AGENDA ITEM:

OVERVIEW & SCRUTINY BOARD

10 JANUARY 2012

HEALTH SCRUTINY PANEL
NEUROLOGICAL SERVICES – FINAL REPORT

PURPOSE OF THE REPORT

1. To present the outcome of the Health Scrutiny Panel's investigation into the topic of Neurological Services.

Introduction

2. Neurological Conditions are very common in the UK. They affect a wide range of people, to differing levels of severity, yet the average person does not know a great deal about them, or what the term 'neurological conditions' covers.

3. According to figures published by the *Neurological Alliance*, there are around 10 million people in the UK living with a neurological condition, which has a significant impact on their lives[1]. The Neurological Alliance predicts that the number of people with neurological conditions will grow sharply in the next two decades due to improved survival rates, improved general health care, infection control, increased longevity and improved diagnostic techniques.

4. The following text, taken from the Neurological Alliance website, outlines some useful introductory information about Neurological Conditions:

   Neurological conditions result from damage to the brain, spinal column or nerves, caused by illness or injury. Many of the precise causes of neurological conditions are not yet known. Neurological conditions affect young and old, rich and poor, men and women and people from all cultures and ethnicities.

   Some neurological conditions are life-long and people can experience onset at any time in their lives. Others, such as cerebral palsy, are

[1] Please see *Neuro Numbers,* Published by the Neurological Alliance, ISBN 1901893324

present from birth. Some conditions, such as Duchenne muscular dystrophy, commonly appear in early childhood, some, such as Alzheimer's disease and Parkinson's disease affect mainly older people.

There are also conditions which have a sudden onset due to injury or illness, such as a head injury or stroke, or cancers of the brain and spine. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, affect people mainly in adulthood and will cause deterioration over time, affecting a person's quality of life and their ability to live independently.

Some neurological conditions are life threatening, most of them severely affect people's quality of life and many cause life-long disability. Caring for someone with a debilitating illness often means that carers have to give up their own employment, in addition to the person with the condition being unable to continue to be economically active. This will have a devastating impact on the family's economic situation.

Neurological conditions are very poorly understood by the general public. Levels of awareness are low even about relatively common conditions, such as epilepsy. There are also a large number of rare conditions, such as Guillain-Barré syndrome and ataxia-telangiectasia, which are largely unheard of by most health and social care professionals[2].

5. The Panel was keen to consider the topic of Neurological Services for a number of reasons. The Panel felt that it didn't have a great deal of knowledge about neurological conditions and the services provided for those conditions, so it wanted to improve its knowledge of the subject area. Secondly, the Panel was aware from research and informal conversations with NHS colleagues that Neurological Conditions were a field that Health Scrutiny, certainly in the North East, had not really given a great deal of attention to. As such, the Panel identified it as a topic that was worthy of exploration, as any major issues facing the service area may not have been discussed in detail within an open, political forum. Thirdly, the NHS faces one of its most financially challenging periods of its history, with a need to generate significant efficiencies, whilst undergoing a period of significant organisational turbulence. As such, the Panel was interested to gather views on how such an challenging period in the NHS' history would impact upon a service area that is little understood and does not, normally, attract headlines or mainstream media interest. This report is a record of what the Panel found.

[2] http://www.neural.org.uk/living-with-a-neurological-condition/what-is-a-neurological-condition

Terms of reference

6. To govern and direct the investigation, the Panel drafted the following terms of reference:

6.1 To gain a detailed understanding of what is meant by, and classified as, *neurological conditions*

6.2 To establish the extent to which neurological conditions affect the population of Middlesbrough

6.3 To establish what services are available for neurological conditions in Middlesbrough, including the level of diagnostic and assessment support.

6.4 To establish what service gaps exist in Middlesbrough relating to Neurological Conditions.

6.5 To gather the views of interested parties on the current performance of neurological conditions in Middlesbrough and to ascertain how those services need to develop to meet future challenges.

6.6 To draw conclusions and make recommendations as the Panel views as appropriate, on the basis of the evidence received.

Methodology

7. The Panel conducted this review by holding roundtable discussions with a number of representatives, each with a particular area of expertise regarding neurological services. This included NHS service providers, specialised and local commissioners, the Neuroscience Network and independent sector providers of care. The Panel also instructed its support officer to conduct a significant amount of research. The views expressed and information submitted by those attending Panel meetings, as well as the research undertaken on behalf of the Panel, is what forms the basis of this final report.

Evidence gathered from NENN

8. The Panel was keen to consider the views of the North East Neurosciences Network(NENN). By way of background, the Panel heard that 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).

9. It was confirmed that the NSF was published in March 2005, 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.

10. The panel was advised that, in the view of the NENN Chair, PCTs in the North East were slow to adopt and implement the NSF. 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. A network leader and Chair were appointed.

11. 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.

12. The Panel was advised that 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.

13. The NENN advised the Panel that 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 Panel was informed that the establishment of the NENN 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.

14. The key areas focussed on during implementation were:

14.1 making progress in delivering each quality requirement;

14.2 building capacity in staffing, facilities, equipment and range of service providers to ensure access to appropriate services for people with long term neurological conditions;

14.3 developing a more integrated approach to delivering services with an increase in working with a range of agencies and using joint budgets.

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

15.1 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).

15.2 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.

15.3 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.

15.4 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.

16. Following its consideration of the background to the NENN, the Panel turned its attention to a paper that the NENN had provided.

17. By way of introduction into Neurological Conditions, NENN advised the Panel that clinical neurosciences services have undergone a period of significant 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. The Panel was informed that 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.

18. It was confirmed to the Panel that 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 Panel heard that the scale of the problem 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. The Panel was advised that at the same time, however, 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

19. It was reported to the Panel that Neurosciences poses a major challenge in ensuring that patients have prompt access to specialist expertise (e.g. for diagnosis and key treatment decisions) combined

[3] National Service Framework, Long term conditions.

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. It was emphasised to the Panel that at points of injury or illness, a tertiary centre such as JCUH's immediate task is to treat a patient, ensure that their condition is stabilised, and then for longer term rehabilitation and therapy needs, community based services should take the lead.

20. The Panel was interested to hear that 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[4].

21. As such, in August 2009 NENN led a South Tees review, establishing a steering group with membership from local commissioners, specialist commissioner and clinicians from South Tees NHS Foundation Trust.

22. The objectives of the 2009 review were:-

22.1 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 Co-ordinator for acquired brain injury/newly diagnosed cognitively impaired patients.

22.2 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.

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[4] The Panel has subsequently heard from NESCG thatr it did a review in 2006, before Walkergate Park was built, which talks about the various rehab facilities which were available then, one of which was Hunter's Moor. There is some activity data from Hunter's Moor within the report, below is the narrative that went with it:

There are also considerable variations year on year even within PCTs which probably reflects the nature of the services. The lack of usage of Hunters Moor by PCTs in the southern part of the Northern Specialised Commissioning Group area is quite surprising, despite the geographical issues. It needs to be queried if those patients are receiving rehabilitation elsewhere (possibly The Hawthorns) and/or if the level of care therefore being provided to those patients is appropriate to meet their needs. This issue was also raised in the report produced by County Durham and Tees Valley Strategic Health Authority as part of their Review of Mental Health and Specialist Learning Disability Services. However, no overall conclusion was given in this report and it was not queried if patients were receiving suitable treatment at any alternative service provision.'

The Panel has subsequently been advised that it was not suggested that it is an access issue, although it is acknowledged that the majority of patients were from the North of the patch.

The Panel has also been subsequently advised that NESCG did not do a review in 2008, so I am not sure what this refers to.

22.3 Prevent unnecessary hospital admissions through preventable secondary complications.

22.4 To promote self management at home and support community living through MDT /inter agency approach

23. It was reported to the Panel that the evidence contained in the report, enabled local commissioners in the south of the region to secure funding for an ABI Co-ordinator. This was agreed as a variation to contracts with STHFT for a pilot period of 12 months and to develop self management programmes. The Panel was told that whilst it was recognised that much work was still to be done to achieve the outcomes of the review; this was a step in the right direction.[5]

24. The Panel was advised that at a meeting in September 2010, NENN 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 specialised neurosciences commissioner.[6]

25. In addition to the locally led review outlined above, The panel was advised that in 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. NENN agreed to collect the information for all PCTs in the region. The main points to come from the research (published 2010) were:-

25.1 Users and carers need to be involved more in shaping PCT business

25.2 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

25.3 Specialist nurses are not well spread across the region

25.4 Services are not spreading into the community – on average only 28% are community based, and some are totally acute hospital orientated

25.5 There is a lack of day opportunities that provide peer support

25.6 Access to Neuro physiotherapy services are unequal across the region

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[5] The Panel has subsequently heard that funding was secured for an ABI Coordinator for a period of 12 months but this wasn't agreed as a variation to the South Tees contract and the role wasn't to develop self management programmes. The post has recently been appointed to; updates and progress will be provided via the Tees Neuro Forum.

[6] The Panel has subsequently heard that this work is not being taken forward by NESCG, as community services are not the responsibility of NESCG. NESCG will be involved with the work as necessary and as directed by the Directors of Commissioning from the PCTs.

25.7 Neuro psychology services are difficult to access and waiting times are long

26. The Panel was keen to hear the NENN's views on the challenges it has faced and the prospects for developing Neurological Services in the next few years.

27. The Panel heard was advised that although NENN has achieved a great deal over the last 3 years, it has been 'in the somewhat turbulent and ever changing environment of the NHS':-

27.1 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.

27.2 Due to such changes' impact on personnel, NENN now has its 3rd lead in 3 years.

27.3 Joint procurement of services has been an added challenge and a theme across the region.

27.4 The short term nature of the funding for the administrative co-ordinator, which was a key role within the Network, left the team with substantially reduced support.

27.5 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.

27.6 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.

27.7 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[7]. NENN 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.

28. 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. The following is a good example.

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[7] The Panel has subsequently been advised by NHS Tees that The Health Needs Assessment is being refreshed and should be available early 2012.

29. It was reported to the Panel that on behalf of local commissioners and in partnership with NENN the North East Specialised Commissioning Team (NESCT) progressed the need for “step forward” rehabilitation beds and services. Procurement processes were facilitated by ProNE[8]. 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. In a message that the Panel has heard on numerous occasions, The panel was advised that 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.

30. The Panel was interested to hear what the future holds for NENN and the work it has been engaged in.

31. The Panel was advised that although only funded until March 2012, NENN 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.[9]

32. It was reported that 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.

33. The Panel heard that 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 NENN, but progress has been made by sharing resources and approaches.

34. It was said, however, that there is a confidence that local neuro forums are the mechanism to ensure that commissioners deliver on the Government’s strategy. The Panel heard that 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

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[8] ProNE – Procurement North East

[9] Subsequently, the Panel has heard that Directors of Commissioning have agreed to support the NENN’s operation for a further year.

Neurological Alliances. The Panel was advised that it is 'imperative' that they be given funding during this period of transition.

35. The Panel heard that the NE Neurosciences Network made recommendations to NHS Directors of Commissioning, to enable sustainability and delivery of the 5 year commissioning framework:-

35.1 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.

35.2 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

35.3 Develop 2011/2012 Work plan based on priorities in the updated Health Needs Analysis

35.4 Encourage PCTs to continue funding both Neurological Alliances to ensure the work of the Network is based on robust feedback[10]

35.5 Responsibilities regarding commissioning neuro rehabilitation services should be made clearer once the definition sets for specialised services are released from the Department of Health

35.6 Support the continuation of PROMs research, in line with national PROMs guidance to be revised during 2011

35.7 Establish robust reporting on performance from Neurological Alliances to feed into local forums to inform future priorities, including patient feedback.

35.8 Consider setting up integrated planning and commissioning arrangements with social services departments with agreements for shared financial responsibility, including pooled budgets.

35.9 Keep spot purchasing under constant review with the aim of achieving different more flexible contracts.

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[10] The panel has subsequently heard that NHS Tees have agreed to fund/ extend the SLA with the Tees Valley, Durham and North Yorkshire Neurological Alliance for the period 1st February 2012 – 31st March 2013. NHS Durham have also agreed to provide funding.

36. The Panel heard that there are a number of other key issues which need dedicated attention, including:

36.1 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 specialised services on one site in the south of the area is crucial.[11][12]

36.2 Develop evidence based cases of need to re-adjust and increase investment in both specialist and continuing neuro-rehabilitation.

36.3 Reconsider the need for a specialist social worker in neurosciences, as in the spinal service.

36.4 Paediatric neurosurgical services.[13] 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.

37. The Panel was advised that the coming Health and Well Being Boards are high on the Network's agenda and there support will be essential to ensure that neurosciences developments continue.

38. In additon, the Panel heard that there is still a need locally for a multi-disciplinary approach to rehabilitation, which includes occupational advice and support. There is also a continuing difficulty in finding appropriate support for those with neurological condition and challenging behaviour.

Evidence from the South Tees Hospitals NHS Foundation Trust

39. The Panel was very much aware that James Cook University Hospital plays hugely significant role in the treatment of neurological conditions in Middlesbrough and the wider Tees Valley area. As such, the Panel felt it very important that it engaged with senior clinical and managerial personnel from the STHFT to consider their perspective on how

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[11] The Panel has subsequently been advised that the national standards for Major Trauma Centres is that all patients should have in place, before discharge, a prescription for rehabilitation.

[12] The Panel has subsequently heard that in the view of NESCT, the full range of specialised services on one site in the south of the area is ' not crucial' to the Trauma service and even in Newcastle the specialised neuro-rehab facility is not on the same site as the major trauma centre nor even provided by the same Trust.

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

neurological services are currently provided and where they could be improved.

40. The Panel met with the STHFT in September 2011and considered a paper the submitted by the Trust, before answering questions.

41. The Panel heard that the STHFT's Department of Neurology has expanded dramatically over recent years. This is best demonstrated by the expansion of consultant neurologists from two whole-time equivalents, based at Middlesbrough General Hospital in the 1980s, to the current contingent of ten whole-time equivalents (one post currently filled in a locum capacity) based in a state of the art neurosciences unit, at the James Cook University Hospital (JCUH).

42. The Panel was advised that as well as consultant neurologists, STHFT has four trainee neurologists (Speciality Registrars) and three ward-based junior trainees. It was reported that the STHFT provides neurological services to a population of approximately 1.2 million and last year carried out approximately 8,500 new patient assessments, with around 10,000 follow-up assessments also carried out in the out-patient department.

43. The Panel heard that neurology is part of the Division of Neurosciences and that there are extremely close links with Neurosurgery, Neurorehabilitation, Neurophysiology, Neuroradiology and Neuropsychology. It was confirmed that Neurology services (incorporating Neurophysiology) are commissioned as specialised services by the North East Specialised Commissioning group (NESCG), as are Neurosurgery and Neuroradiology. The Panel was interested to hear that neurorehabilitation is currently not commissioned as a specialised service, but commissioned separately by local Primary Care Organisations.

44. As a fact-finding exercise, the Panel was keen to establish what conditions are managed within neurological services.

45. It was reported to the Panel that a large number of urgent (acute) and non-urgent (both short-term and long-term) conditions are seen within neurology. Patients are often referred with no specific diagnosis and the job of the neurologist is to assess, investigate, diagnose and initiate management. The Panel was advised that the following list is by no means exhaustive, but provides a good indication of the spectrum of disorders, that may be seen and managed within the neurology department.

Acute ("urgent") disorders

45.1 Brain and spine infections
Meningitis, encephalitis, TB, HIV, lyme disease

45.2 Strokes and brain haemorrhages

particularly more unusual or complex presentations

45.3 Fits and other causes of loss of consciousness

45.4 Acute headaches
severe migraine, cluster headache, trigemminal neuralgia
thrombosis of brain veins / spasm of brain arteries
tears (dissection) to brain and neck arteries

45.5 Acute muscle weakness
muscle diseases e.g. polymyositis
neuromuscular diseases e.g. myasthenia gravis
nerve diseases e.g. Guillain Barre Syndrome

45.6 Brain and spine inflammations
flare-ups & first presentations of multiple sclerosis
neurosarcoid, neurolupus, autoimmune inflammatory disorders

45.7 Toxic disorders
nutritional deficiencies
central nervous system poisons
disorders of normal body metabolism

45.8 Brain and spinal tumours

Non-acute, long-term and short-term management

45.9 Extrapyramidal disorders
Parkinson's Disease, Progressive Supranuclear Palsy (PSP) etc.

45.10 Inflammatory disorders
multiple sclerosis etc.

45.11 Cognitive disorders
Alzheimer's Disease, dementia with Lewy bodies, fronto-temporal dementia etc.

45.12 Motor neurone disease

45.13 Epilepsy

45.14 Nerve and muscle diseases
peripheral neuropathy, myasthenia gravis, muscular dystrophy

45.15 Hereditary and acquired ataxias (disorders affecting balance)

45.16 Chronic (long-term) headache disorders

45.17 Functional (psychological) disorders / patients with medically unexplained symptoms

45.18 Degenerative spinal diseases

45.19 Sleep disorders

45.20 Dystonia and movement disorders

46. It was confirmed to the Panel that on the whole, patients with neurological disorders will be seen either on the acute medical ward (for those with urgent presentations) or in the out-patient department.

Acute Service South of Tees

47. The panel was advised that patients presenting at JCUH may be admitted through Accident and Emergency (A&E) or the Medical/Acute Assessment Unit (MAU/AAU). Patients initially presenting to other hospitals (North Tees, Hartlepool, Darlington, Bishop Auckland, Friarage Hospital Northallerton) may be referred and subsequently transferred to the on-call neurology team. This, however, is dependant upon the bed-availability on the neurology ward (there is a single neurology ward at JCUH with 21 beds, 2 of which are specialised for complex assessment of patients with fits). Alternatively, these patients may be managed in the other hospital and seen by a visiting JCUH neurologist as a ward consult, inevitably with some delay.

48. It was reported that many patients will initially be managed by the on-call medical team who may involve the on-call neurology team by means of a ward-consult request. Following assessment, patients may be transferred to the care of the neurology team or alternatively would remain under the medical team with advice on further investigation / management. The Panel was advised that a sizeable number of patients will be managed entirely by the medical team during their admission. It was noted by the Panel that, therefore, these patients may be referred to the neurology out-patient clinic or else may never get to see a neurologist.

49. The Panel was very interested to learn that the model of acute care described above mirrors that widely practised around the UK and that its appropriateness has frequently been questioned, most recently in the document "*Local Adult Neurology Services for the next decade*[14]". It was said that one of the main criticisms levelled, is that neurologists now spend too much time seeing increasing numbers of "worried well" in the out-patient clinic. This, in turn, can lead to a scenario where patients with serious acute neurological disorders, may not see a neurologist for some days following their presentation, or in some cases may never see a neurologist.

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[14] Please see http://www.abn.org.uk/abn/userfiles/file/Local%20Adult%20Neurology%20Services%20for%20the%20Next%20Decade.pdf

50. The Panel was keen to hear how services within JCUH interact, to ensure that those patients requiring neurological input to their care receive it. It was reported that in general, a good relationship exists between neurological services and their medical colleagues within JCUH. Neurology offers a same-day neurological opinion if requested through the ward-consult service and have developed daily ambulatory emergency clinics to accommodate those patients who have been seen with urgent problems in A&E/MAU, or by their GPs and who do not require immediate admission. The Panel noted, that in the view of those presenting evidence, patients presenting to the surrounding hospitals are, however, somewhat disadvantaged. This is because they would either be relying emergency transfer to JCUH (and therefore bed availability) or else a ward consult which will typically be once a week, less if the consultant happens to be on leave.

Out-patient Services South of Tees

51. The Panel was told that Neurology out-patient clinics are provided daily at JCUH, twice-weekly at Friarage Hospital in Northallerton and Hartlepool and weekly in the case of Darlington and Bishop Auckland. There are also regular clinics carried out in Whitby.

52. It was confirmed that clinics will typically involve a consultant neurologist, with or without a trainee (Speciality Registrar). There are also clinics carried out by specialist nurses in epilepsy, multiple sclerosis and Parkinson's disease, largely confined to the JCUH. Finally, there is a multidisciplinary motor neurone disease clinic, supported by a consultant neurologist, MND care co-ordinator, various therapists and social worker[15].

53. It was explained to the Panel that clinics may be “general” (appointing patients with any of the wide variety of conditions classed as neurological), or “specialist” (confined to patients with a particular disorder or group of disorders). The Panel heard that a consultant or specialist nurse, with particular interest and expertise in that disorder conducts the specialist clinics.

54. The Panel heard that Consultant delivered specialist clinics at JCUH cover patients with stroke and transient ischaemic attacks (“mini-stroke”), epilepsy and blackouts, Parkinson's disease, motor neurone disease, dementia and cognitive disorders, sleep disorders, autonomic disorders (conditions which the nervous control of blood pressure, sweating, digestion etc.) and disorders requiring botulinum toxin therapy (certain movement disorders). Specialist nurse clinics include Parkinson's disease, epilepsy and multiple sclerosis. Visiting neurologists (from Newcastle) provide specialty clinics for patients with muscle diseases and neurogenetic disorders.

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[15] The Panel has subsequently been advised that JCUH is a Motor Neurone Disease Care Centre, with support from the Motor Neurone Association. It is led by a Clinical Director.

55. The Panel was advised that it is not possible, without employing a very large (and probably unfeasible) number of consultants, to have specialty clinics covering all of the neurological conditions. The Panel heard, however, that there are important areas where STHFT would like to strengthen its consultant speciality interests, notably in the areas of movement disorders and neuroinflammatory conditions (such as multiple sclerosis). To this end, two of the neurologists in the department are developing their expertise in MS and the STHFT has identified a movement disorder specialist for a currently vacant post. In the future, it may be possible to increase the specialist nurse provision both to support the current specialty nurses but also to include other conditions such as headache disorders.

56. It was confirmed to the Panel that the specialty clinics are currently confined to JCUH. Patients seen in these clinics, with the exception of stroke and transient ischemic attack (TIA) which is also catered for within surrounding hospitals, are expected to travel to Middlesbrough. The Panel was advised that, in the view of the specialist clinicians from STHFT, there are arguments for and against organising specialty clinics away from JCUH. These centre on the convenience for the patient versus the availability of sophisticated resources at JCUH, but this may ultimately be seen as desirable assuming the issue of resources can be resolved.

57. The Panel was interested to hear from STHFT that there seems little doubt that patients increasingly wish to be seen by specialists in the condition they have. It was explained that a practical implication of this was that in recent years, this has led to a large number of patients previously seen and managed by general practitioners, or general physicians, being referred into neurology clinics. It was heard that super-specialisation in other medical specialties has led to the demise of the general physician and general practitioners are now rarely exposed to neurology in their training years. The panel was advised that the result is an increasing (and understandable) reluctance from non-neurologists to manage patients with neurological symptoms.

58. It was confirmed to the Panel that it is this demand for specialist input from patients and the diminishing neurological skills of general practitioners and physicians, that has fuelled the increased provision of neurologists across the UK in the last 20 years. One consequence of this, alluded to above, is that the pattern of referrals to neurology clinics has altered. The Panel heard that a significant proportion of out-patient neurology now involves seeing patients with complex symptoms which sound neurological in origin, but which ultimately turn out to have a non-neurological basis. It is, of course, a perfectly appropriate role for a specialist to rule-out or reverse an inappropriate neurological diagnosis. Nonetheless, the Panel was advised, the case has been made for improving the provision of neurological expertise in primary care, either by involving general practitioners with a specialist interest (GPwSI) or else developing primary-care based specialist nurses.

59. It was reported to the Panel that the suggestion is that, if the majority of patients who do not have neurological conditions can be appropriately managed within primary care, then the remainder will be able to be seen more quickly or more frequently by the specialist. Currently there is considerable pressure on review slots for patients with neurological disorders, with no vacant slots in some clinics in excess of six months. For patients with unstable conditions, when decisions need to be made sometimes at weekly intervals, this poses obvious problems.

60. The Panel was told that it has been suggested that new referral to follow-up ratios in neurology outpatient clinics are too high and should be reduced, i.e. fewer review slots. It was confirmed that a regular specialist review is a requirement of national guidance relating to chronic neurological conditions, (including that of NIHCE) and if the skills to do this are unavailable in primary care it seems self-evident that this will need to be provided from secondary care clinics. The Panel heard that it is not clear how this will be achieved whilst reducing the availability of review appointment slots.

61. The Panel was keen to hear the views of the STHFT regarding the strengths of its current range of neurological services.

62. It was said that, in the view of the STHFT, it has developed a good skill mix in the neurology department with a group of like-minded neurologists and specialist nurses, dedicated to providing and developing the service. Further, from the patient's perspective STHFT provides a wide variety of general and specialist neurological services with excellent access to timely supporting investigations.

63. The Panel heard that in the view of the STHFT, it offers convenience of local general neurology clinics to patients from around the region, with the physician colleagues in JCUH and surrounding hospitals value and appreciate the support that STHFT's Neurology Team provide them. The Panel was pleased to hear that the majority of patients can have their illnesses diagnosed and managed close to home. Visits to tertiary centres in London, Leeds, Newcastle or other large university hospitals are now rarely required. This, it was felt, was a powerful indication of how far neurology services at JCUH had come over recent years.

64. In addition, the Panel heard that STHFT's specialist nurses have significantly improved the accessibility of the department for patients with epilepsy, Parkinson's disease, MS and MND.

65. The Panel was also advised that, in the view of the STHFT, some specialties are extremely well supported. The neurologists have made major contributions to the development of acute stroke/TIA management in JCUH. Epilepsy services have been dramatically improved in recent years and we have gone from having no dedicated MND support structures to being a Motor Neurone Disease Association Care Centre. Patients with cognitive disorders, sleep disorder and

autonomic conditions can now all receive highly specialised neurological assessment and management locally.

66. Following the Panel's consideration of the current strengths of neurological services at JCUH, the Panel heard that are aspects of the service that could be developed and improved upon.

67. The Panel heard that whilst still meeting national targets, STHFT struggles to see patients who are newly referred, as quickly as they would like. STHFT particularly struggles to offer patients short-term review appointments, with clinics booked up for some months in advance.

68. The Panel noted with some concern, that patients presenting acutely to surrounding hospitals, and to a lesser extent JCUH, do not always see a neurologist as quickly as would be desirable (or in some cases at all). It was confirmed that whilst STHFT provides regular clinics to surrounding hospitals, these do not occur during periods of consultant leave and one large neighbour (North Tees & Hartlepool NHS Hospitals Foundation Trust) has no regular neurological presence on its own site.

69. It was also reported that there are some specific areas of neurological practice where benefit would be gained from greater local expertise, notably the management of patients with movement disorders and multiple sclerosis.

70. The Panel was concerned to hear that, in the view of senior clinicians with Neurology at STHFT, links with primary care are fragile. The Panel heard that there is much less direct contact and communication between consultants and GPs than in the past. It was said that developing a properly integrated neurological service, with seamless boundaries between primary and secondary care must be to the advantage of patients, though if anything the direction of travel in recent years has been the opposite. These seamless boundaries should ideally encompass the full range of services necessary to the management of patients with long-term conditions including in-hours and out-of-hours general practice, physiotherapy, occupational therapy, speech and language therapy, social services, wheelchair services and palliative care services.

71. The STHFT advised the Panel that there has been a growth in specialist nurse roles over recent years and this could be an opportunity for further development, as well as seeking opportunities to increase therapeutic psychologist input.

72. The Panel was interested to hear the STHFT's views on the future of Neurological Services and specifically where those services need to improve.

73. The Panel heard that there was a pressing need to develop services that are better integrated with primary care. It was said that this may

involve identifying and training GpwSIs, or developing and expanding the role of the specialist nurse practitioner.

74. The Panel was advised that the local health and social care economy needs to strengthen the specialist support available, particularly for patients with MS and movement disorders. The Panel was also advised that the local health and social care economy needs to identify better ways to deliver neurological services to the patients in their own locality. This is likely to involve investing in specialist nursing support, with or without specialist GPs, if there is the enthusiasm within primary care to develop this role.

75. The Panel was also advised that the local healthcare system also needs to find better solutions for patients with acute neurological disorders, that will result in more timely access to specialist neurological opinions, whatever the geographical location of the patient.

Rehabilitation paper from South Tees Hospitals NHS Foundation Trust

76. During its consideration of this topic, the Panel became quickly aware of how integral rehabilitation services were to the debate on neurological services. As such, the Panel was very grateful to the STHFT's senior clinicians for preparing an additional paper, focussing specifically on rehabilitation matters.

77. The Panel was advised that rehabilitation facilities at the JCUH can be better understood, in the context of rehabilitation facilities available in the North East in general. In the view of senior STHFT clinicians, the Panel heard that the rehabilitation facilities in the North East are limited. It was reported that there are limited inpatient acute specialised rehabilitation facilities, while community services are also limited and disease specific. There are nine rehabilitation consultants working in five centres in the North East. Five consultants are based at Walkergate Park in Newcastle while others are based in Middlesbrough, Sunderland, Northallerton and Carlisle. There are level 1 rehabilitation facilities at Newcastle, with level 2 facilities at the other centres[16].

78. There are three disability services centres for prosthetic rehabilitation in the North East, with one each in Newcastle, Middlesbrough and Carlisle. The regional spinal injuries rehabilitation centre is based at JCUH, which is staffed by two consultants.

[16] It has subsequently been pointed out to the Panel that Wickham Villa's service at Chase Park also has a consultant in Rehab Medicine (i.e one more centre in Gateshead – the figures above are NHS services only) The UKROC have also designated the service as a Level 1 facility in reference to the complexity of its clients, geographic population spread and the outcome data its provides. The Panel heard that this provides even more evidence to the fact that JCUH should also be a level 1 unit.

Rehabilitation facilities at JCUH

79. Spinal Injuries Rehabilitation Unit: It is situated in a purpose built unit supported by two consultants, two staff grade doctors and three specialist nurses with a well resourced multi-disciplinary team (MDT) and dedicated psychology input. This unit provides level 1 rehabilitation services and serves as a regional specialised spinal rehabilitation unit.

80. Neurorehabilitation: The department of rehabilitation is based in the Division of Neurosciences and provides inpatient acute specialist neurorehabilitation and outpatient services. The consultant in rehabilitation was appointed in August 2007 to develop these services. The inpatient unit has dedicated eighteen beds on ward 26 with a well developed multi-disciplinary team providing these services. The unit is supervised by the neurorehabilitation consultant supported by a trust grade doctor. Outpatient rehabilitation clinics have been developed in the last two years providing general neurorehabilitation clinics and specialist spasticity clinics.

81. Disability Services Centre: This centre provides prosthetic rehabilitation and regional wheelchair services. A consultant physiotherapist in prosthetic rehabilitation was appointed in the year 2008 to run the service on a day to day basis under the supervision of the consultant in neurorehabilitation.

Recent Development of Rehabilitation Services

82. Specialist Spasticity Management Service: A spasticity clinic has been developed which provides the spasticity management facility in a MDT environment. The clinic is run by the consultant in neurorehabilitation in conjunction with neuro-physiotherapists. Patients have access to all modalities of treatment including oral medication, neuro-physiotherapy, botulinum toxin injection therapy and intrathecal baclofen therapy. In the last two years two senior neuro-physiotherapists have been trained in the administration of botulinum toxin injections, and the use of portable EMG machine.

83. A Trust Grade Doctor in Rehabilitation Medicine has been appointed to support the rehabilitation team on ward 26.

84. Funding and appointment of head injury co-ordinator/head injury nurse: In collaboration with Headway and local Primary Care Trusts, funding has been secured for the appointment of a head injury coordinator/specialist nurse and community support worker. These posts are currently being advertised.[17]

85. Accreditation of Prosthetic Rehabilitation Services as a Training Facility: Middlesbrough disability services centre has been approved as

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[17] These posts have now been filled

the training facility for prosthetic rehabilitation for the rehabilitation trainees in the Northern deanery.

Opportunities for Development

86. The Panel was advised that the Division of Neurosciences at JCUH is one of the two neurosciences centres in the North East, providing services to a large catchment area extending from North Yorkshire in the south, to Durham and Sunderland in the north. It caters for a population of about 1.2 million. The Panel heard that it has a neurosurgical department consisting of seven whole time equivalent consultants and a neurology department with ten whole time equivalent consultants. There is currently one vacant Neurologist post that is being covered by a locum consultant. These two departments are complemented by neuro-radiology, neurophysiology and neuro-rehabilitation departments. In addition, there are specialist nurses in multiple sclerosis, Parkinson's disease, and epilepsy.

87. It was confirmed to the Panel that the neurorehabilitation department provides acute specialist in-patient rehabilitation services, outpatient services, prosthetic rehabilitation services and regional specialist wheelchair service. The in-patient specialist rehabilitation service is a level two facility which is providing service to patients with complex needs. The Panel was advised that as a result, very few patients have been referred to Walkergate Park hospital in Newcastle in the last few years. The patients with complex rehabilitation needs include patients in a minimally conscious state, patients with locked-in syndrome and patients with severe cognitive impairments. Similarly, outpatient clinics have been developed including a specialist spasticity management clinic, thereby providing these services to patients close to their homes as laid down in the national service framework (NSF) for long term conditions[18].

88. The Panel noted with interest that there is no waiting list or excessive waiting time for admission to the neurorehabilitation ward at JCUH. When a referral is received the patients are assessed on the neurosurgery/neurology wards by the neurorehabilitation MDT consisting of the Consultant in Neurorehabilitation, physiotherapists, occupational therapists and speech and language therapists. The patients are transferred to the neurorehabilitation ward as soon as they are medically stable and able to engage with the rehabilitation process.

89. The Panel was interested to explore which areas of rehabilitation would benefit from greater development. The Panel was advised that the

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[18] NESCG has subsequently advised the Panel that whilst the trust may be treating Category A patients this does not mean they are getting 'specialised' treatment - this is what needs to investigated further. NESCG has subsequently advised that clarity is needed around the 'lack of referrals' to Walkergate Park – which is currently being looked into. If there have been 'very few' then the reasons for this would need to be known i.e. is it because patients did not need WGP/did not want to go to WGP/could be treated at STHFT.

areas of required further development include the need for dedicated neuro-psychology therapeutic input, local access to neuro-psychiatry services, provision of vocational rehabilitation and to improve therapy staffing levels for in-patient rehabilitation.

90. It was reaffirmed to the Panel that the rehabilitation facility at Walkergate Park in Newcastle upon Tyne is a level one facility which is commissioned by the North East Specialised Commissioning Group (NESCG). The Panel was reminded that Neurorehabilitation at JCUH, is currently not commissioned as a specialised service (although it is providing services to category A patients) and is commissioned separately by local primary care organisations. The Trust is working in collaboration with commissioner colleagues to review the current commissioning arrangements with a view to develop consistent arrangements across the North East. It was confirmed to the Panel that this is important as accessing facilities at Walkergate Park hospital in Newcastle is difficult, due to long waiting times, the long distances and travelling times involved.

Community Rehabilitation Facilities

91. The Panel was advised that due to a large catchment area, the neurorehabilitation department at JCUH relies on the local services/hospitals for the provision of outpatient/community therapy services. The Panel heard that community rehabilitation facilities in the North East in general are limited and are disease specific. The areas for development include increasing the provision of dedicated rehabilitation beds in surrounding hospitals with medical leadership, increasing community provision and development of multidisciplinary teams (MDTs). This will significantly improve the co-ordination of the rehabilitation process once the patient is discharged from the hospital.

Evidence submitted from North East Specialised Commissioning Group

92. In evidence submitted and considered, the Panel had learned about the role played by, and the services commissioned by the North East Specialised Commissioning Group, relating to Neurological Services. Given the role played by the NESCG and the level of involvement in Neurological Services, the Panel posed a number of questions to NESCG. Those questions were addressed in a paper submitted to the panel by the NESCG.The questions posed by the Panel are outlined below.

92.1 What aspects of Neurological services for the people of Middlesbrough are commissioned by the specialised commissioning function?

92.2 What level of resource is the regional specialised commissioning function responsible for relating to neurological services in Middlesbrough and the North East?

92.3 Where is that money spent?

92.4 From the perspective of a regional specialised commissioner, where are the service gaps in Neurological Services in Middlesbrough?

92.5 What level of intelligence does the regional specialised commissioning function have about the level and type of neurological need in Middlesbrough?

92.6 How is it decided which parts of Neurological Services should be commissioned locally and which should be commissioned regionally?

92.7 The Panel has heard a view that patients from Middlesbrough are placed at a disadvantage when compared to Tyneside based patients. Whilst Neurosurgery is available in the Newcastle & Middlesbrough, it would seem that there is only one neuro rehab unit is commissioned through the higher tariff specialised commissioning route, which is in Newcastle. Is this a position that the specialised commissioning function recognises?

92.8 In the view of the specialised commissioning function, where does the commissioning or provision of neurological services in Middlesbrough need to develop?

93. By way of introduction, The Panel heard that the North East Specialised Commissioning Group (NESCG) has delegated responsibility for commissioning a range of specialised services on behalf of primary care organisations (PCOs) across the North East.

94. It was confirmed that the NESCG membership comprises all the chief executives from the PCTs across the North East, together with directors from the SHA; decisions made by NESCG are binding for all PCT members. The NESCG plans specialised health services for a population of approximately 2.8m (2.5m North East Strategic Health Authority (NESHA), and 0.3m North Cumbria).

95. The NESCG is supported by the North East Specialised Commissioning Team (NESCT), an integrated management team hosted by NHS North of Tyne. NESCT is responsible for leading the day to day commissioning of most specialised services in the North East and also commissioning services on behalf of North Cumbria residents at the request of the North West SCG.

96. It was confirmed that 'specialised services' are those services provided for relatively rare conditions, in relatively few specialist centres, to populations of more than one million people. They are generally high cost, low volume services and are either commissioned regionally, by the 10 Specialised Commissioning Groups (SCGs) - one SCG per SHA - or nationally by the National Commissioning Group (NCG).

97. The Panel was advised that ‘specialised commissioning’ is defined nationally - the Specialised Services National Definitions Set (SSNDS) describe these services in more detail, there are currently 34 specialised services definitions. The definitions provide a helpful basis for service reviews and strategic planning and enable commissioners to make comparisons on activity levels and spend. The definitions help with the identification of activity that should be regarded as ‘specialised’ and therefore subject to collaborative commissioning arrangements.

98. It was confirmed to the panel that as far as neurological services are concerned, NESCT commissions services described in Definition 7, Specialised Rehabilitation Services for Brain Injury and Complex Disability and Definition 8, Specialised Neurosciences Services. There are also aspects of other definitions which overlap with neurological services, such as Definition 5, Assessment and Provision of Equipment for People with Complex Physical Disabilities; Definition 6, Specialised Spinal Services; and Definition 22, Mental Health, for which NESCT will commission.

99. The Panel was interested to learn that all services commissioned by NESCT are available to the whole North East region – the collaborative arrangement does not commission any services on behalf of any individual PCTs. Neurological services commissioned by NESCT in Middlesbrough are provided by South Tees Hospitals NHS Foundation Trust. They include all neurology services, in-patient and out-patient, neurophysiology, neuropathology, neuroradiology, neuropsychology and neurosurgery.

100. It was confirmed that Middlesbrough patients are also able to access any neurological services commissioned by NESCT and provided elsewhere in the region including Newcastle and Sunderland. The regional Specialised Neurorehabilitation and Neuropsychiatry service provided by Northumberland Tyne and Wear Trust at Walkergate Park in Newcastle upon Tyne is a regional service and accepts referrals from Middlesbrough.

101. The Panel was particularly interested to explore NESCG’s views on Neurorahbilaition services, which had previously been identified as a area for development. It was clarified that the Definition for Specialised Rehabilitation Services for Brain Injury and Complex Disability describes the levels of service provision for neurorehabilitation and the categories of rehabilitation need. Specialised rehabilitation services are provided by Level 1 units for Category A patients. Non-specialised rehabilitation services are provided by Level 2 and Level 3 units. Level 2 units provide ‘local specialist rehabilitation’ to patients with Category B needs, they may also accept certain patients with Category A needs depending on the facilities, expertise and staffing levels available. Level 3 units provide rehabilitation in the context of acute or intermediate care services to Category C and D patients.

102. It was confirmed to the Panel that NESCT are responsible for commissioning Level 1 neurorehabilitation services for Category A patients. The panel heard that in the North East this service is provided by Northumberland Tyne and Wear Trust at Walkergate Park. This is a regional, purpose-built facility, opened in 2006, providing in-patient and out-patient services to the population of the North East.

103. The Panel had previously been told that the Walkergate facility and its geographical location (in Newcastle upon Tyne), raised access issues for people from Middlesbrough and the wider Tees area, which were a cause for concern. The Panel heard that NESCT is aware that access to Walkergate Park is sometimes limited and waiting times can be long, this is currently being discussed with the Trust. STHFT provides Level 2 neurorehabilitation at JCUH for category B patients and occasionally category A patients; the service is commissioned by NHS Tees. The Panel noted with interest that NESCT is working in collaboration with South Tees Foundation Trust and colleagues from NHS Tees to review the current commissioning arrangements with a view to develop consistent arrangements across the North East. It was also noted that the prices involved are not part of a tariff per se, but local prices that were negotiated between provider and commissioner.

Resource

Table 1 below shows the 2011/12 contract baseline amounts for each Trust that NESCT holds a contract with for neurosciences and neurorehabilitation.

Total Contract Value for NE PCTs and North Cumbria	South Tees Hospitals NHS FT	Newcastle upon Tyne Hospitals NHS FT	City Hospitals Sunderland NHS FT	NTW FT (Walkergate Park)	Total
Neurology IP	£2,362,430	£3,794,835	£684,669		£6,841,934
Neurology - high cost drugs	£1,726,406				£1,726,406
Neurology OP	£2,420,278	£3,665,757	£1,006,175		£7,092,210
					£0
Neurosurgery IP	£5,232,057	£16,517,896			£21,749,953
Neurosurgery - high cost drugs, devices & HDU	£2,272,161				£2,272,161
Neurosurgery OP	£1,302,571	£4,208,492	£70,659		£5,581,722
					£0
Clinical neurophysiology OP	£743,433				£743,433
					£0
Neurorehab IP				£4,544,179	£4,544,179
Total	£16,059,336	£28,186,980	£1,761,503	£4,544,179	£50,551,998

Note: the above figures exclude CQUIN value.

Table 1: 2011/12 contract baseline

Table 2 below shows the contribution from Middlesbrough PCT to NESCT contracts for neurosciences and neurorehabilitation. This is based on a risk share arrangement across all the PCTs within NESCG. The risk share amount is based on a 5 year rolling average of activity to 2009/10.

Middlesbrough PCT contribution based on risk share apportionment	South Tees Hospitals NHS FT	Newcastle upon Tyne Hospitals NHS FT	City Hospitals Sunderland NHS FT	NTW FT (Walkergate Park)	Total
Neurology IP	£424,641	£3,563			£428,204
Neurology - high cost drugs	£310,318				£310,318
neurology OP	£471,137	£4,178	£284		£475,599
					£0
Neurosurgery IP	£806,552	£26,153			£832,705
Neurosurgery - high cost drugs, devices & HDU	£350,267				£350,267
Neurosurgery OP	£163,158	£3,492			£166,650
					£0
Clinical neurophysiology OP	£131,778				£131,778
					£0
Neurorehab IP				£79,602	£79,602
Total	£2,657,851	£37,386	£284	£79,602	£2,775,123

104. The Panel was interested to ascertain the type of data that NESCT has access to, in order to plan services and consider the performance of those services.

105. The Panel heard that NESCT receives quality and performance data, including waiting times, MRSA and C-Diff rates, as well as activity information at PCT level from all of their providers on a monthly basis. This information is reviewed with each Trust at monthly contract monitoring meetings. This information allows NESCT to develop a

picture of needs across the region and work with the Trusts to manage waiting times and demand for the service.

106. The Panel was interested to learn that NESCT carried out a review of neurology services in the North East, which looked at the incidence and prevalence rates of neurological conditions; this is taken into account when commissioning services. The Panel noted that NESCT plan services based on the needs of the population in the North East and not individual PCT population needs.

107. In relation to other sources of intelligence, the Panel heard that The North East Public Health Observatory (NEPHO) published a Health Needs Assessment for Long Term Neurological Conditions in 2009, this document is currently being updated and will provide NESCT with valuable information on the neurological needs of its population.[19]

108. The Panel was particularly interested in hearing the views of the NESCT regarding where gaps in service exist and where there are opportunities for development. The Panel heard that one of the reasons for long waiting lists at Walkergate Park and potential 'bed blocking' in the neurorehabilitation ward at JCUH, is the lack of appropriate community based neurorehabilitation facilities. The Panel was interested to hear that this fact was recognised as a gap in 2009 and NESCT put out a collaborative tender for 'Step Forward' neurorehab beds on behalf of the North East PCTs. The Panel learned that the tender was unsuccessful due to the lack of competitive pricing from bidders, who based prices on spot purchase rates and failed to provide a discount for collaborative purchasing. It was confirmed to the Panel that there remains a need for 'Step Forward' neurorehab facilities across the region, in order to prevent long waiting times and inappropriate and expensive neurorehabilitation.[20] [21]

109. The panel noted with interest that the lack of community rehabilitation services in Middlesbrough was also recognised during a review of neurorehabilitation services, carried out by NHS Tees in August 2010. The provision of all levels of neurorehabilitation across the region needs to be addressed to ensure consistency, appropriate care and equity of access for all patients.

110. The Panel was keen to speak with the NESCG representatives about their views on the future of specialised commissioning function. The Panel was advised that Subject to the enactment of the Health and

[19] The Health Needs Assessment was commissioned by NENN. A Draft is expected by January 2012.
[20] The Panel has subsequently learned that on 2 December 2011, Directors of Commissioning have agreed to review 'step forward' contracts.
[21] Whickham Villa has subsequently advised the Panel that along with spot purchases of some of the tender companies being an issue, the second key issue for the tender not progressing was the 'equity of access' issue. That is, there was no organisation able to meet the tender specification in Teesside.

Social Care Bill, Specialised Commissioning will become a function of the NHS Commissioning Board (NCB). Specialised Commissioning Groups (SCGs) have already aligned into clusters synonymous with the SHA clusters. Work is being undertaken nationally to ensure a smooth transition to the NCB by April 2013, this includes developing national service specifications and quality dashboards to which all SCGs will be required to commission. The Panel heard that this means that all specialised neurological services across the country will follow the same service specification and report on the same outcomes. The final list of services which will be commissioned as specialised services will be agreed once the Bill has passed through legislation, however the NHS are working on the assumption that all services within the current definitions set will be included.

Evidence from Whickham Villa

111. As part of its review into Neurological Services, the Panel was particularly interested in understanding the current level of service provision available to people in Middlesbrough. The Panel had become aware of the Whickham Villa LLP and particularly the services on offer at its Chase Park Rehabilitation Centre. The Panel was informed that it specialises in neurological rehabiltiation and has 28 en-suite bedrooms and 2 ‘step-through’ apartments. It was confirmed that all staff are specifically trained in neurological conditions and the treatment thereof.

112. The Panel heard that Chase Park has a high level of referrals for rehabilitation clients. The Panel heard that a particular strength of the centre was the expertise of staff, which included:

- Consultant in Rehabilitation Medicine
- Specialist Community Therapy Team
- 1:1 Opportunities Team
- Specialist Nursing Team

113. The Panel was advised that Chase Park has been widely praised for the services it provides, including the following.

- CQC Excellent (3 Star) Rated
- 2007 Pinders/Caring Business award for Best New Specialist Care development
- Headway Approved Provider status

114. The Panel was advised that a particularly positive aspect of the Chase Park service, in the view of Whickham Villa, was the presence of a Clinical Lead, of Consultant rank, in Neuro rehabilitation. The Panel learned that the Consultant has worked as a consultant at Walkergate Park, as a G.P. and as a specialist registrar in Neuro Rehabilitation in Liverpool. The Panel heard that he also has a professional interest in complementary and psychological approaches to healthcare.

115. Following an introduction into the Chase Park, The Panel was advised about the type of service on offer and the culture within which those services are provided.

116. The Panel heard that

“Chase Park Rehabilitation Centre provides Step Forward and Step Up Rehabilitation. All input and interventions are focused on planned discharge prior to admission and are focused on clients individual life goals and around enabling the individual to move forward in their lives towards providing as independent a living environment as possible and a sustainable high quality of life”.

117. The Panel was advised that every package of care at Chase Park is constructed ‘from the ground up’ around the needs of the individual and there was nothing generic about the service provided to clients. Each package of care would be drawn up to meet, as near as possible, the goal of the client. It was reported that the goal of most clients tends to be as much independent living as is possible, which is something that Chase Park embraces through its belief in ‘Step Forward’ care. The features of Step Forward care are:

- Positive
- Flexible
- Person Centred
- Goal Focused
- Emphasis on moving through the service towards the most independent life possible

118. The Panel was interested to hear that the majority of Chase Park clients come from living in the community, where their support package has failed to maintain them in independent living.

119. The Panel was advised that 58% of Chase Park’s clients are discharged within one year, which, the Panel heard was due in no small part to the belief in planning for someone’s discharge as soon as possible. The Panel heard that it was the belief in this approach that set Chase Park apart from more ‘generic’ service providers. The Panel was also advised that, Chase Park reviewed every clients care package and its associated costs, every 12 weeks. As such, whilst the initial costs may be high, it was said that the impact on the client was typically such that the costs would fall substantially as the client’s condition improved.

120. The Panel heard that in considering the rehabilitation of neurological patients, less emphasis needs to be placed on a strictly medical model of rehabilitation, with more focus being placed on what the individual would like to achieve. The Panel heard that too much focus is presently placed on what medicine says they should do next.

121. By way of example, the Panel heard that there is only so much rehabilitation that can be provided in an acute setting and there seemed to be more of an acceptance that providing someone with the best possible rehabilitation required many organisations' input.

122. The Panel heard that the growing acceptance of the importance of collaboration in people's care, also came at a time when huge changes within the structure of the NHS were underway. Whilst these changes posed some threats, particularly around the loss of knowledgeable staff and the erosion of organisational memory, they did also present an opportunity to do things differently in arranging neurological rehabilitation.

123. Whilst the Panel was impressed with the range of services that Chase Park offered, its ethos and the apparent impact it had on people, it did also note that it is a Tyneside based facility that is typically not accessed a great deal by people from the Tees area. Indeed, according to data supplied by Whickham Villa, 88% or referrals originate from Gateshead, Northumberland, Newcastle and Sunderland. Whickham Villa can only accept the referrals it receives, so the Panel was, and remains concerned, that a similar facility is required in the Tees area to ensure that people from Tees with similar complaints can have access to similar services.

124. On the point of rehabilitation, the Panel heard that it is relatively well known in neurological circles that Middlesbrough and the wider Tees Valley has a unsatisfactory amount of rehabilitation facilities. It is, the Panel heard, often the case that patients will receive outstanding care at JCUH, but the same capacity for rehabilitation outside the hospital does not exist. To expand, the Panel heard that Middlesbrough has a lack of good quality transitional housing for such people, which can mean that they are placed in generic care homes, when they do not really need to be there and they are not the best for their needs.

125. The Panel heard that the fact that STHFT had taken on responsibility for Community Services was a positive, as it would now have more of an organisational stake in ensuring that when people are discharged from an acutesetting, they are greeted by community services of sufficient capacity to cope with their needs.

126. The Panel heard that a big step forward in the provision of community facilities would be the realisation of the Gateway Project in Middlesbrough. The Gateway Project will focus upon

- Step Forward Rehabilitation
- Step Up Wellbeing Centre & Community/Resource Hub
- Transitional Housing & Long Term Housing

127. It is a collaboration of the following organisations

- South Tees Hospitals NHS Foundation Trust

- Middlesbrough Council
- Middlesbrough PCT
- Housing (Erimus/Fabrick)
- Middlesbrough College
- Teesside University
- Vocational Rehab
- Social Enterprise
- TVDNY & 3rd Sector
- Community Rehab Team
- Teesside LA's
- Telecare and Technology
- ONE
- HCA
- Tees Valley Unlimited

128. The Panel heard that it will provide a certain equity of access for people in the Tees Valley, with people who live in the Tyneside area. The Panel heard that it will also provide investment in the Middlehaven area, as well as having very close links with Middlesbrough College and providing training opportunities for students.

129. The Panel was keen to hear the views of Whickham Villa on the topic of 'where do we go from here?' in relation to neurological services? The Panel heard that a greater emphasis needs to be placed upon the idea of commissioning services for the 'whole' person and avoiding the social care and health split in funding, that can still be the case today and complicate the delivery of 'seamless care'.

130. The Panel heard that there is undoubtedly a greater need for neuro rehabilitation services in the Tees area, to ensure an equity of provision. It was confirmed that at present there is insufficient neuro rehab capacity in the Tees area and this is something that needs to be improved as a priority.

131. This, the Panel heard, should be linked to a review of neurorehab commissioning to ensure that the commissioning strategy matches need and that appropriate specialised capacity is effectively commissioned. Connected to commissioning strategy, the Panel heard that it would be also be a highly worthwhile exercise to assess the numbers and locations of people, currently on out of area placements receiving neuro rehab. Those people may be able to be repatriated into the area, bringing benefits for them and keeping more NHS monies in the local area.

Evidence collected during the roundtable debate – 28 November 2011

132. During the course of the review into Neurological Services, the Panel considered a great deal of evidence from a wide range of sources. To finalise its evidence base, to make further enquiries and to bring different perspectives together, the Panel was keen to hold a roundtable debate with witnesses it had spoken to previously.

133. The panel had identified a number of questions that it wanted to explore at the roundtable debate, which are outlined below.

133.1 The Panel has heard from a number of separate sources that community based neuro-rehabilitation services in Middlesbrough are particularly poor. This, the Panel has heard, is a significant factor in Middlesbrough having high readmission rates for neuro conditions. Is this a picture that those around the table recognise? If so, where do we go from here to improve the reality?

133.2 Connected to the above, does Community Services becoming part of the South Tees Hospitals Foundation Trust represent an opportunity to do improve things? If so, what should happen? Should this include the development of primary/community services to allow the effective management of more neurological patients, thereby allowing hospital based expertise to be reserved for the most appropriate cases?

133.3 The Panel has heard from a number of sources that there are concerns over the ease of access to rehabilitative services based at Walkergate in Newcastle, for people based in Teesside. The Panel has heard that these difficulties include the ability (or not) of people to travel to Tyneside on a regular basis, as well as a concern over the equity of access to these services for people from Teesside. Is this a concern that those around the table share? Why? What should be done about it?

133.4 The Panel has heard the view expressed, on more than one occasion, that there are people with neurological conditions placed inappropriately in generalist facilities, or in the community without appropriate support packages, who have very little chance of ever making any significant rehabilitative progress. What are the views of those around the table as to why that happens? How do should it be tackled?

133.5 The Panel has been exposed to an ongoing debate around the nature of neuro-rehab services that are currently provided at James Cook University Hospital and their status. The Foundation Trust has asserted that it provides Level 1 neuro-rehab services and should be designated as such, with the benefits that flow from that. The North East Specialised Commissioning Group has informed the Panel it would like to see evidence of the relevant activity undertaken at JCUH. Do those around the table feel that neurological services in the Tees area, and the patients accessing those services, would benefit from having a level 1 rehabilitation centre locally?

133.6 Are there any other important aspects of Neurological Services that those around the table would like to raise with the Panel?

134. As such, the Panel held that debate with representatives of NHS Tees, North East Specialised Commissioning Group, South Tees Hospitals

NHS Foundation Trust, Whickham Villa and the North East Neurosciences Network.

135. The Panel started by exploring a theme it had heard repeatedly, namely that neuro rehab services in the Tees area were insufficient. There was unanimous agreement around the table that community based neuro rehab services, whilst those available are very good, there is nothing like as much capacity as needed. The Panel heard that the term ‘patchy’ was a good adjective to use to describe the services available.

136. The Panel was advised by STHFT that it would contest the idea that readmissions are high in neurological services, although there are specific aspects of epilepsy that can require frequent admission. Still, all around the table accepted the point that the amount of services available to a neuro patient upon discharge, from rehabilitation to welfare rights advice was not as comprehensive as it should be.

137. Whilst accepting the unanimous view that the capacity of support services to recovering neuro patients needed to improve, the Panel was also conscious of the fiscal reality facing public services and wanted to explore what was achievable within that context.

138. There was widespread agreement that should the Gateway Development at Middlehaven become what is envisaged, that would be a significant contribution to services on offer locally. Specifically, the Panel was interested in the idea of the Gateway project’s connections to Erimus Housing and the potential to explore supported housing for people in neuro rehabilitation. That was felt to be a very good option over the concept of people having to be accommodated in generic care homes that may not be appropriate.

139. The Panel was interested to hear, connected to neuro rehab, that a number of neurological patients living in the community could benefit from a periodic spell of treatment, such as intense physiotherapy, to maintain their condition and prevent any worsening. An analogy was drawn with a service that a car may receive, to eliminate any possible problems before they develop and to ensure that things are working as they should. The panel found this comparison quite helpful. The Panel heard that there is not, as things stand, any facility in Middlesbrough that this could happen, yet it would be hugely beneficial to offer this.[22]

140. The Panel heard that Community Services now being part of the STHFT organisation would be advantageous in planning people’s care and ensuring a more seamless experience. Whilst it is early days in

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[22] The panel has subsequently heard that this is exactly one of the services that the Gateway will be specifically providing – ‘Step Up’ rehab for non residents from the community from day services or as part of short term residential rehab blasts/services is very much at the heart of maintaining client independence/at home. It was reported that this improves outcomes for the clients and avoids expensive hospital admissions and or alternate long term care options as clients needs deteriorate.

that organisational relationship it was felt that small positive developments were already starting to happen, such as Occupational Therapy and Community Physiotherapists having a much closer working relationship with the Trust.

141. On the topic of provision of services in the Community, the Panel heard that historically, when people's condition has not been maintained or worsened, patients have ended up being readmitted into an acute ward, for a form of rehabilitation, which is not the best use of resources or the most appropriate place to be. Historically some people may even have gone into generic nursing homes for this purpose, which, the Panel heard, is far from he best option. Thus, the unanimous view was that the case for some form of active rehabilitation service in the community was quite clear. The idea was suggested that the new Redcar hospital could be utilised for this purpose, to serve the South of Tees area.

142. The Panel was interested to hear that those around the table felt that historically, Neurological Services and the needs of patients, probably suffered from a lack of profile or a lack of prominence. This, the Panel heard, had resulted in those in primary care not knowing as much about neurological services as other areas of service. This was also probably allied to the relative rarity of General Practice coming across neurological conditions.

143. The Panel was interested to explore further the experience of someone in the community, should they start to suffer neurological problems following discharge. It was said that whilst they may approach their GP for assistance, the expertise probably doesn't exist there. The possibility of the acute sector having a three month check up with a discharged patient would be ideal, although the system currently isn't sophisticated enough to allow for this.

144. The Panel heard that a particularly good idea may be the development of advocates in the community to work with patients and their families to secure the assistance they require. An argument for a specialist social worker in the neuro field was put forward as a potentially important step forward, as the Panel was advised that a similar role works very well in spinal services. The Panel heard that the role would provide someone to talk to, who knows the system, knows how the advance a patients case if needed and someone to help get things done.

145. The impact of a social worker and their role in bringing different service strands together was highlighted as a way of guaranteeing that people's care packages were ready and waiting upon discharge and there was no lead in period once someone was home.

146. The Panel was particularly interested to explore a debate it had heard previously, specifically around whether JCUH was providing Level 1

neuro services and should, therefore, receive an increased rate of income from the Specialised Commissioner.

147. The Panel had heard previously that in the view of STHFT, JCUH was treating a substantial number of Category A patients, and should be commissioned accordingly (at a higher rate) by NESCG, in a similar vein to how the Walkergate facility in Newcastle is commissioned.

148. The Panel put this to the NESCG and heard that the specialised commissioning function would require evidence to substantiate this, before any additional commissioning (and therefore financial[23]) decisions were made. The Panel heard that this conversation is currently ongoing and it is for the STHFT to present evidence to NESCG that they are undertaking sufficient level 1 activity to be designated and commissioned as a Category A service.

149. The panel felt, and heard the view expressed, that Walkergate in Newcastle presents access problems for people from the South of the region and its location does present inequities in access to the services that needed to be addressed. Quite apart from getting additional resources into JCUH, if the evidence supported that, the Panel felt that the widely perceived problems in accessing Walkergate for people in Tees and North Yorkshire needed to be tackled. Without being tackled, it would be hard to argue that the people in the South of the region have the same level of access to a very bespoke and specialist service. It was also said that if JCUH received additional funding, it could then bring its staffing ratios in line with what would be expected of a Level 1 centre, although it would be difficult to argue against a Level 1 designation because it did not have Level 1 staff ratios. The funding would have to flow first.

150. The Panel was advised that those discussions between NESCG and STHFT were ongoing and would be very interested to hear the outcome.

151. The point was made to the Panel again that the local health and social care economy should conduct an audit on out of area placements to see ‘who is where, what they are there for and how much it is costing’. The Panel heard that Out of Area placements are something that has developed over time and an audit of them was long overdue. It may be that some of those people could be repatriated at a benefit to them and a lower cost to the health and social care economy.

[23] The Panel has been advised that the financial decision would be around increasing the staffing level/facilities to a Level1 standard. This is not necessarily the bed day rate.

Conclusions

152. On the basis of the evidence considered, it is clear that Middlesbrough does not have sufficient capacity to deal with the need for neuro-rehabilitation. The Panel has consistently heard that what is available is good, but it is not of sufficient capacity to meet the demand. Until this is addressed, it cannot be argued that Neurological patients in Middlesbrough have all the services they require. The Panel feels that there is a very strong argument for Neurological Rehabilitation services and intelligence around local need being included in the refresh of the Joint Strategic Needs Assessment.

153. On the basis of the evidence heard, there is a strong argument to suggest that the emerging Clinical Commissioning Group, together with the current PCT, should start to consider developing community based expertise in neurological conditions, and their rehabilitation. The Panel has heard this would be an important step as historically, neurological patients have been admitted into acute wards when it has not been necessary.

154. The Panel notes that the concern over the amount of community based rehabilitative services will be eased to some extent, if the Gateway project is delivered as envisaged. That project promises to be an important addition to what is already on offer in Middlesbrough.

155. The Panel has heard quite a lot of comment about the importance and potential impact that a specialist Neurological Services Social Worker could have. The Panel is mindful that it does not have sufficient expertise to make a judgement as to whether this should or should not be implemented, although it does feel that the idea is worthy of discussion, given the expertise of those who raised it in evidence.

156. The Panel has noted that there is an element of uncertainty, which needs to be resolved, around JCUH and its rehabilitation capacity. The uncertainty centres around whether JCUH provides a sufficient amount of level 1 rehabilitation, to be officially designated by Specialised Commissioners as a Level 1 facility. If JCUH obtained this classification it would probably mean that it would receive a greater level of funding and prestige, as well as the increase in staff resources that this funding would allow. It would also ensure that the south of the region had realistic access to Level 1 rehabilitation facilities, as well as supporting and supplementing the fact that JCUH has recently being designated as a Major Trauma centre. The work to identify whether this designation should be made is currently ongoing and the outcome should be known soon.

157. The Panel has heard from a number of sources that patients based in Middlesbrough, and the surrounding areas, do not seem to have the same level of access to the specialist rehabilitation facility on Tyneside, as those patients based in the north of region. Whether this is solely

down to geography is not entirely clear, although it seems to be an issue that is widely accepted and requires attention.

158. The Panel feels that there should be ongoing support given, by the local statutory sector, to NENN. For a relatively little money, it seems to provide good value for commissioners as well as other interested parties. It is perhaps even more important that it continues to operate in a period of structural turbulence, so it could ensure a great deal of organisational/service expertise is not lost and passed onto new commissioners.

Recommendations

It is recommended that:

159. James Cook University Hospital should be designated as a Level 1 neuro rehabilitation centre. This would ensure that the south of the region has appropriate access to Level 1 facilities and services. It would also be seem a logical step, given that JCUH has recently being designated as a major trauma centre. The North East Specialised Commission Team and South Tees Hospitals NHS Foundation Trust should expedite their work to ascertain the precise level and type of rehabilitation activity performed at JCUH. The Panel would like to hear the outcome of this work and the rationale behind a decision, as soon as possible after its completion.

160. Connected to the above work and whatever its outcome, action needs to be taken by commissioners to tackle the perceived inequality of access to specialist rehabilitative services for those in the south of the region. If it is perception and not reality, it should be rebutted with evidence. If, after investigation, a genuine inequality of access exists, action must be taken to ensure better access to such specialist support for those in the south of the region. The panel would like to know what that action will be.

161. That NHS Tees leads a piece of work to ascertain the current capacity of neuro rehab services in Tees, against the current level of evidenced need. It should then develop a commissioning strategy to ensure that there is a plan to ensure service capacity for accessible neurological rehabilitation is more closely aligned to actual need. Connected to the point of rehabilitation, the Panel would emphasise the importance of service (and provider) integration when providing someone with rehabilitation services. Specifically around the proposed Gateway project at Middlehaven, the Panel would like to receive a report on how service integration will be ensured.

162. That the local health and social care economy investigate whether a specialist, neurological services based social worker would be worth introducing. The Panel would like to know the outcome of that work.

163. That the next iteration of the Joint Strategic Needs Assessment has a section on Neurological Services and the services required, versus those currently provided. All of this should be presented against the backdrop of current and rigorously obtained intelligence about local prevalence of Neurological conditions.

164. That a plan be developed as to how the NENN will be supported to operate in the future.

ACKNOWLEDGEMENTS

This Report would not have been possible without the input of a number of people. The Panel is very grateful for the assistance and expertise of the following:

- Glenys Marriott – Chair, North East Neurosciences Network
- Jill Moulton – Director of Planning, South Tees Hospitals NHS Foundation Trust
- Sue Geldart – Divisional Manager of Neurosciences, South Tees Hospitals NHS Foundation Trust
- Prof. Philip Kane – Chief of Neurosurgery, South Tees Hospitals NHS Foundation Trust
- Dr Gavin Young – Consultant in Neurology, South Tees Hospitals NHS Foundation Trust
- Dr Khalid Anwar – Consultant in Neurology Rehabilitation, South Tees Hospitals NHS Foundation Trust
- Mr Boda Gallon – Chief Executive, Whickham Villa LLP
- Lisa Barber – Specialised Commissioning Manager, North East Specialised Commissioning Group
- Peter Dixon – Deputy Director, North East Specialised Commissioning Group
- Paul Whittingham – Commissioning Manager, NHS Tees.

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- National Service Framework, Long term conditions © Department of Health. Please see www.dh.gov.uk

- *Neuro Numbers,* Published by the Neurological Alliance, ISBN 1901893324. Can be found at http://www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

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