neuroscience commissioning failed to have a high priority but strong attempts were made to have it included in a 'long term conditions' envelope. Two of the key commissioners in North of Tyne and Durham left and whilst others were eventually appointed, their work-loads now include many other commissioning responsibilities. We have inherited therefore new people, in short term interim positions, some of whom have little knowledge of neurosciences. With the support of the chairman of the NE Strategic Health Authority, and two of his key directors, I developed a proposal to 'safe haven' the Network under the umbrella of the North of England Cardiovascular Network, and on 1st April transferred the work and remaining monies from NHS Tees (£40,000). Since then the Network has been supported part time by Corinne Wilson, as part time lead, and her Director Peter Mercer.

4b Quality and Effectiveness	

Priority commissioning objectives	• Dashboard of data collation developed
	• Personalization
	  o Continuing healthcare/individual budgets
	  o Self management developments
	• Workforce development
	  o Specialists, Generalists
	  o Primary Care
	• Joint commissioning
	  o Supported living options
	  o Telecare/health
	• Rehabilitation
	  o Community based
	  o Vocational/employment
	• Community based services
	  o Outpatient clinics
	  o Availability of specialist nurses
	  o Integration with social/community care and voluntary sector
	  o Access to high quality information via the website

4b Quality and Effectiveness	

World Class Commissioning (WCC)	Whilst WCC is no longer a measurable requirement for commissioners, it was and still is a mechanism to demonstrate quality commissioning. The Network was able to demonstrate and align activity to the WCC competencies as set out by the previous government. The Network's 2009 – 2010 work plan priorities directly corresponded to the WCC cycle. Achievements include:
	
	• Building local knowledge through forums – mapping of services
	• Gathering evidence from a user perspective to use as recommendations for region wide patient related outcomes through Evidence Based Practice sub group
	• Application of data provided in NEPHO health needs assessment
	  - Epilepsy
	  - headaches
	• Commissioning Framework developed (5 Years)
	• Joint Commissioning Strategy
	  - Clinical engagement - local forums
	• South Tees review: agreement in principle of the report presented in January 2010
	• Users and Carers
	  - Financial support for 'Mind of Information' events by Network
	  - sharing users / carers' stories and production of DVDs for training purposes

Business Cases	• Parkinson's Disease nurse • ABI Co-coordinator for South Tees • Specialist rehabilitation for ABI • Self management programmes for South of Tyne and South Tees
South Tees Review	Following the production of the NSF and Quality Requirements in 2006 reviews by the specialist commissioner NESCG in 2006 and 2008 acknowledged shortfalls in access to specialised neuro-rehabilitation services in the south of the region. In August 2009 the Network led a South Tees review, establishing a steering group with membership from local commissioners, specialist commissioner and clinicians from South Tees NHS Foundation Trust. The objectives of the 2009 review were:- • To improve access to in-patient rehabilitation services and range of environments with a fully implemented rehabilitation ethos including ongoing 'step forward' facilities and a Coordinator for acquired brain injury/newly diagnosed cognitively impaired patients. • To improve community neurology services including providing access to community neuro-rehabilitation services for outpatient and follow on services, linking to intermediate care and other community and low level services that support self help and maintenance of independence at home. • Prevent unnecessary hospital admissions through preventable secondary complications. • To promote self management at home and support community living through MDT /inter agency approach The evidence contained in the report enabled local commissioners in the south of the region to secure funding for an ABI Co-ordinator which was agreed as a variation to

4b Quality and Effectiveness	
	contracts with South Tees FT for a pilot period of 12 months and to develop self management programmes. It was recognised that much work was still to be done to achieve the outcomes of the review; however, this was a positive step in the right direction. It is hoped that this post can finally be filled this summer. The review was revised in August 2010 by the interim Network lead Paul Whittingham who took over when Lynne Barr retired from the NHS. At a meeting in September 2010 the Network considered an action plan to achieve equity and access to neuro-rehabilitation services across the whole of the North East region and to consider what services can realistically be provided in the community. This work is currently being taken forward by the specialist neurosciences commissioner Lisa Barber.
National Benchmarking Survey – Findings for the North East	2009 the Social Policy Research Unit at the University of York designed an Audit to collect information on services commissioned by PCTs. The aim was to use the results of the audit to set benchmarks against which PCTs could monitor their progress implementing the NSF. The Network agreed to collect the information for all PCTs in the region. The main points to come from the research (published 2010) were:- • Users and carers need to be involved more in shaping PCT business • There are a number of easily accessible interdisciplinary neuro-rehab teams in the north of the SHA region, leaving a gap in the south, particularly Teesside • Specialist nurses are not well spread across the region • Services are not spreading into the community – on average only 28% are community based, and some are totally acute hospital orientated • There is a lack of day opportunities that provide peer support • Access to Neuro physiotherapy services are unequal across the region • Neuro psychology services are difficult to access and waiting times are long

5. Influences, Issues and Challenges

Although the Network has achieved a great deal over the last 3 years it has been in the somewhat turbulent and ever changing environment of the NHS:-

- Changes in PCT structures –the Network has seen varying levels of capacity for commissioners to engage with the Network depending on national and organizational priorities.
- Lynne Barr who set up and led the Network left the post during the summer of 2009 requiring an interim lead to be appointed, Paul Whittingham. The Network now has its 3rd lead in 3 years.
- Joint procurement of services has been an added challenge and a theme across the region.
- The short term nature of the funding for the administrative coordinator, which was a key role within the Network, left the team with substantially reduced support.
- Increasing workload and changing priorities within PCOs for commissioners meant that neurosciences became one of many priorities – but without the protection of ring fenced budgets or national targets.
- Despite best efforts and intentions the loss of continuity and leadership within adult social care to support the Network has been felt. The Regional Disabilities Network meetings have stopped as North East ADASS will be re assessing the structures of all the regional policy networks, in line with the ADASS nationally. We have been in contact with Elaine O'Brien in Darlington to flag up our need to be closely involved with any new group.
- Lack of data and intelligence: whilst the Network published an assessment of Health Needs for the region it now needs reviewing to refresh the data. We would like to include GP Practice data to assist clinical commissioning groups to understand the needs of their population. Although

this is a big piece of work which should be crucial to clinical commissioning groups, it requires funding.

- Following the 2006 and 2009 reviews of rehabilitation services, commissioners developed business cases to support some of the findings and recommendations. It has been difficult to progress some of the changes to services, for example:

a. On behalf of local commissioners and in partnership with the Network the Northern Specialist Commissioning Team (NESCT) progressed the need for "step forward" rehabilitation beds and services. Procurement processes were facilitated by ProNE[6]. NESCT was unable to evidence value against the current services when bidders submitted higher tariffs than those charged for spot purchase and therefore could not get approval from CEOs to continue with procurement of "step forward" beds. These are still urgently needed across the north east to ensure the best long-term outcomes for patients. Some innovative care packages are now being developed in the independent sector but their very flexibility makes it more challenging for commissioners to contract. One package does not fit all patients.

b. Although examples of good joint working were demonstrated in the commissioning of Self Management Programmes for Tees PCOs and South of Tyne PCOs, differences in procurement processes and continuous changes in Tees PCO meant that the commencement of services in Tees was delayed. The closing date for bids was 22nd July 2011 and I am pleased to report that there were 10 bids, 3 of which were successful.

i. **Middlesbrough Department of Social Care**. To fund a designated Careers Support Worker for 2 years to provide appropriate information, advice and support for adult carers of patients with long term neurological conditions
ii. **University Hospital of North Tees**, physiotherapy, Neurology team. To provide a site at the recently established Forum Leisure Centre to enable people to continue with exercise programmes on a longer term basis.
iii. **'My life Programme' proposed by Lynne Barr.** To support people to manage the interface between health, welfare and community services. The programme will build self sustainability and community inclusion for individuals and encourage strengthening individual social networks.

6. The current position

The chairman of the Network and NHS Middlesbrough, the original PCT host of the Network, reported to NHS NE Chief Executives and subsequently to the Directors of Commissioning in December 2010. The reports were prepared at a time when key members of the commissioning team were leaving or had left their roles either taking voluntary redundancy or had been appointed to roles unconnected with neurosciences.

The options report described the national uniqueness of the Network, the need for it to continue, achievements and lessons learned and finally recommendations for the Network to continue for 18 months to enable the Network 5 year commissioning strategy to continue, expertise and skills to be retained, and the need to support emerging GP commissioners.

Chief Executives agreed that the Network should be hosted by the North of England Cardiovascular Network alongside the stroke, CHD and vascular work streams. CEOs agreed the £10k contributions from each of the PCOs for 2011/2012. Tees PCO however removed the salary of the half time Lead (£30k).

With support from the North of England Cardiovascular Network we are managing our core business but with a number of new partners and 3 new commissioners. We are part of a new Network of

[6] ProNE – Procurement North East

Networks group being chaired by the SHA which is currently reviewing all the work being done with a view to making recommendations to future clinical commissioning groups.

The latest transition letter from Sir David Nicholson confirmed that from 3rd October 2011 there will be four SHA clusters (North, South, Midlands, and East and London.) These arrangements will mirror the four commissioning sectors of the new national commissioning board, which will become operational from April 2013.

The new 'north' area will be made up of NHS North East, Yorkshire and the Humber, and North West. The four SHA cluster chairs have been announced and Kathryn Riddle, current chair of NHS Yorkshire and the Humber will become chair of the new north SHA cluster from 3rd October 2011. Sir Peter Carr, the current SHA chairman, will chair a new national steering group to establish the NHS Trust Development Authority (NTDA) to support remaining NHS trusts to achieve foundation trust status. The new north cluster will cover a population of 14.7 million, PCT revenue allocations of £26 billion, 126 statutory NHS organizations, 107 clinical commissioning groups and 50 local authorities.

During this period clinical commissioning groups will require support to carry out their commissioning functions. During the transition period there are plans to have commissioning support units in place by October and by March 2012 to have service level agreements in place.

In the meantime there are plans for the current specialist commissioning teams to merge to match the new SHA boundaries.

7. The way forward

Although funded only until March 2012, the Network hopes to continue to play its part in this transition period to keep neurosciences on the commissioning agenda. As outlined above, this work is complex and impacts on the lives of many thousands of people. Yet the diseases are relatively rare and the needs of patients misunderstood.

Local PCO commissioners and Network members see the continuation of the Neuroscience Network as a vital component in supporting clinical commissioning consortia to make the right decisions on commissioning the right care in the right place for people with a neurological condition. This needs to be achieved whilst ensuring that the new commissioners and the NHS Commissioning Board deliver the current requirements of the Government's health strategy in the White Paper Equity and Excellence: Liberating the NHS, the Operating Framework and the Quality Outcomes Framework.

During this period of corporate turbulence, rationalisation and interim management structures, commissioners are uncertain as to their capacity to dedicate to individual projects and work streams. This has had a direct impact on the experience and skill set of the current PCO representatives on the Network but progress has been made by sharing resources and approaches.

However, we are confident that local neuro forums are the mechanism to ensure that commissioners deliver on the Government's strategy. Local forums can continue to offer expertise from primary, community, secondary and specialist healthcare services through clinicians and Allied Health Professionals, as well as patient and carer input from voluntary organisations and the Neurological Alliances. It is imperative that they be given funding during this period of transition. They do bring enormous value for a small investment.

The NE Neurosciences Network made recommendations to NHS Directors of Commissioning to enable sustainability and delivery of the 5 year commissioning framework:-

- Dedicated support to ensure sustainability of the local forums, to promote engagement, facilitate transition and take on local work streams to enhance the quality and relevance of commissioned services.
- Priorities of the forums to be in line with:-

  i. Engagement with clinical commissioning groups and local Health and Well Being boards.
  ii. Align priorities to GP commissioning intentions, QiPP efficiencies, Reablement agenda and the Operating Framework key indicators
  iii. Use the National Benchmarking Survey as a way of reporting performance to measure success of the forums

- Develop 2011/2012 Work plan based on priorities in the updated Health Needs Analysis
- Encourage PCTs to continue funding both Neurological Alliances to ensure the work of the Network is based on robust feedback
- Responsibilities regarding commissioning neuro rehabilitation services should be made clearer once the definition sets for specialised services are released from the Department of Health
- Support the continuation of PROMs research, in line with national PROMs guidance to be revised during 2011
- Establish robust reporting on performance from Neurological Alliances to feed into local forums to inform future priorities, including patient feedback.
- Consider setting up integrated planning and commissioning arrangements with social services departments with agreements for shared financial responsibility, including pooled budgets.
- Keep spot purchasing under constant review with the aim of achieving different more flexible contracts.

Other key issues which need dedicated attention include:

- Supporting the trauma centre provision at South Tees Hospitals Foundation Trust which is essential for good outcomes. Having consistent high quality trauma services with the full range of specialist services on one site in the south of the area is crucial.
- Develop evidence based cases of need to re-adjust and increase investment in both specialist and continuing neuro-rehabilitation.
- Reconsider the need for a specialist social worker in neurosciences, as in the spinal service.
- Paediatric neurosurgical services.[7] Ensuring excellent care for children and young people is one of the NHS's highest priorities. In the field of children's neurosurgery, the extremely complicated and specialised nature of this work makes achieving this especially challenging. In order to ensure the best outcomes for children who need neurosurgery, surgeons in the field and other clinicians have called for a review of how we deliver these neurological services to children in England. It is crucial that the needs of local children are addressed in this review and that local submissions are made.
- Health and Well Being Boards are high on the Network's agenda and there support will be essential to ensure that neurosciences developments continue.
- There is still a need locally for a multi-disciplinary approach to rehabilitation which includes occupational advice and support.
- There is a continuing difficulty in finding appropriate support for those with neurological condition and challenging behaviour.
- The importance of registries in benchmarking care and supporting research.

[7] http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-neurosurgical-services

8. Partners who influence the work of the Neurosciences Network

The strength of the Network is in its robust partnership with key players. These have brought rich debate and live problems to the Network which has contributed directly to the improved commissioning of care pathways.

- NHS Tees as the local commissioner [8]
- GP commissioners
- Specialist Commissioners NESCG [9]
- South Tees Hospitals NHS Foundation Trust (now including community services)
- The TVDNY Neurological Alliance chairman Phil Dyson [10] and all the neurological charities who are members.
- Key independent sector specialist neuro-rehab providers supporting the Network such as:

    i. Whickham Villa LLP which is in the process of developing a specialist 'step forward' neuro rehabilitation centre in Middlesbrough. The centre will have a 40 bed rehabilitation unit for people with brain and spinal injuries, as well as those with long term neurological conditions, a well-being hub and housing. The new service will open in April 2013 in Middlehaven. [11]

    ii. The Hawthorns Neurological Rehabilitation Centre at Peterlee which specialises in the recovery care and rehabilitation of people with a traumatic or non-traumatic brain or spinal injury and works closely with the team at James Cook[12]

    iii. Housing Associations such as Eribus Housing prepared to support the special needs of those with long term neurological conditions

- Directors of Adult Social Services (ADASS) through the Regional Disability Group. (Although this group disbanded in March its future is being reviewed and whatever emerges needs to be closely aligned with the Network.)
- Pre-April 2011 the DH Long Term Conditions Team from Leeds, but this too was disbanded. The ex-lead is however still in the area – Lynne Barr [13] and continues to contribute to our work.

This list is not exhaustive, but merely flags up the wide range of interested and committed parties working in the field of neurosciences. This paper gives an overview of the situation but each of the Network's partners will be able to add more information.

I have attached a number of appendices for Panel members for background information and look forward to meeting on 24th August.

GLENYS MARRIOTT

Chairman
NE Neurosciences Network

12th August 2011

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[8] Paul Whittingham email Paul.Whittingham@middlesbroughpct.nhs.uk
[9] http://www.nescg.nhs.uk/ Specialist commissioner Lisa Barber Lisa.Barber@newcastle-pct.nhs.uk
[10] http://www.nenp.org.uk/tvdny.aspx
[11] http://www.whickhamvilla.co.uk/ Boda Gallon
[12] Hawthorns Email Julia Atherton hawthorns@barchester.com
[13] Lynne Barr email lynne@advancingpotential.co.uk

Appendix 1

There are 11 Quality Requirements in the NSF. They cover the following:

1. A person-centred service

This is a main theme that runs throughout the NSF. All people with long-term neurological conditions are offered a full assessment of their health and social care needs. In addition, they are to be offered information and education about their condition; the chance to make decisions about their treatment; and to be involved in writing a plan about how their needs will be met (a care plan).

2. Early recognition followed by prompt diagnosis and treatment

Anyone suspected of having a long-term neurological condition is to quickly see a doctor or other professional, with expert knowledge of that condition. They should have tests, be given a diagnosis and have any treatment they need. This should be as close to home as possible. This is so that a correct diagnosis and appropriate treatment happens as soon as possible.

3. Emergency and acute management

Anyone admitted to hospital for a neurosurgical or neurological emergency is assessed and treated by professionals with the right skills and experience who have access to the right facilities and equipment.

4. Early and specialist rehabilitation

Anyone with a long-term neurological condition who would benefit from rehabilitation is to receive timely, high quality rehabilitation services in hospital or other specialist settings when they need them. When ready, they are to receive the support they need to return home for more community rehabilitation and support.

5. Community rehabilitation and support

People with long-term neurological conditions living at home are to receive a full range of rehabilitation, advice and support to meet their continuing and changing needs. This is to increase their independence and help them to live as they wish.

6. Vocational rehabilitation

People with long-term neurological conditions are to have appropriate support to help them find or regain employment, to remain in work or to pursue educational opportunities.

7. Equipment and accommodation

People with long-term neurological conditions are to have the equipment they need (such as wheelchairs), within an appropriate time frame and to have adaptations made to their homes as and when needed, to support them to live independently; help them with their care; maintain their health; and improve their quality of life.

8. Personal care and support

Health and social care services are to work together to ensure that people with long-term neurological conditions are given the care and support they need to live independently in their own homes wherever possible.

9. Palliative care

People with long-term neurological conditions nearing the end of their life are to have access to a range of palliative care services as and when they need them, to control symptoms and offer pain relief, and to meet any personal needs they may have.

10. Support for family and carers

All carers of people with long-term neurological conditions are to receive appropriate support and services which recognise their needs as a carer and as an individual in their own right.

11. Care during admission to hospital or other health and social care settings

All people with long-term neurological conditions are to have their specific neurological needs met when they are receiving care for any other reason in any health or social care setting.

Appendix 2 Definition No 8 Neurosciences edition

Def No 8
Neurosciences Editior

Appendix 3 Service Definition for Specialised Rehabilitation

Third Edition
Specialised_Rehabilita

Appendix 4 Neurosurgery Service Specification

Neurosurgery
Service Spec 2011-12

Appendix 5 Neurology Service Specification

Neurology Service
Spec 2011-12 v4.doc

Appendix 6 Walkergate specialist neuro rehabilitation services, Newcastle.[14]

Walkergate Neuro
rehab data 1011.xls

This data has been provided by the Specialist Neurosciences Commissioner Lisa Barber. Whilst rehabilitation services at Walkergate are commissioned by the specialist commissioner, rehabilitation services in South Tees, which cater for similar patients, are commissioned locally by NHS Tees. As a result of these different approaches, South Tees NHS Foundation Trust, which is the clinical centre for the southern area, can offer only short term acute in- patient neurology rehabilitation, outpatient neuro physiotherapy, neuro-psychology assessment and very limited outpatient occupational therapy. The

[14] http://www.ntw.nhs.uk/sites.php?site=4 Part of the Northumberland, Tyne and Wear NHS Foundation Trust

services available are in sharp contrast to those patients who are geographically close to Walkergate Park in the north of the region.

This is an anomaly which also results in different tariffs being applied to the providers.

An assumption that patients from the south of the patch (including North Yorkshire) would travel to Walkergate is often unrealistic, and in any case it is difficult for vacant beds to be found.

The new commissioning arrangements (2011) for specialist commissioning within the NHS has the potential to consider this situation with the Network and place the South Tees service on an equal footing.