South Staffordshire NHS
Primary Care Trust

REPORT TO THE TRUST BOARD
TO BE HELD ON: 26th MAY 2010

Enclosure:	Fourteen					
Subject:	SSPCT Strategy for Progressive Neurological Conditions					
Lead Director:	John Wickes					
Lead Officer:	Chris Oliver (Pam Bostock, Clinical Champion for Long Term Neurological Conditions).					
Recommendation:	**For Approval**	**x**	**For Discussion**		**For Information**	

PURPOSE OF THE REPORT:

To present the Progressive Neurological Strategy for South Staffs PCT for Board approval. PEC have already received and approved this strategy.

KEY POINTS:

This strategy has been analysed against, and details requirements of the NSF for long term conditions, which is now 5 years into the 10 year implementation plan. It has been developed in partnership with providers of acute and community care, clinicians, service users and the voluntary sector across SSPCT following the WCC process.

The key points of the strategy detail:

Analysis of care provision for progressive neurological conditions (PNC) in SSPCT, along with detailed description of individual services
Disparities across the geographical area for each consortia

Assessment of services against policy (NICE NSF LTC /WCC/Standards for health)

Provides a gap analysis

Proposes an ideal service specification for PNC

Details recommendations required to adhere to national, regional and local requirements and service user/clinical and voluntary sector expectations.

Progressive neurological conditions are often highly complex, requiring a multidisciplinary approach, and can be extremely costly on health care resources, for example the last year of life for a person with motor neurone disease has been conservatively calculated at £340,000.

Unscheduled admissions into acute care in SSPCT for PNC for the period 2008/9 is calculated at nearly £1.5 million (see over). Delivering care in the community could potentially save 68% of this figure. It is now the task of the QIPP agenda and Practice Based Commissioners to drive this initiative forward.

CORPORATE OBJECTIVES: CP1. Improve South Staffordshire PCT's World Class Commissioning rating, Objective: CP6.Improve the PCT's annual Health Check rating to at least good for quality of services, Strategic Theme: 5. Improve Care of people with long term conditions

RESPONSIBLE COMMITTEE:

NAME: SSPCT Board

APPROVED at cmte: YES/NO Date of Cmte:

IMPLICATIONS:

Legal and/or Risk	
Standards for Better Health	C3,D1, C5, C6, D2, D5, C13, D8, D10, C17, C18, D11
Patient Safety	The strategy addresses the NSF-LTC to improve patient safety, quality, information and choice.
Patient Engagement	The strategy has been developed in consultation with, and with invaluable contributions from Service users/carers, voluntary organisations, clinicians and commissioning staff in community and acute sectors within all SSPCT consortia. Recommendations include the development of consortia based service user groups for the proposed specialist teams, and a SSPCT Neurological Alliance to continue engagement between aforementioned interested parties and PCT commissioners.
Financial	From figures taken form 2008/9 SSPCT data , Progressive neurological conditions contribute to approximately 1.5 million in unscheduled admissions to acute services, 68% of which receive no coded interventions. This money could perhaps be better utilised to improve services across SSPCT in line with national recommendations to give: timely access to specialist treatment and advice in locally based teams maximise independence in self management strategies improve quality of care improve patient experience and choice reduce unnecessary hospital admissions.
PBC	The PBC are essential partners in delivering this strategy
Training	There are training implications to primary care in training and developing the workforce to implement evidenced based care.

RECOMMENDATIONS / ACTION REQUIRED:

The SSPCT Trust Board is asked to:
Accept and ratify the strategy
Recommend the implementation of the strategy recommendations

South Staffordshire NHS
Primary Care Trust

Progressive Neurological Conditions Strategy

(short version)

SOUTH STAFFORDSHIRE PRIMARY CARE TRUST

The Progressive Neurological Conditions Strategy has been developed by the Long Term Conditions Service Improvement Board sub group 'Progressive Neurological Conditions Strategy Task & Finish group' .

December 2009 revised April 2010

Our Vision

‘ ..to work in partnership to deliver equitable, high quality and innovative person centred health care for people affected by a progressive neurological condition in South Staffordshire..’

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Executive Summary

A long term neurological condition results from disease of or damage to the body's nervous system.

Long-term neurological conditions cover a spectrum consisting of:

Sudden onset conditions (e.g. brain or spinal injury)
Intermittent and unpredictable conditions (epilepsy or certain headache)
Stable Neurological Conditions, but with changing needs due to development or aging (e.g. adults with cerebral palsy or post-polio syndrome)
Progressive Neurological Conditions (NSF, 2005).

Recent audits in SSPCT have demonstrated local inequalities in care, historical under spend in resources and a poor understanding of the complexity of those neurological conditions with no cure, such as Motor Neurone Disease, Multiple Sclerosis, and Parkinson's disease. These **Progressive Neurological Conditions** often result in;

….'progressive deterioration in neurological function leading to increasing dependence and care from others' …..(NSF- LTC, 2005:p9:17).

It was decided therefore, to concentrate on Progressive Neurological Conditions as the first part of what is hoped will be an evolving strategy for all long term neurological conditions (e.g. epilepsy, headache, brain and spinal cord injury, cerebral palsy and post-polio syndrome).

Progressive Neurological Conditions are often highly complex, requiring intervention from a spectrum of specialist multi-disciplinary neurological rehabilitation professionals, as well as intensive packages of personal care, specialist equipment, housing adaptations, benefits and advice, respite care, education and psychological support for carers and those directly affected by the condition. For some conditions the deterioration can be rapid. These services can also be costly for commissioners, for example it has been estimated that care for the last year of life for a person with Motor Neurone Disease, is an average of £340,000 (MNDA, 2008).

The Strategy document was developed by a dedicated working group comprising clinical staff from primary and secondary care, service users, representatives from regional and national voluntary organisations and SSPCT commissioning staff. Although Social Care was unable to directly contribute to the process, references to the necessity and benefits of joined up health and social care provision is detailed throughout the document.

The aim of this strategy is to analyse and describe current availability of services for PNC, identify good practice, and gaps in provision, and provide a visionary but realistic service specification. This specification would enable high quality cost effective health and social care for people with Progressive Neurological Conditions throughout South Staffs PCT to be delivered, with improved productivity, reduced hospital stays, and afford enhanced quality of life for users of the service.

National Drivers
A number of national drivers have influenced the development of this strategy, namely the National Service Framework for long term Conditions (NSF-LTC) (2005). This tool makes recommendations to ensure delivery of the key concepts of the NHS Improvement plan (2002) by providing efficient, supportive and appropriate services at every stage from diagnosis to end of life. The DoH Social Care green paper (2005) recommends services for people with a long term condition should be person-centred, proactive to minimise the need for unscheduled in-patient care, and that care should be seamless across organisational boundaries – a theme reinforced by 'Our Health, Our Care, Our Say'(DoH 2006). Supporting people with Long term Conditions (DoH, 2009) guides commissioners in the provision of personalised health and social care and supports key themes detailed in World Class Commissioning (2008).

Key Themes/Service Development Priorities identified:
Inequitable service provision across SSPCT for Progressive Neurological Conditions.

All regions (except East Staffs) noted the need for community based specialist neurology teams, encompassing specialist nursing and rehabilitation staff, with adequate staffing levels to meet national clinical guidance recommendations. A theme reinforced by WMRHA (November 2009).

Integrated health and social care teams are required, with establishment of generic health care assistants.

greater and more timely access to specialist Neuropsychological services required across the Trust (except South East Staffs)

Communication difficulties between services e.g. acute and community services, rehabilitation services and GP's, health care and social care exist, with demonstration of disparate working. Where designated interagency teams meeting regularly are in place, many of the communication difficulties especially between health and social care have been resolved.

A need for a neurological network across SSPCT to address some of the communication difficulties mentioned above.

Recognition of palliative care needs and development of services for PNC across the trust, including training for specialist neurological teams. Access to adequate night-sitting services for people with PNC.

Greater consistency with continuing care assessment and provision across the trust, with greater relevance for condition specific conditions

Improvement in timely access and provision of equipment and wheelchairs for both health and social care

Better information directories required to improve knowledge for service users and clinical staff
Written detailed protocols for service provision required to establish consistency of service provision and for audit of standards across SSPCT

Need to analyse current working practices across organisations

Summary
Despite many national policy changes over the last 10 years to encourage joint working, achievement of real integrated services nationally remains patchy, with services for

people with Long Term Neurological Conditions lagging behind (Bernard et al, 2008).
This strategy has demonstrated examples of exemplary care provision for PNC, but also that the trust and partner organisations are failing to meet best practice guidance and government recommendations. Additionally huge disparities in care provision across SSPCT, have been demonstrated, both within health and social care, leading to a post code lottery of care provision.

Recent NHS indicators for quality improvement, which focus on patient experience against exact national policy aims, demonstrate that people with long-term conditions want greater control of their lives, to be treated sooner before their condition causes more serious problems and to enjoy a good quality of life. This means transforming the lives of people with long-term conditions to move away from the reactive care based in acute settings towards a more systematic person-centred approach, where care is rooted in primary and community settings and underpinned by strong partnerships across the whole health and social care spectrum. Delivering high quality care down steam from traditional acute settings is affordable and by supporting people to live and die safely in the community they have a better experience which is clinically safe and is cost effective.

It is essential, therefore, that as well as the availability of specialised neurological care teams providing care as close to home as possible, that there is integrated working between health and social care to provide a whole range of health care and support. To meet Government guidelines and recommendations the challenge for SSPCT is to consider investment in new services where obvious gaps exist, reorganisation of care provision in other areas, and partnership working with social care, other public and third sector organisations, in order to make these recommendations a reality.

NATIONAL STRATEGY/CONTEXT

The Department of Health charges PCT's to ensure there is appropriate capacity and capability to commission services for long term neurological conditions, 'using the NSF-LTC (DoH, 2005), as the basis for clearly articulated commissioning intentions' (CSIP, 2007: p15).

It is recommended that PCT's undertake a needs assessment of local populations, taking advice from service users, professional and other experts to expand knowledge of conditions and service requirements, and establishing commissioning alliances between health and social care. Additionally the whole range of services should be tested, from critical care and specialist rehabilitation to maintenance care, home adaptations, supported housing and assistive technologies (CSIP, 2007).

National Service Framework- Long term Conditions (DoH, 2005)

The NSF-LTC (2005) was developed as a tool for health and social care services, to ensure delivery of the key concepts of the NHS Improvement plan (2002) to support people with long term conditions, by providing efficient, supportive and appropriate services at every stage from diagnosis to end of life. The 11 Quality requirements were derived from a raft of specific neurological research (quantitative /qualitative and expert opinion) and cover elements of: timely diagnosis and treatment, access to relevant information and support, person centred care and choice, access to community based rehabilitation, equitable access to continuing health and adult social care, and specialist neurological palliative care.

Independence, well-being and choice: our vision of the future of social care for adults in England (DoH, 2005).
The adult social care green paper recommended in particular that services for people with a long term condition should be person-centred, proactive to minimise the need for unscheduled in-patient care, and that care should be seamless across organisational boundaries. It is suggested that this be achieved by joint working between health and social care services, at all

organisational levels in both planning and providing care. Furthermore, 'Our Health, Our Care, Our Say', (DoH 2006), continued this theme, recommending an integration of personal health and social care plans and provision of care.

Multiple Sclerosis Clinical Guideline 8- (NICE, 2003)
NICE (2003) offers recommendations for specific interventions of care for people with MS, focusing on: rapid diagnosis and timely access to diagnostic services and follow up appointments, seamless responsive services with access to specialist care and rehabilitation, thorough problem solving assessments and self referral after discharge.

Parkinson's disease Clinical Guideline 35 (NICE 2006)
Similarly offers guidelines for clinical interventions for specific professional groups, incorporating referral to an expert for diagnosis, guidelines on review of pharmacological interventions, regular access to a multi-disciplinary specialist neuro-rehabilitation team, and appropriate access to condition specific palliative care. Like the NSF (2005) and NICE (2003) this guideline reiterates the importance of person centred care.

A guide to good practice in Dystonia (The Dystonia Society, 2009)
This document, designed for health and social care professionals as well the general public details information about Dystonia and how to seek a timely diagnosis and effective treatment and management. The society emphasises the importance of person centred care and avoidance of long delays in diagnosis and treatment. Additionally because Dystonia has traditionally been poorly recognised, and under resourced, the document is intended as a beginning of a pathway of care demonstrating excellence in treatment and management which it is hoped, ultimately will receive NICE guidance.

'Your Health, Your Way' (DoH 2008)
Key themes of 'Your Health, Your Way' (DoH 2008), are to 'empower and support people with long term conditions to understand their own needs and be able to make an informed choice about self care support'. According to the recommendations this will occur by giving people: relevant information, skills, and training to improve health knowledge.

Supporting people with Long term Conditions (DoH, 2009)
This document – a commissioning guide to provision of personalised health and social care for people with long term conditions describes how personalised care planning underpins excellent management of long term conditions and end of life care, and supports key themes detailed in World Class Commissioning (2008), Commissioning for Health and Well Being, Putting People First, and High Quality Care for All.

There is evidence that by making services more individualised with greater information to make health care choices and also by providing proactive care closer to home, can reduce health inequalities and disease complications (DoH 2007b). Evidence of greater self care/management can reduce GP and outpatient appointments, enhancing self control and empowerment, key quality of life indicators (Walley Hammell, 2004).

Summary
It is essential, therefore, that as well as the availability of specialised neurological care teams providing care as close to home as possible, that there is integrated working between health and social care to provide a whole range of health care and support. The challenge for SSPCT is to consider investment in new services where obvious gaps exist, reorganisation of care provision in other areas, and partnership working with social care, and other public and third sector organisations, in order to make these recommendations a reality.

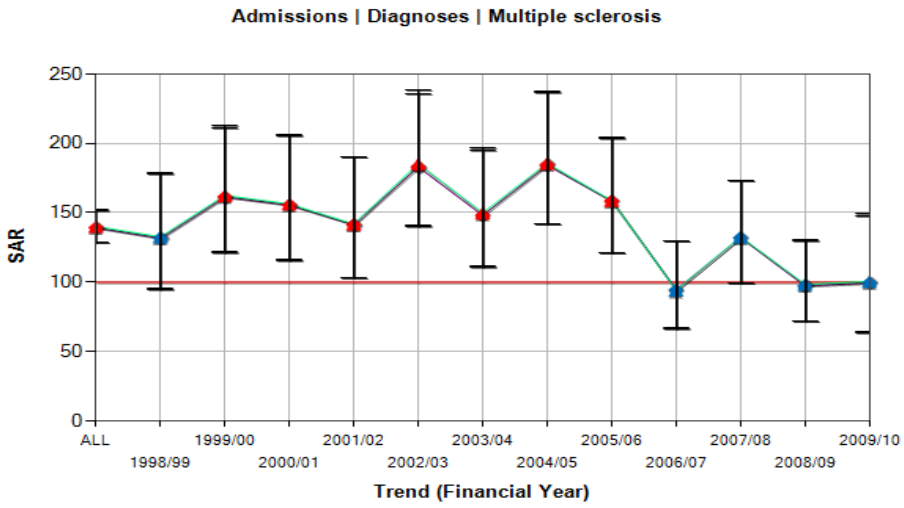
LOCAL CONTEXT

Because of a lack of consistency of service provision for Progressive Neurological Conditions (PNC), locally and nationally, it has been difficult to determine accurate data and analyse against national standards, across SSPCT. This is compounded by Progressive Neurological Conditions not being an essential coding requirement for primary care QOF data and by inaccurate coding of these conditions by secondary care services. There is an obvious local need to improve data collection and coding, in SSPCT.

However, early analysis by Dr Foster data would imply that where community based specialist neurological teams exist in SSPCT non elective admissions into acute care are reduced, and in patient bed days following admission are significantly lower than the national average. This is demonstrated in the table below. When services for progressive neurological conditions were TUPED from the acute sector in East Staffs in 2005/6 and a specialist team for progressive neurological conditions established in the community, admissions for Multiple Sclerosis fell below the national average, and has continued to fall. A similar picture can be demonstrated for Parkinson's Disease.

Figure 1 – Dr Foster data re Multiple Sclerosis graph

- **Basket**: Diagnoses - ALL | **Outcome**: Admissions
- **Chapter**: Nervous System | **Diagnosis**: Multiple sclerosis
- **First / Last**: Apr-98 / Sep-09 | **Admission Type**: All | **Sex**: All | **Deprivation**: All | **Age Range**: All
- **Admissions**: 585 (0.4) | **Expected**: 420.0 (0.3) / 417.4 (0.3) | **SAR**: 139.3 (128.2-151.0) | **SAR (excl dep)**: 140.2 (129.0-152.0)



First bar: Adjusted for deprivation
Second bar: Not adjusted for deprivation

Table 1 below is the breakdown of the graph (Figure 1) above. It shows the SAR (Standardised admission rate) for the East Staffordshire locality for MS. The SAR will take into account deprivation and not adjusted for deprivation.

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				Adjusted for deprivation					Not adjusted for deprivation				
Trend (Financial Year)	Adm	Pop	Rate/k	Exp	Rate/k	SAR	Low	High	Exp	Rate/k	SAR	Low	High
ALL	585	120128	0.4	420	0.3	139.3	128.2	151	417.4	0.3	140.2	129	152
1998/99	42	115481	0.4	31.9	0.3	131.7	94.9	178	31.7	0.3	132.7	95.6	179.3
1999/00	53	115481	0.5	32.8	0.3	161.5	121	211.2	32.6	0.3	162.5	121.7	212.5
2000/01	50	115481	0.4	32.1	0.3	155.6	115.5	205.2	32	0.3	156.4	116.1	206.2
2001/02	44	115481	0.4	31.1	0.3	141.5	102.8	189.9	31	0.3	141.9	103.1	190.5
2002/03	60	115481	0.5	32.8	0.3	183.2	139.8	235.8	32.4	0.3	185.3	141.4	238.5
2003/04	51	115481	0.4	34.4	0.3	148.2	110.4	194.9	34	0.3	149.9	111.6	197.1
2004/05	62	115481	0.5	33.6	0.3	184.5	141.5	236.6	33.4	0.3	185.6	142.3	238
2005/06	61	126716	0.5	38.5	0.3	158.5	121.2	203.6	38.4	0.3	158.8	121.5	204
2006/07	38	127694	0.3	40.3	0.3	94.3	66.7	129.4	40.3	0.3	94.2	66.6	129.3
2007/08	53	127478	0.4	40.1	0.3	132.1	98.9	172.8	40	0.3	132.6	99.3	173.5
2008/09	47	127478	0.4	48.3	0.4	97.4	71.6	129.5	47.8	0.4	98.4	72.3	130.9
2009/10	24	127478	0.4	24.1	0.4	99.5	63.7	148	23.9	0.4	100.5	64.4	149.6

National Incidence and prevalence of long term neurological conditions

Condition	Incidence per year 100,000	Prevalence per 100,000
Parkinson's Disease	17	200
Multiple Sclerosis	3-7	100-120
Motor Neurone Disease	2	7
Dystonia	n/k	65
Ataxia	n/k	
Creutzfelt-Jacob Disease	n/k	
Congenital Basal Degeneration	3	n/k
Hereditary Sensory Motor Neuropathy (Charcot Marie tooth)	n/k	40
Huntington's Disease (HD)	n/k	13.5
Malignant Brain Tumours	n/k	
Multi-systems Atrophy (MSA)	3	
Muscular Dystrophy	n/k	50
Progressive Supra-nuclear palsy (PSP)	6	

Area Population Data

Area	2009 Population
Cannock & Rugeley	130,174
Burton & Uttoxeter	130,599
Wombourne & Kinver	50,087
Tamworth, Lichfield & Burntwood	158,021

Stafford & Stone	146,469
All South Staffordshire PCT	615,350

Estimates of number of new cases per year (incidence) in SSPCT

Area / Condition	Parkinson's Disease	Multiple Sclerosis	Motor Neurone Disease	Dystonia
Cannock & Rugeley	24	9	3	1
Burton & Uttoxeter	25	9	3	1
Wombourne & Kinver	16	4	1	0
Tamworth, Lichfield & Burntwood	30	11	3	2
Stafford & Stone	28	10	3	2
All South Staffordshire PCT	123	43	13	6

Estimated pool of existing cases (prevalence) in SSPCT

	Condition			
Area	Parkinson's Disease	Multiple Sclerosis([3])	Motor Neurone Disease	Dystonia ([2])
Cannock & Rugeley	260	201	13	86
Burton & Uttoxeter	263	201	13	87
Wombourne & Kinver	100	77	5	33
Tamworth, Lichfield & Burntwood	316	244	15	105
Stafford & Stone	292	226	15	97
All South Staffordshire PCT	1231	949	61	408

1. The incidence and lifetime prevalence of neurological disorders is taken from the NSF-LTC (2005)
2. A more recent study by Butler et al 2008 confirms the long held belief that dystonia has a higher prevalence than previously thought it is at least 1:1500.
3. A new study by the MS Society has now revealed that there are around 100,000 individuals in the United Kingdom living with a diagnosis of multiple sclerosis. This is an increase of approximately 17.5% from the previous estimate of 85,000.

For a copy of the full report please visit www.mssociety.org/research

Admissions Data for Progressive neurological conditions:
Whilst some data is available via Dr Foster information, as mentioned above there still seems to be difficulties with primary coding of conditions on admission. It is suggested that this become a priority for commissioners so that a true picture for PNC can be analysed.

Admissions
The Data set taken for analysis for all hospital episode statistics for emergency admissions in 08/09 were defined by any the following ICD10 codes: G 1*,G2*,G32,G35,G36,G37,G60,G61,G70,G71,G72

The cost to SSPCT for these unscheduled admissions was £1,487,687.88 (please refer to table 6 in the full strategy for a more detailed summary)

Table 6 – Primary diagnosis admission by ICD10 code for PNC 2008/09

ICD-10 code	Full description	Primary diagnosis
G048	Other encephalitis myelitis and encephalomyelitis	1
G09	Sequelae of inflammatory diseases of central nervous system	13
G10	Huntington's disease	6
G111	Early-onset cerebellar ataxia	1
G112	Late-onset cerebellar ataxia	1
G121	Other inherited spinal muscular atrophy	1
G122	Motor neuron disease	39
G20X	Parkinson's disease	81
G231	Progressive supranuclear ophthalmoplegia	1
G232	Striatonigral degeneration	
G238	Other specified degenerative diseases of basal ganglia	1
G240	Drug-induced dystonia	1
G243	Spasmodic torticollis	5
G244	Idiopathic orofacial dystonia	2
G245	Blepharospasm	15
G248	Other dystonia	5
G249	Dystonia unspecified	24
G252	Other specified forms of tremor	2
G255	Other chorea	1
G259	Extrapyramidal and movement disorder unspecified	7
G318	Other specified degenerative diseases of nervous system	1
G319	Degenerative disease of nervous system unspecified	29
G35X	Multiple sclerosis	206
G371	Central demyelination of corpus callosum	
G373	Acute transverse myelitis in demyelinating disease of CNS	3
G378	Other spec demyelinating diseases of central nervous system	1
G379	Demyelinating disease of central nervous system unspecified	19
G608	Other heradeditry and idiopathic neuropathies	2
G618	Other Inflamatory polyneuropathies	17
		485

Mortality trends Not available at this time

Current Health Care Services available for Progressive Neurological Conditions in SSPCT

Burton and Uttoxeter (East Staffs)

South Staffordshire PCT Adult Ability Team (AAT) is a community based, specialist neurological, inter-disciplinary team of health care professionals, offering health care services to adult clients with a progressive neurological condition. The team is also intra-organisational, closely liaising with representatives from health and community care services, and the voluntary sector, in management of individual clients, via monthly case management meetings.
Team members operate a person centred approach to assessments and treatment interventions to enable and enhance ability to cope with the disabling effects of ill-health, by encouraging proactive self management of the condition and thus assist in maintaining optimal functional independence within chosen environments.

The Adult Ability Team are currently extending their range of group educational symptom management programs on offer to clients in their area, as well as extending clinical services with partners e.g. home-based intravenous steroid therapy for M.S. relapses. Clients can refer themselves to the service, and are offered regular clinical reviews throughout the course of their condition. The team liaise closely with secondary care staff if clients are admitted, to facilitate discharge. The team hold regular clinics with QHB neurology staff, to optimise communication in case management.

(Note: this service is not replicated in secondary care. Following a whole service review in 2005 it was decided that specialist neurological services for people with progressive neurological conditions should be based entirely in the community, for ease of access and to help manage problems where they exist in the persons own environment.)

Tamworth

The Rehabilitation Unit is based at Sir Robert Peel Hospital. It is a multi-disciplinary team consisting of Physiotherapists, Occupational Therapists and Speech and Language Therapists.

The team delivers assessments, advice and treatment to in-patients admitted to Andrew Ward at Sir Robert Peel Hospital and to out-patients in the Tamworth locality. Referrals are also accepted for out-patients living within the South Staffordshire PCT catchment area who have specifically requested treatment in the Unit and can make their own transport arrangements.

Rehabilitation services are provided to adults with wide ranging complex conditions including falls, multi-pathologies, amputations, fractures, cold orthopaedics, general frailty associated with ageing, neurological conditions and other Long Term Conditions. It is people with such conditions that benefit from the holistic approach used by multi and interdisciplinary working practice of the Rehabilitation Unit.

Specialist Nurses for Progressive Neurological Conditions Tamworth/Lichfield
There is currently an establishment of one specialist Parkinson's disease nurse, and one specialist nurse covering Multiple Sclerosis and Motor Neurone Disease in Tamworth and Lichfield. The nurses are based in the community supporting clients within their home environment, as well as assisting Neurologists in clinics at Sir Robert Peel and Samuel Johnston hospitals. They also contribute to neurological multi-disciplinary team working, with close liaison with therapists in both hospitals.

Dietetics for Progressive Neurological Conditions Tamworth/Lichfield
Dietetic services are not based within the rehab team but they are integral to the interdisciplinary team. Referrals are generally received from Consultant neurologists, GP's or AHP's within the rehab team notably the speech and language therapists. The Dietetic team see patients on the ward or as outpatients or on domiciliary visits and regularly attend IDT meetings for patients.

Lichfield/Burntwood
The Rehabilitation Unit is based at Samuel Johnson Community Hospital. It is a multi-disciplinary team consisting of Physiotherapists, Occupational Therapists and Speech and Language Therapists, Physiotherapy Technicians and Generic Assistants.

The team delivers assessments, advice and treatment to in-patients admitted to Erasmus Darwin and Anna Seward Wards at Samuel Johnson Community Hospital and to out-patients in the Lichfield and Burntwood locality. Referrals are also accepted for out-patients living within the South Staffordshire PCT catchment area who have specifically requested treatment in the Unit and can make their own transport arrangements.

Rehabilitation services are provided to adults with wide ranging complex conditions including falls, multi-pathologies, amputations, fractures, cold orthopaedics, general frailty associated with ageing, neurological conditions, such as Parkinson's Disease, Multiple Sclerosis, brain injury, Cerebrovascular accidents and other long term conditions. It is people with such conditions that benefit from the holistic approach used by multi and interdisciplinary working practice of the Rehabilitation Unit.

Wombourne/Kinver
At present Seisdon area has a lack of specialist community neurological support for conditions such as Parkinson's disease, Multiple Sclerosis, Motor Neurone and Huntington's disease. Service users with neurological conditions have some limited support from community intermediate care services e.g. Physiotherapy, Occupational therapy and District Nursing. However whilst there are staff within these teams with specialist neurological skills, care is usually reactionary in response to a crisis, with little evidence of regular or proactive maintenance rehabilitation, in line with national clinical recommendations. In a recent survey assessing provision of care against the National Service framework (2005), care provision scored either 'not met', or 'partially met' in all of the 11 quality requirement dimensions,

Acute episodes are treated predominantly by the acute units at Dudley Group of Hospitals and Royal Wolverhampton Hospitals Trust, where there is evidence of lengthy stays in secondary care. After acute care, inpatient rehabilitation facilities are available at Wolverhampton West Park Hospital and at Dudley Russell's Hall Hospital. Outpatient specialist rehabilitation can be accessed at West Park only by patients who have their own transport.

Cannock & Rugeley and Stafford - Mid Staffordshire NHS Foundation Trust
The following information is based around Cannock Hospital where there are two services for Neurological Long Term Conditions: The Rehabilitation Day Unit and an Out-patient service, both covering a large geographical area. There is no out-patient neuro-rehabilitation team based at Stafford, although Parkinson's Disease nurses offer outpatient clinics at Stafford, and will also see clients in their own home if necessary, on a needs basis.

The Rehabilitation Unit at Cannock Chase Hospital has a multi-disciplinary team offering out-patient rehabilitation services and disability management to adults with neurological Long Term Conditions. Patients in the Mid Staffs area are referred to the Unit via GPs, Consultant Out-patient clinics, or from the hospital to facilitate early discharge and for continuing support and rehabilitation.

Patients have access to a Consultant, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Clinical Psychology (for people with stroke, epilepsy and seizures only), Clinical Nurse Specialists (MS and Neuro Nurse) and a nursing support. The unit works closely with many other services, for example, Wheelchair Service, Headway, Stroke Association, Orthotics, Driving Assessments and Social Services.

After a multi-disciplined assessment, appropriate treatments and rehabilitation programmes are agreed which are individual to each patients agreed goals. The patients are able to have relatives and/or carers present at the initial assessment and future reviews. Education for patients, relatives and carers is an important part of their treatment plan. A realistic and professional opinion of patient's potential abilities and how the patient and their family will manage in their own home is provided.

The facilities at Cannock Hospital include workshops, gardens, kitchens, gym and hydrotherapy pool where a variety of activities are performed either in small groups or on an individual basis. These include woodwork, horticulture, domestic skills, pottery, hand therapy, cognitive skills training.

Assessments, splinting and monitoring for the neurologically impaired hand, are provided.

In addition to the above the Rehabilitation Day Unit provides a day case service where specialist treatments and procedures are undertaken such as lumbar puncture and methylprednisolone infusions.

The Out-patient Service has a different structure, although generally it is the same MDT, many of the same treatments and facilities are offered. Patients are referred via GPs, consultants, clinical nurse specialists (CNS) and inter-professionally. Physiotherapy neurological outpatients are seen at Stafford and Cannock. OT is only available at Cannock or on home visits. If appropriate, home visits may be completed by MDT. The CNS in Rehabilitation also undertakes outpatient clinics and home visits for those with complex needs.

Support is available for long term condition management based on an individual need. This may include Botox, spasticity management, splinting, home assessments, medical and exercise programmes.

Stone Rehabilitation Service

Stone Rehabilitation Service (SRS) is a community rehabilitation team serving the patients registered with a Stone or Eccleshall GP. An open referral system operates for any patients over the age of 16 years with a physical condition which has recently changed their ability to carry out daily living activities.

The rehabilitation team comprises of physiotherapy, occupational therapy, speech and language therapy, counselling, podiatry, dietetics and rehabilitation technicians. Referral to the service can initiate referrals to any of these professions. The team also manage 2 step up/down beds in a nursing home in Stone. The rehabilitation services can be provided at the Stone Rehabilitation Centre, within the patient's home or in residential or day care, as appropriate to patient need.

The service receives approximately 550 referrals each year. Reasons for referral range from falls, post operative hip and knee surgery, co-existing age related conditions, neurological conditions, and palliative care needs. Progressive neurological conditions represent approximately 20% of referrals.

Additional Specialised Services

Neuropsychology Provision to South Staffordshire PCT.

(detailed in Appendix 3 page 118)

Current position

The Neuropsychology service, based in Tamworth provides a highly specialist secondary/tertiary service to the areas of Burntwood, Lichfield and Tamworth only Whilst negotiations are taking place with Burton Hospitals for the provision of a neuropsychology service, this has yet to be formalised. Thus at present, Burton PCT has no access to Neuropsychology Staffing is provided by 0.8 wte Consultant Neuropsychologist, 1 wte Assistant Psychologist, and 0.6 administrative support.

Referrals are made by members of the Multi-Disciplinary Team (MDT) based at Sir Robert Peel Hospital and the Samuel Johnson Hospital, specifically members of the Occupational Therapy service, Physiotherapy, Speech and Language Therapy, Neurology & Rehabilitation Consultants, and Specialist Nurses. At present there is no facility to accept referrals from General Practitioners, Social Services, Community Mental Health Teams, nor self-referral.

Patients must be older than 18 years of age (or over 16 and not in further education) and below the age of 65. All patients must have a primary diagnosis, or suspected diagnosis of an organic neurological disorder.

All referrals receive a compulsory opt-in form which they are requested to complete (responding in the affirmative that they wish to be seen). Additionally, a detailed questionnaire is also sent out, however this is voluntary and patients will be seen without having completed the questionnaire. Upon receipt of a completed opt-in form the patient is offered an initial consultation within four weeks and a treatment protocol is determined with their agreement.

HRGs and Related Costs

As mentioned, the cost to SSPCT for unscheduled admissions for progressive neurological conditions for the period 2008/9 was £1,487,687.88

Of these patients **68% had no procedure coded against them**. It would be feasible to assume that a significant proportion these patients could have been cared for in the community with the appropriate resources.

Of the patients with a progressive neurological condition admitted:

22% had a primary diagnosis of a neurological condition
13% had a primary diagnosis of respiratory condition
12% had a primary diagnosis of musculoskeletal condition (e.g. fall/ fracture)
10% had a primary diagnosis of urinary tract infection.

These patients equated to £942,010 in terms of the payment by results tariff.

Where specialist neurological community based teams exist in East Staffs, length of hospital stay (LOS) was lower by between 4-5 days, and this figure reduces further still if only primary diagnosis of neurological condition is analysed. In this case LOS varied between 12 days (East Staffs), and 28 days (South East) with Cannock demonstrating an average LOS of 18 days.

Excess bed days

Excess bed days were also significantly higher for consortia without a community based neuro-rehab team. East Staffs and Cannock have comparable populations (approximately 130,000). The cost of excess bed days for the East where a specialist team exists was £19,815, whilst Cannock had an excess bed days cost of £34,526. South East with excellent in patient and hospital based out patient facilities in Tamworth and Lichfield where £26,298 beyond the 'trim' point compared with Stafford with little out patient facilities and no community service at £42,542. However, for preventative care to be fully effective, a full compliment of specialist and non specialist multidisciplinary professionals is required.

Overview of current situation-problems/issues

The following information has been primarily taken from an audit of services for people with progressive neurological conditions carried out between Winter 2008/Spring 2009 in 5 areas of SSPCT. This audit utilised the Quality Neurology (QN) Audit Tool in pilot version. The QN tool was developed by the Multiple Sclerosis Society in conjunction with partner organisations and analyses current provision of care against national evidenced based markers. These markers include the NSF-LTC, Better Metrics, Investing for health (7 key Challenges), Care Homes for Adults 16-65, and World Class Commissioning.

Services have been evaluated by clinical staff from community and acute provider services, health and social care, local voluntary organisation representatives and the public sector, and additionally further information gained from service user focus groups.

Quality neurology data

The following tables represent an overview of attainment of NSF-Long Term Conditions recommendations indistinct geographical SSPCT regions. Each of the 11 Quality requirements has been assessed against their individual Evidenced Based Markers (EBM).

Results detailed demonstrate a lack of attainment of many of the expected National Service Framework quality requirements by health, social care and public services in SSPCT, although some services are more successful than others.

There is a clear disparity in service provision across the geographical area. Also some services are under resourced with clients with a PNC are not routinely reviewed by a designated clinical group, care being reactionary to a particular crisis only.
This evidence is the most accurate data achieved thus far, to inform future planning towards achievement of all of the NSF 11 quality requirements by 2015- the final year of the [plan

An overview of attainment of NSF quality requirements assessed against individual Evidenced Based Markers (EBM) as recommended for each specific Quality requirement is demonstrated.

The individual Quality Requirements (QR's) relate to:
1 - A person centred service
2 - Early recognition, prompt diagnosis and treatment
3 - Emergency and acute management
4 - Early and specialist rehabilitation

5 - Community rehabilitation and support
6 - Vocational Rehabilitation
7 - Providing equipment and accommodation
8 - Providing personal care and support
9 - Palliative care
10 - Supporting family and carers
11 - Caring for people with neurological conditions in hospital or other health and social care settings
* Note: Not all EBM relate to health services.

Burton /Uttoxeter

Overview			EBM	EBM	EBM	EBM	EBM
			1	2	3	4	5
QR 1	Part Met	QR 1	Part Met	Met	Part Met	Not Met	Not Met
QR2	Not Met	QR2	Part Met	Not Met	Not Met	Part Met	Not Met
QR3	Not Met	QR3	Not Met	Part Met	Not Met	Met	Not Met
QR 4	Not Met	QR 4	Met	Not Met	Not Met		
QR 5	Part Met	QR 5	Part Met	Met	Met		
QR 6	Not Met	QR 6	Not Met	Not Met	Not Met		
QR 7	Part Met	QR 7	Part Met	Part Met	Met	Part Met	Met
QR 8	Not Met	QR 8	Not Met	Part Met	Part Met	Not Met	
QR 9	Not Met	QR 9	Not Met	Part Met	Part Met		
QR 10	Not Met	QR 10	Not Met	Met	Not Met	Not Met	Part Met
QR 11	Not Met	QR 11	Not Met	Not Met	Part Met	Met	

Tamworth/Lichfield/ Burntwood

Overview			EBM	EBM	EBM	EBM	EBM
			1	2	3	4	5
QR 1	Not Met	QR 1	Not Met	Not Met	Not Met	Not Met	Not Met
QR2	Not Met	QR2	Not Met	Not Met	Not Met	Part Met	Not Met
QR3	Not Met	QR3	Not Met	Not Met	Not Met	Not Met	Not Met
QR 4	Not Met	QR 4	Met	Not Met	Not Met		
QR 5	Not Met	QR 5	Part Met	Not Met	Part Met		
QR 6	Not Met	QR 6	Not Met	Not Met	Not Met		
QR 7	Part Met	QR 7	Met	Part Met	Met	Part Met	Met
QR 8	Not Met	QR 8	Not Met	Not Met	Part Met	Not Met	
QR 9	Not Met	QR 9	Not Met	Not Met	Not Met		
QR 10	Not Met	QR 10	Not Met	Part Met	Not Met	Not Met	Part Met
QR 11	Not Met	QR 11	Not	Not	Part	Part	

Overview			EBM	EBM	EBM	EBM	EBM
			Met	Met	Met	Met	

Cannock/Rugeley

Overview			EBM	EBM	EBM	EBM	EBM
			1	2	3	4	5
QR 1	Not Met	QR 1	Not Met	Part Met	Not Met	Not Met	Not Met
QR2	Not Met	QR2	Not Met	Not Met	Not Met	Not Met	Not Met
QR3	Not Met	QR3	Not Met	Not Met	Not Met	Not Met	Not Met
QR 4	Not Met	QR 4	Met	Part Met	Not Met		
QR 5	Not Met	QR 5	Not Met	Not Met	Not Met		
QR 6	Not Met	QR 6	Part Met	Not Met	Not Met		
QR 7	Not Met	QR 7	Not Met	Not Met	Not Met	Not Met	Not Met
QR 8	Not Met	QR 8	Not Met	Part Met	Part Met	Not Met	
QR 9	Not Met	QR 9	Not Met	Not Met	Not Met		
QR 10	Not Met	QR 10	Not Met	Not Met	Not Met	Not Met	Not Met
QR 11	Not Met	QR 11	Not Met	Not Met	Part Met	Part Met	

Stone/ Stafford

Overview			EBM	EBM	EBM	EBM	EBM
			1	2	3	4	5
QR 1	Not Met	QR 1	Not Met	Not Met	Not Met	Not Met	Not Met
QR2	Not Met	QR2	Not Met	Part Met	Not Met	Not Met	Not Met
QR3	Not Met	QR3	Not Met	Not Met	Not Met	Not Met	Not Met
QR 4	Not Met	QR 4	Met	Not Met	Not Met		
QR 5	Not Met	QR 5	Part Met	Not Met	Not Met		
QR 6	Not Met	QR 6	Not Met	Not Met	Not Met		
	Not Met	QR 7	Part	Not	Met	Not	Not

Overview			EBM	EBM	EBM	EBM	EBM
QR 7			Met	Met		Met	Met
QR 8	Not Met	QR 8	Not Met	Not Met	Part Met	Not Met	
QR 9	Not Met	QR 9	Not Met	Not Met	Part Met		
QR 10	Not Met	QR 10	Part Met	Part Met	Not Met	Not Met	Not Met
QR 11	Not Met	QR 11	Not Met	Not Met	Part Met	Part Met	

Wombourne/Kinver

Overview			EBM	EBM	EBM	EBM	EBM
			1	2	3	4	5
QR 1	Not Met	QR 1	Not Met	Not Met	Not Met	Not Met	Not Met
QR2	Not Met	QR2	Not Met	Not Met	Not Met	Not Met	Not Met
QR3	Not Met	QR3	Not Met	Not Met	Not Met	Not Met	Not Met
QR 4	Not Met	QR 4	Not Met	Not Met	Not Met		
QR 5	Not Met	QR 5	Part Met	Not Met	Part Met		
QR 6	Not Met	QR 6	Not Met	Not Met	Not Met		
QR 7	Part Met	QR 7	Not Met	Part Met	Part Met	Not Met	Part Met
QR 8	Not Met	QR 8	Not Met	Not Met	Part Met	Not Met	
QR 9	Not Met	QR 9	Not Met	Not Met	Not Met		
QR 10	Not Met	QR 10	Part Met	Not Met	Not Met	Not Met	Not Met
QR 11	Not Met	QR 11	Not Met	Not Met	Part Met	Not Met	

Key Service development Priorities

The following priorities have been identified from the Quality Neurology audit data:
There is inequitable service provision across SSPCT for Progressive Neurological Conditions. Integrated health and social care teams are required, with establishment of generic health care assistants.

With the exception of East Staffordshire all regions noted the need for community based specialist neurology team, encompassing Specialist nursing and rehabilitation staff, with adequate staffing levels to meet national clinical guidance recommendations. These teams to have a central point of access and designated administrative staff to coordinate team functions. Clients would also be allocated a key worker to assist case management, with a protocol for review of care plans.

With the exception of South East Staffs, greater and more timely access to specialist Neuropsychological services required across the Trust

Communication was noted to be a problem in most areas, for example between acute and community services, rehabilitation services and GP's, health care and social care, with demonstration of disparate working. There were some areas, with designated interagency teams who met regularly, who had resolved many of the communication difficulties especially between health and social care.

*(Note many of the acute trusts in SSPCT did not send representatives to the scoping events, and failed to return the appropriate Quality requirement templates, sent in paper copy. Therefore an accurate picture of acute services could not be determined).

There has been a need demonstrated for a neurological network across SSPCT to be established which could address some of the communication difficulties mentioned above.

Recognition of palliative care needs and development of services for PNC across the trust, including training for specialist neuro-teams, especially advanced directives and end of life care planning. Access to adequate night-sitting services for people with PNC
Greater consistency required with continuing care assessment and provision across the trust, and relevance for condition specific conditions

Improvement in timely access and provision of equipment and wheelchairs for both health and social care (this can lead to delays in discharge / avoidable admissions to secondary care).

Better information directories required to improve knowledge for service users and clinical staff

Other emergent themes demonstrated across the trust:
Written detailed protocols for service provision required to establish consistency of service provision and for audit of standards across SSPCT

Need to analyse current working practices across organisations

Need for a SSPCT neuroscience group to continue to develop services and clinical skills

Person centred vocational support required for PNC across the trust

Adequate carers for BME populations in all health and social care services.
More local and timely access to specialist interventions e.g. spasticity management, gait clinics

Current Commissioning Capacity

Area	Service	Staffing Resource - WTE		Registered Clients	Available Capacity
Burton & Uttoxeter (East Staffs)	Neurology Out Patient Clinic - QHB	2007/08 : Total New patients – 698 2008/09 : Total New patients – 91		Total Follow ups - 644 Total Follow ups - 1046	
	Adult Ability Team (AAT)	Occupational Therapy	2.57	362 - 2009/2010 (inc. 65 Derbyshire clients)	2140 - (Each intervention has been averaged to one hour. Some interventions may be slightly less; many are well in excess of one hour, due to the complex nature of conditions seen.) This means that each service user could be seen 6 times throughout the year; however some have fewer and some more interventions than the average). There is a short fall of both SALT and Physiotherapy
		Physiotherapy	1.09		
		Nurse Specialist MS & PD	2.00		
		Co-ordinator / Admin	0.83		
		Speech & Language Therapist	0.29		
		(The OT WTE includes team leader working 27 hrs per week, clinically involved for at least 3rd of this time.			
	Neuro Psychology	Provided on a goodwill gesture only. One assessment per month for the AAT. No treatment available and no capacity to increase this provision			
	Dietetics	No Community service available			
Area	Service	Staffing Resource - WTE		Registered Clients	Available Capacity
Tamworth & Lichfield	Sir Robert Peel	Occupational Therapy	2.82	371 – 2008/2009	For Jan-Dec 08 each client on average had 9 treatments for each profession involved which equals 297.5 hours of treatments each month. These figures do not include SALT out patients, or hand patients, these are just for rehab
		Occupational Therapy Assistant	2.00		
		Physiotherapy	4.42		
		Physiotherapy Assistant	2.17		
		Admin	0.70		
		Speech & Language Therapy	0.80		
		Speech & Language Therapy Assistant	0.60		
	Clinical Nurse Specialists	MS / MND Nurse	1.00	300	Equates to individual patient contacts of approximately 1020 per year for each nurse, plus patients seen in clinics or in the multidisciplinary rehab unit, which equate to a further 400-500 contacts per year per nurse which is data not captured in Lorenzo contacts
		Parkinsons Nurse	1.00		
	Dietetics	There is currently no dietetic time funded			

		specifically for PNC. Patients are seen within the existing service which is already stretched due to rapid increase in home visit referrals. Dietitians are currently not positioned within the rehab team			
	Neuro Psychology	Neuro- psychology in Burntwood, Lichfield and Tamworth consists of 0.8 Consultant Neuropsychologist and 1wte Assistant Neuropsychologist covering Neurology and Rehabilitation, including although not exclusively PNC (also includes acquired brain injury, psychiatric conditions etc.)			
	Samuel Johnson Rehab Unit	Physiotherapy Physiotherapy Assistant Occupational Therapy (term time only) Speech & Language Therapy Rehab Assistant Admin	2.00 1.00 1.20 1.40 0.80 0.80	New referrals from January – December 2008 = 731(Average per month= 61) Each patient has 1 assessment and ideally at least on average 9 follow up appointments i.e. 10 hours clinical time	At 10 hours per patient with 61 patients = 610 hours of clinical time per month. Staff hours available per month = 345. Hence a shortfall of 265 hours. These figures have many variables. Some patients won't need 9 follow up appointments but some will need more. The shortfall of 265 hours identified, would merely ensure that the present service is adequate. To improve future services into the community would obviously need even more than guide above has identified would merely ensure that the present service is adequate. To improve future services into the community would obviously need even more than guide above has identified
Area	Service	Staffing Resource - WTE		Registered Clients	Available Capacity
Stafford & Stone	Stone Rehab Service	Occupational Therapy Physiotherapy Speech & Language Therapy Counsellor Rehab Technician Approx. 0.6 of OT wte is team leader role	1.75 1.69 0.80 0.67 2.00	Of 600 referrals to the team approx. 100 were PwNC	Each patient contact for patients is approx 1 hour and each patient's episode of care approx 8 contacts
	Stafford	Information has not been provided for this area, but there is no community based			Information has not been provided for this area. However for further descriptors of service refer to

		neuro-rehabilitation for PNC and limited out patient access		Appendix 5 of full strategy
	Neuro Psychology	Not available		
Area	Service	Staffing Resource - WTE	Registered Clients	Available Capacity
Cannock & Rugeley	Cannock	Information has not been provided for this area but there is no community based neuro-rehabilitation for PNC and limited out patient access		Information has not been provided for this area,
	Neuro Psychology	Not available for Progressive Neurological Conditions. There is 0.2 senior grade Psychologist available for stroke only		
Area	Service	Staffing Resource - WTE	Registered Clients	Available Capacity
Wombourne & Kniver		More detailed analysis not possible due to the limitation of services in Wombourne/ Kinver		
	Neuro Psychology	Not directly available. This is out-sourced to Wolverhampton as ECR's - hence a cost implication for the Trust		

Palliative Care and Specialist Palliative Care - *Progressive Neurological Conditions*

End of life care services for people with progressive neurological conditions have been developed locally and are different across the PCT. However, in general access to specialist palliative services via in patient beds (variable), day care, community based specialist palliative care nurses e.g. Macmillan CNS's and hospice outreach specialist teams, as well hospice at home services is available (the latter is not usually classified as a specialist service).

Specialist Palliative Care services are provided to the population of South Staffordshire by four hospices, one community Macmillan specialist team, (PCT employed) two hospital based Macmillan specialist teams (Hospital employed) and Marie Curie. Hospitals not within the PCT geographical boundary also provide these specialist services during admission periods.

Community Matrons and condition specific specialist nurses provide general palliative care for those with non malignant palliative and end of life care needs. They link in with specialist palliative care services available in the local area on an ad hoc basis. Patients in East Staffs also have access to condition specific specialist clinicians with specialist knowledge and expertise and they are usually identified as key worker, but these services have not been developed in the West locality. The role and function of the community matron is also under developed, in some areas in the west PCT, where some of the functions of CM are undertaken by members of the intermediate care team. It is clear that access to a range of general level palliative care services in the community is vastly different across the PCT and that this impacts on core services such as district nursing.

It is likely, that as a consequence, different patterns of referral and usage to acute based services, nursing home beds and specialist palliative care services and beds have emerged. It is unknown as to what extent these differences affect or reflect patient / carer preferences, choice or experiences.

Current evidence suggests that patients with non malignant progressive life limiting diseases currently have limited access to specialist palliative care services and specialist providers report that they do not receive referrals for these patients.

Following identification and recognition of the end of life phase, the MDT (primary and/or secondary care) should continue to support the service user and the carer in the palliative phase of the condition, communicating with general practice to ensure inclusion on the palliative care register and proactive end of life care planning using Gold Standards Framework and advanced care planning. End of Life care is part of a much wider area of palliative care where people can live with a life threatening condition for years.

BENCHMARKS/OTHER MODELS

There are a variety of national condition specific guidelines for models of care for Progressive Neurological Conditions, a sample of which are demonstrated in Figures 5,& 7 of the full PNC strategy.

Common themes to all of these pathways is timely access to care (investigations, diagnosis and follow up reviews), access to a range of specialist health care professionals and specialist therapeutics, offering person centred care and choice of delivery, (incorporating care closer to home), and a named key worker. Access to educational programs and culturally appropriate information features highly as well as access to regular respite and specialist palliative care. Additionally pathways reflect the need for excellent communication and joint working between organisations providing services, and robust working with support groups and the voluntary sector.

Service User experience

The following are sample case stores of people's experiences of using different services within the SSPCT geographical area.

Generalised Dystonia

At the age of four I had a slight limp in my right foot, and I found it very painful to put it down. No-one knew what it was not even GP or physio I saw, it gradually get worse. I got bullied at school because I was different at 19 started having memory loss and kept losing things. When I left school I started work as a welder but got laid off because my hands and body shook I haven't worked since. Still no-one knew what it was. In 1984 at age 25 married with a small child I was seen by a specialist professor in London and diagnosed with DYT1 generalised dystonia. Over the next few years I was prescribed lots of drugs to try and manage the pain and spasm some of which were at very high doses but most had little or no-effect. My quality of life got progressively worse I could do little for myself and couldn't go out as the dystonia affected my speech, neck, arms, back, hips and legs. I would often fall over or fall downstairs when trying to walk anywhere. Isolation and depression kicked in badly not helped when often asked to leave restaurants when out with my family because other diners thought I was drunk.

Then three years ago I was considered suitable for Deep Brain Stimulation, after two years of battling with the PCT to get agreement to fund the operation I finally had the surgery in April this year. My life has been totally transformed I am no longer in pain; I can stand upright and move more easily without falling over. I haven't been able to access any physiotherapy because it is too far go back to Oxford and I haven't been offered anything locally so I am having to struggle to get myself going again which after so many years of not being able to get around I know will take time.

Multiple System Atrophy – C's Story

It took us a long, long time to get any help from social services. The consultant contacted them and once they had been out and assessed Dad, together with the nurses input, they got in touch with PCT and we had a big meeting about the care provision required.

This was 9 May last year. At the meeting, PCT agreed to assist with the funding for the care and the care package started on 19 May, with Mom and Dad contributing as well. Since then, we have had one review meeting - no changes were made although they tried to get more carers time for Mom to go out, but this was unsuccessful.

We had a problem when the nurses and doctor recommended a hospital bed and special mattress for Dad. When the bed arrived it was the wrong one - to cut a long story short, it caused us major problems and in the end we had to hire a bed from a private company until the correct bed came. This was caused by the nurse ordering the wrong bed - we don't know if this came from PCT or just the nurses but PCT's input and management would certainly have been useful in this case.

The OT recommended a specific chair for Dad and PCT have provided that willingly.

Both ladies we have met from PCT are senior managers but have been helpful to us. Often, you're not aware of what equipment and help is available and maybe a deeper understanding of MSA might enable PCT to offer more to sufferers.

Service User Comments – D's Story

At least 2 years ago the specialist referred my wife to an orthotist for advice on a neck support collar as her head was beginning to incline forward and onto her right shoulder due to the effects of the Parkinson's disease. The orthotist advised that a rigid collar would not be suitable, and recommended that she be referred to the Rehab Unit at Selly Oak. Unfortunately the orthotist had a stroke and both we and our specialist were unaware that no action had been taken. After not hearing for some weeks I made some phone calls which lead to the specialist making a referral to the Rehab Unit. Again several weeks passed without any contact. When I phoned The Rehab Unit I was told that the referral had been received but the person dealing with it was on long term sick leave. However my call prompted some action, and we were re-referred to the orthotist at Good Hope Hospital. When we attended the appointment we were again told that a rigid collar would be unsuitable, and that the Rehab Unit at Selly Oak would be the best place to deal with the problem. In all this time my wife's neck problem had been getting worse, so that when we finally attended an appointment at the Rehab Unit (April 2008) we were told that it was unlikely that they could do anything to make a real difference.

As the neck problems were causing my wife to lean over to the right hand side the Community OT arranged for a 'sleep system' to keep her straight in bed, and the wheelchair service arranged for side support pads and a head support to be fitted to her wheelchair. These measures were taken promptly and have made a positive difference. Also, to help counter the Parkinson's effect on my wife's neck muscles she is having regular Botox injections. These are being administered by the specialist at home on a prompt basis, and are proving to be effective.

Burton on Trent Story. Life with Muscular Dystrophy.

I have been able to access the Adult Ability Team, a specialist team in the community, for over 10 years, and without their support I would be totally lost. The services they have provided have been invaluable, and I couldn't ask for more, whenever I need the help, I just call, and they come.

They are so knowledgeable about my MD, more aware of how it affects me on a daily basis than anyone else I have come in contact with. The physio provided me with exercises to reduce my back pain and a flotron to help keep the swelling down in my legs. But it is the Occupational Therapist who I have had most contact with. She really seems to understand me, and has organised so much from providing equipment to help me to cook, to advice and equipment to help me in and out of bed and shower. She finds a way around everything, even got 3 different charities to fund a scooter for me so that I could get out and about. The OT also made me aware of the different services available locally like social services to provide direct payments, which help me to be more in control of the care I receive.

I have also had a lot of emotional support from the team, and from the post diagnostic support worker, who works with them, which is really important if things aren't going well and you feel really down.

I can honestly say that without the help of the Adult Ability Team I would not have the same quality of life I have now. It is reassuring to know that whatever else life throws at me; their support will always be there at the end of a telephone.

THE VISION

Using the NSF-LTC, NICE 2003/2006 clinical guidelines, and the national guidelines detailed in section 3 of the unabridged PNC strategy document (4/3/10), the Progressive Neurological Strategy Group developed an ideal service specification to be used to provide consistent care for Progressive Neurological Conditions across SSPCT (see page 146 figure 9) of the PNC strategy (4/3/10).

The Strategy Group recognises that the critical point which will determine whether service users and their carers embark on the progressive neurological conditions pathway is the initial interface between the service user and the clinician communicating their diagnosis

On confirmation of a diagnosis the specialist clinician must offer the service user relevant information providing them with the details and means of contacting other services. This should include the specialist nurse and the interdisciplinary team which includes physiotherapist, occupational therapist, speech therapist, council and social services, benefits officers and the nearest branch of the specialist disease society. Timely access to local, specialist neuro-psychology services is also essential.

Additionally a key worker must be provided for the person with the diagnosis and their carer, along with access to any urgently required services.

Rehabilitation

Every service user with a progressive neurological condition living within the geographical boundaries of SSPCT should have access to an Interdisciplinary specialist neuro- rehabilitation team of health care professionals for ongoing, life-long support. These teams will operate in an inter-agency manner, demonstrating close liaison between health and community care services and the voluntary sector. However, it is vital that health care is offered as close to the person as possible, and in the most appropriate environment where problems associated with the condition exist. This will often be in the persons own home, work, social or leisure environment.

A person centred approach to assessments and treatment interventions, is essential with the main aim of enabling service users to maintain optimal functional independence within their chosen environment. The team will also facilitate strategies to cope with the disabling effects of ill-health, thus encouraging proactive self management of the condition. These recommendations equally apply to palliative stages of a condition, where services users should be offered appropriate services, information and choice.

Ideally the outcome of all health and social care interventions should be a robust partnership of service user, carer and multi-disciplinary team working together to ensure maximum quality and longevity of productive and independent functioning of the service user and proper support for the carer.

Minimum establishment of staffing required:

Consultant Neurologist / Neuro-Specialist(s)	Team leader with specialist skills
Team Administrator / Co-ordinator	Clinical Nurse Specialist(s)
Neuro - Specialist Occupational Therapist(s)	Neuro - Specialist Physiotherapist(s)
Speech and Language Therapist	Dietician
Podiatrist	Neuropsychologist
Counsellor	Health care support workers

Direct Access to:

Primary mental health workers
Social Services and Benefit Advisor
Splinting
Hydro-therapy
Dental Care and Opticians
Counsellor/talking therapies
Orthotics,
Spasticity management
Wheelchair services
And where appropriate specialist movement disorder specialists.

KEY SERVICE DEVELOPMENT PRIORITIES FOR SSPCT

The table below correlates the immediate requirements identified from the Quality Neurology Audit and the strategy group's local experience. The priorities identified are those necessary to be addressed in order to provide services for people with PNC which meet National Standard Quality Requirements.

(Please note: ticks indicate requirements for each area)

	Burton/Uttox	Tamworth/Lichfield /Burntwood	Cannock/Rugeley	Stone/Stafford	Seisdon	NSF Dimension
Community based specialist Neuro rehab Team for PNC	(in existence but requiring additional physiotherapy, SALT and Dietetic staffing)	√	√	√	√	4,5
Key worker Approach	(in existence)	√	√	√	√	1,5,8,11
Integrated social care and health teams (including single point of access)	√	√	√	√	√	1,5,7,8
Timely access to neuro-psychology	√	(in existence)	√	√	√	2,3,4
Timely and regular review of care plans	(in existence)	√	√	√	√	1,4,5
Timely provision of equipment & wheelchairs including assistive technology	√	√	√	√	√	7

	Burton/Uttox	Tamworth/Lichfield /Burntwood	Cannock/Rugeley	Stone/Stafford	Seisdon	NSF Dimension
Consistent provision of palliative care including the availability of night sitters	√	√	√	√	√	9,10
Palliative care education.	√	√	√	√	√	9,10
Generic healthcare workers between health and social care	√	√	√	√	√	1,5,8,10,11
Improve communication across organisation	√	√	√	√	√	1,8,11
Accurate data with appropriate coding	√		√	√		All
Availability of specialist community based interventions e.g. IV steroids, spasticity management	√ (community based IV steroids for people with MS available)			√	√ (community based IV steroids for people with MS available)	4,5
-Detailed protocol for service provision		√	√	√		All
Person centred vocational support	√	√	√	√	√	6
Directory of services	√	√	√	√	√	All
Neuroscience network/reference group	√		√	√	√	

	Burton/Uttox	Tamworth/Lichfield /Burntwood	Cannock/Rugeley	Stone/Stafford	Seisdon	NSF Dimension
More consistent provision of continuing care	√	√	√			1,7,8,10
Additional staffing for rehabilitation	√	√	√	√	√	3,4,5
Improvement in Neurologist waiting times	√	√	√	√	√	2,3,4
Access to service user education	√	√	√	√	√	1,4,5,8,10
Improve CIT to prevent acute hospital admission		√			√	2,3,4
Improved respiratory services in the community	√	√	√	√	√	3,4,5
Improved Specialist Neurological Dietetic service	√	√	√	√	√	3,4,5
Age appropriate options for residential care, respite care and day care	√ (Some respite care for PNC available)	√	√	√	√	1,8,10

Individual service requirements have not been costed but a skill mix is required to deliver services based on a competency framework, please refer to the ideal service specification detailed in section 8.

13 CONCLUSION

Government attention on progressive long-term neurological conditions has only recently been directed at community services, but has demonstrated lack of flexibility. According to Wilson et al (2009) multidisciplinary, integrated health and social care is considered essential and also patients and carers highly valued the use of key workers.

Recent NHS indicators for quality improvement, which focus on patient experience against exact national policy aims, demonstrate that people with long-term conditions want greater control of their lives, to be treated sooner before their condition causes more serious problems and to enjoy a good quality of life. This means transforming the lives of people with long-term conditions to move away from the reactive care based in acute settings toward a more systematic person-centred approach, where care is rooted in primary and community settings and underpinned by strong partnerships across the whole health and social care spectrum.

This working group would like to acknowledge and congratulate the foresight of SSPCT in supporting a group to develop a strategy for progressive neurological conditions. At present, however, it has been demonstrated that the trust is failing to meet best practice guidance and government recommendations for progressive neurological conditions. Additionally there are huge disparities in care provision across SSPCT, both within health, and with integrated working with social care, leading to a post code lottery of care provision.

In contrast, SSPCT also has some excellent examples of specialist care for progressive neurological conditions, some cited at nationally. There is an expectation that commissioners will use this document to analyse existing provision and gaps in care, and utilise the service specification developed by the group to support service development and change, through enhancement and re-organisation of services. This will enable SSPCT to commission equitable high quality care, closer to home to improve the service user and carer experience throughout their entire health journey, and thus fulfil an ongoing commitment to people with a progressive neurological condition. The future health care for people with progressive neurological conditions is now reliant on the QIPP agenda and practice based commissioners to drive forward developments.

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