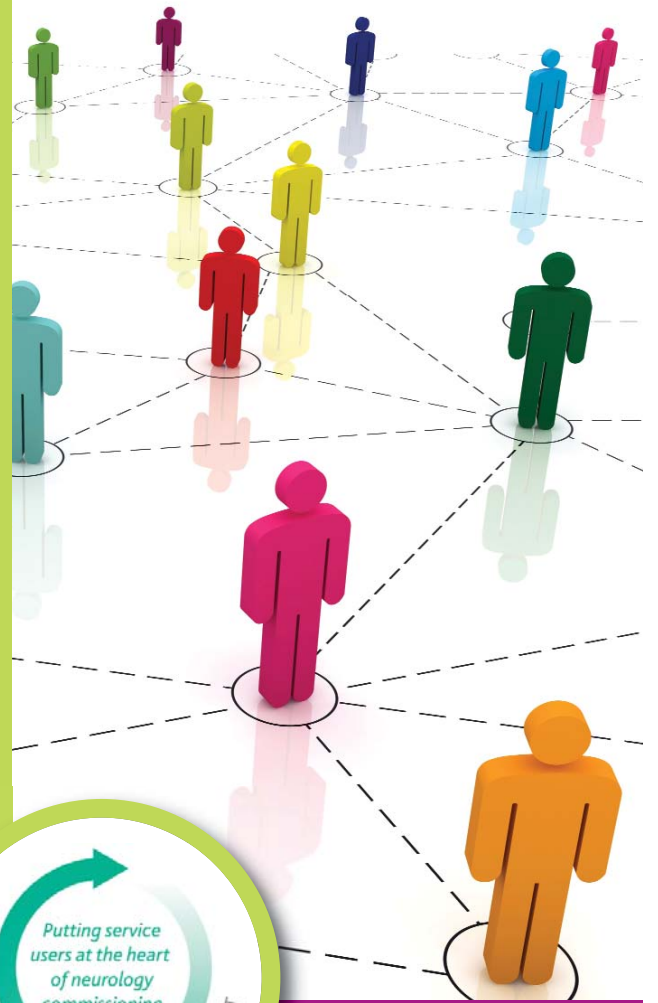


Putting service users at the heart of neurology commissioning



Taking Stock and Moving Forward

An audit of neurological services across Cornwall and the Isles of Scilly

This report was produced by Neurological Commissioning Support Ltd. NCS works alongside health and social care commissioners, to ensure that people affected by long-term neurological conditions are at the heart of commissioning. NCS Ltd is a joint initiative from the MS Society, the MND Association and Parkinson's UK.

Neurological Commissioning Support Ltd is a registered company: 07518070. Registered Offices: 372 Edgware Rd, London NW2 6ND.



Contents

Forewords	4-5
Key findings	6
Suggested Actions	8
Introduction	
Background to this work	1
Outcomes	11
Approximate numbers of people living with a neurological condition in Cornwall	13
Methodology used in undertaking this review	14
Cornwall & Isles of Scilly: the Audit and its Outcomes	
Gathering the Data	17
An Overview of the Outcomes	19
In-depth analysis	
Quality Requirement 1	24
Quality Requirement 2	30
Quality Requirement 3	33
Quality Requirement 4	36
Quality Requirement 5	39
Quality Requirement 6	43
Quality Requirement 7	47
Quality Requirement 8	51
Quality Requirement 9	55
Quality Requirement 10	57
Quality Requirement 11	61
Conclusion	65
Appendices	
Appendix 1 - Quality Neurology	66
Appendix 2 - Evidence-Based Markers of the NSF	66
Appendix 3 - RENEW: An Evaluation	75

Foreword

This thorough and impressive piece of research has been completed on time, despite unprecedented winter snowfall and icy roads which in parts of Cornwall turned journeys into expeditions – and then fog briefly marooned some of the research team on the Isles of Scilly. Altogether almost 1,000 respondents gave evidence and shared their opinions about what was good, what could be better and what needed radical transformation in the field of health and social care for neurological patients in Cornwall and Scilly.

In expressing my gratitude to all who gave so freely of their time, experience and wisdom I want to thank especially those – patients and professionals – who shared their personal experiences. There are areas of consensus and equally some wide variations of opinion and observation, but I am assured that every comment, suggestion and opinion has been noted, recorded and indexed. Thus each individual contribution adds value to this, the final report. I also wish to thank our NCS colleagues for their support and Sue Thomas especially for her insight and industry.

In a period of economic austerity some have asked whether this research has been timely, since funding is often needed if improvements or changes to services are proposed. The answer is simple and clear – in many instances, advancing existing good practice and excellence can improve efficiency and effectiveness in care and treatment, for example in securing shorter pathways to effective management of chronic neurological conditions. The ‘winners list’ is huge and there are plenty of opportunities for early implementation of simple and economic changes which meet the patients’ aspirations and reflect their viewpoints, while providing better as well as cheaper care.

CAN-DO (The Cornwall and Isles of Scilly Alliance of Neural-Domain Organisations), a patient-led alliance, has been privileged to have the opportunity to commission this report. In the past few months we have deepened our excellent relationships with professional health and social care practitioners, and we have established feedback pathways which will provide clearer views of the quality of care and other services. In these turbulent and transient times we greatly appreciate these opportunities for collaboration with those who work so hard to meet our needs. We look forward to continuing to play our part as service users in shaping the future of all neurological services within Cornwall and the Isles of Scilly.



Roger Weatherly
Chair, CAN-DO

Foreword

We are pleased to support this service-user led audit commissioned by CAN-DO (The Cornwall and Isles of Scilly Alliance of Neural Domain Organisations). We recognise and value the experience and expertise that patients, their families and carers have brought to service improvement through this audit, and we are very committed to ensuring that service users are involved in a real and meaningful way.

The Government's White Paper on the NHS sets out plans to give more responsibility to GPs to best meet the health needs of the local population. It also enables patients themselves to have greater control over their own care, and be involved in decisions about wider healthcare issues for their local area. The Government has stated that patients will have more power to make real choices about their healthcare and to be able to say 'no decision should be taken about me, without me'.

'Taking Stock and Moving Forward' is a 'root and branch' review of neurology services across Cornwall and the Isles of Scilly which challenges the statutory agencies to work more efficiently and offer best service and choice to people living with long-term neurological conditions. It also identifies opportunities for service users to work collaboratively in order to help themselves and each other to manage their conditions on a day to day basis.

We are particularly pleased to see that the audit has highlighted some very positive good practice across a range of neurological services in Cornwall and the Isles of Scilly.

We are grateful for the considerable contribution made by CAN-DO, and other service users and carers, to the development of these plans and we gladly anticipate a continuation of that collaborative working.

We now look forward to starting to look at implementing these changes across Cornwall and the Isles of Scilly.



Deborah Matthews

Commissioning Manager – Neurological Conditions
NHS Cornwall and Isles of Scilly

Key Findings

Although Cornwall was not able to fully meet a single Quality Requirement (QR) of the National Service Framework for Long Term Neurological Conditions this mirrors the picture of other PCTs in England at the mid-point of the NSF implementation. There are numerous examples of good practice across Cornwall which have indicated how well some health and social care services are performing and how much they are valued by service users. The geography and poor transport in the county do however present difficulties for equity of access to services, and solutions need to be found so that services can reach out to the whole population. Development of the proposed nine health and social care HUBs will without doubt be one way that equity could be achieved. Key areas to address are:

- **Information** People in Cornwall are not receiving the basic information they need to manage their condition appropriately. A single point of contact for people to find information about managing their condition, and how to access the services they require would be beneficial.
- **Inequality** Services are not equitable across the county and individuals often have to travel long distances to access care. This is compounded by poor transport, in turn made more complex by the rurality of the area. IT solutions might assist with this issue.
- **Integrated services** The care needs of people living with a long-term neurological condition span health and social care, but services are not, on the whole, integrated in Cornwall. There are areas of good practice that could be replicated.
- **Maintaining independence** Access to rehabilitation and timely provision of equipment is a major issue. Rehabilitation can ensure individuals are independent and remain productive in the workforce, providing better quality of life for them, and reaping cost benefits in the long term.
- **Therapy services** Ongoing availability of therapy and exercise services in order to enable individuals to maximise and maintain ability is required. Individuals felt that with access to therapy on a regular basis they could be more independent and therefore less reliant on health and social care services in general.
- **Spinal injury and acquired brain injury** There are issues in relation to rehabilitation and repatriation of those living with spinal cord, and acquired brain, injuries. These relate to age-relevant accommodation, ongoing treatment, organisation of care packages and funding.

- **Mental health services** Finding appropriate support for people with mental health difficulties is exceedingly problematical.
- **Carers** Information on services and education available for carers is currently not as accessible as it could be. Respite opportunities and crisis support could also be better highlighted.
- **Vocational services** There was overall consensus from service users that there were insufficient opportunities for people to remain in work or be supported to retrain following diagnosis or injury.
- **Transitions** People can 'fall through the care net' when moving from one stage of care to another; such as from younger person's to adult services. Most services do not have documented arrangements for transition.
- **Rarer conditions** Special account needs to be taken of those neurological conditions that are low-volume for commissioning but might place high demand on health and social care. Joint commissioning arrangements need to be in place for conditions such as Huntington's disease, motor neurone disease and progressive supranuclear palsy.
- **Involvement of the voluntary sector** Local and national voluntary sector organisations provide a range of support and finance for services in Cornwall but they are not currently viewed as full partners in the delivery of services and thus not used to full effect.



Suggested actions

Leadership and education

- Designate a 'neurology lead' for long-term neurological conditions within the PCT, for effective and strategic leadership of the service.
- Develop a neurology clinical network to ensure the sharing of evidence-based practice and ongoing training, and to assist in building relationships across disciplines.
- Develop 'link' practitioners with enhanced expertise in neurological conditions to supplement specialist practitioners.

Awareness and Information

- Hold a Neurology Awareness event within Cornwall to raise awareness of neurological conditions and services currently available.
- Provide appropriate information and advice for service users by developing neurology care advisers so that all patients receive effective signposting.
- Develop a one-number contact for all service access.
- Develop local provision of self-care and self management for people with long-term neurological conditions into each proposed health and social care HUB.
- Develop a population-based register of people with neurological conditions to inform clinicians and commissioners about service requirements.
- Explore the use of Advanced Decision materials so that people can make choices in relation to palliative and end of life care.
- Provide more information on personal budgets to both service users and carers, and professionals.

Care delivery

- Implement a generic pathway, agreed across agencies, for rarer neurological conditions so that people with these conditions do not 'slip through the net'.
- Use a single or integrated assessment process to reduce duplication.
- Make better use of tele-healthcare, tele-medicine and assistive technology to provide greater service equity for those affected by poor transport or access issues.
- Improve quality in specialised home care and community services by developing key workers to better co-ordinate care and form links with statutory and independent agencies.
- A pathway for the transition of patients from paediatric to adult services, and adult to older peoples services, needs to be developed.
- Better and ongoing access to therapy and exercise facilities needs to be arranged.
- Joint commissioning arrangements need to be used to commission facilities for people with Huntington's disease at Millaton Court.
- Develop an alternative approaches to respite, social crisis and end of life care admissions by making better use of existing services.

Medication

- There is a need to provide targetted botulinum toxin services and joint commissioning might be a way forward for this.
- There is a need to ensure people with Parkinson's get their medication on time when in hospital and other care settings.
- People with epilepsy need to access education on risk management and seizures.

Rehabilitation and therapy services

- Consider how specialist multidisciplinary interventions for early rehabilitation, acute treatment, post-acute spinal repatriations, long-term ventilation, and highly specialist patient treatment needs, can be given.
- Ensure greater access to rehabilitation throughout the course of the condition.
- Provide more targetted exercise facilities.

Partnerships

- Closer partnerships with social services need to be developed so that care is more integrated.
- Voluntary sector partnerships could increase service capacity.



Introduction

1. Background to this work

In 2010, Cornwall and Isles of Scilly Alliance of Neural-Domain Organisations (CAN-DO) initiated a review of neurology services across Cornwall and the Isles of Scilly from a service user perspective. It was hoped that this work would, using a whole systems approach, identify the baseline neurology services currently available, outline service gaps from both a service user and clinician perspective, and produce a commissioning action plan that could help improve services for all people living with a neurological condition across the county.

'A long-term neurological condition results from the disease of, injury or damage to, the body's nervous system (i.e. the brain, spinal cord and or their peripheral nerve conditions) which will affect the individual and their family in one way or another for the rest of their life'¹

The anticipated outcomes desired for neurology services were that Cornwall would work towards equitable neurology standards: better health and social care service delivery and a reduction in wasted resources. To undertake this review CAN-DO commissioned a national organisation: Neurological Commissioning Support (NCS).

The objectives for the project were:

- Support the neurological network CAN-DO in developing this review – ensuring there are appropriate levels of representation across neurological service user groups and local providers, including GPs;
- Undertake a joint strategic needs assessment with Cornwall's Public Health Department;
- Audit current services using the Quality Neurology audit tool² against the National Service Framework³ (NSF) for Long-Term Conditions, and relevant NICE guidelines, and review this via the neurological network;
- Review, in partnership with the local authority, provision of existing services with a view to identifying spend and wastage, commissioning more user-friendly and flexible local services and exploring options for the joint funding of services;
- Co-ordinate services between providers so that clearer pathways are established and communicated to providers and service users of all ages;
- Develop and extend case co-ordination and key working to a wider group of patients of all ages with a long-term neurological condition to provide a single point of access, in line with national guidelines and best practice standards;
- Promote the personalisation agenda by ensuring that service developments respond to the experience of people with neurological conditions.

1. Department of Health (2005) The National Service Framework for Long Term Conditions HMSO London p9

2. The Quality Neurology tool was created collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK, with support from York University Research and Social Policy Unit, and funding assistance from the Department of Health.

3. Department of Health (2005) The National Service Framework for Long Term Neurological Conditions HMSO London

2. Outcomes

The outcomes anticipated from the project are:

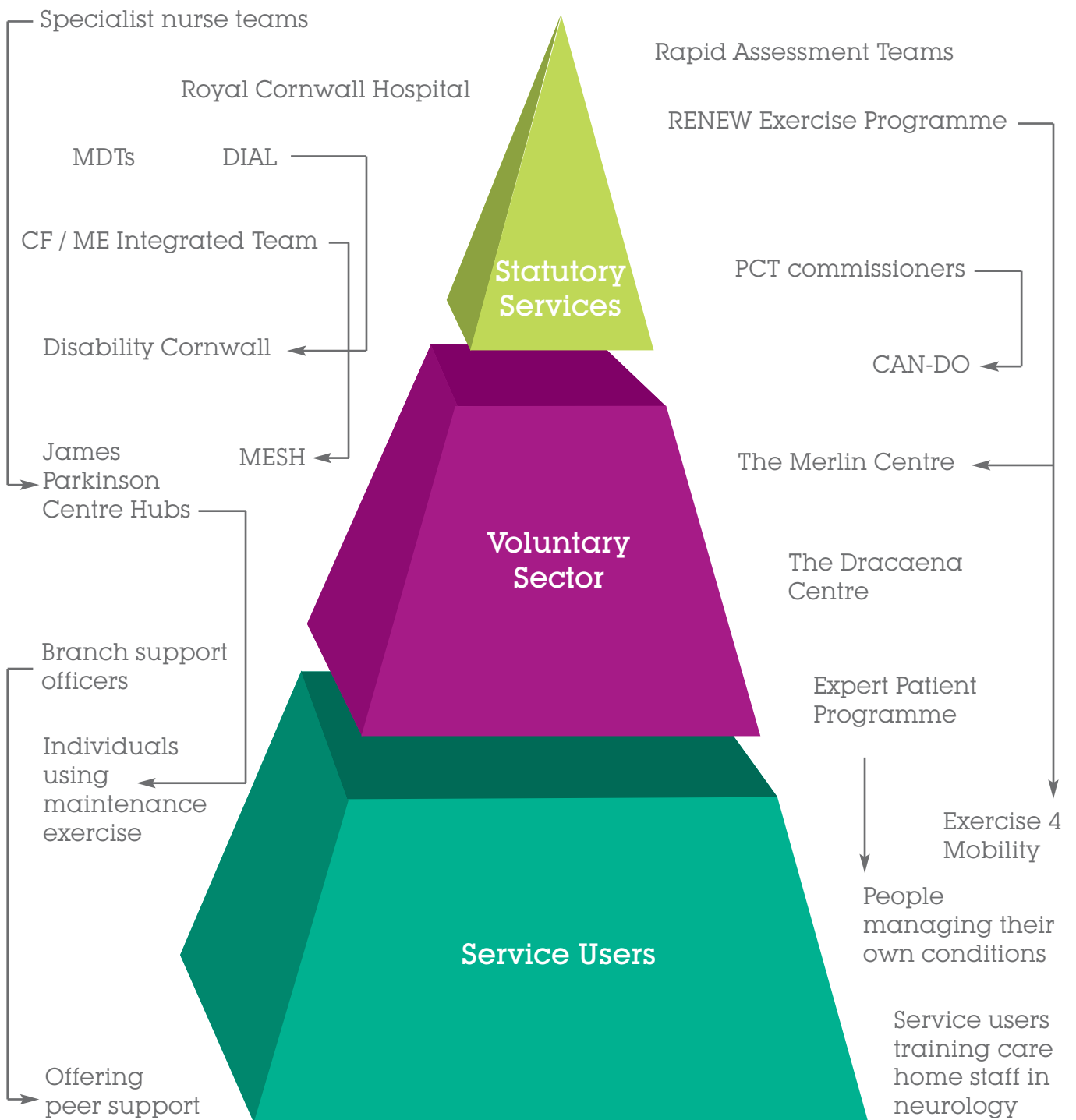
- An outcome-focused approach to the commissioning of services for people with a long-term neurological condition so that the focus is on personal outcomes or goals that the individual living with the condition wishes to achieve;
- To give service users more choice and control over the support they want and the manner in which they receive their care, thus delivering improved, cost-effective services and improved outcomes for individuals and their carers within the current resource envelope;
- To ensure that the personalisation agenda is advanced within Cornwall and the Isles of Scilly so that people are able to exercise choice and control over the services they receive and the way in which they are delivered;
- To ensure that people with a long-term neurological condition receive appropriate, effective, and timely responses to their health and social care needs through the effective commissioning of services;
- To ensure that all people with a long-term neurological condition, and their carers, have access to an integrated community-based service underpinned by quality information to inform choice and decisions, the personalisation agenda and control.

It was felt that in developing this work the onus on delivering services should not fall solely on health and social care services but on the voluntary sector and individuals themselves. Through partnership, much can be achieved.



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Current models of service delivery in Cornwall and the Isles of Scilly



3. Approximate numbers of people living with neurological conditions in Cornwall

Using the Quality Neurology Audit Tool's calculator, the below estimates, based on national prevalence data as set against Cornwall and the Isles of Scilly PCT's population size, show how many people are living in the area with each of the neurological conditions as listed in the NSF for Long Term Neurological Conditions.⁴

Condition	National Prevalence *	Expected Number **
Aphasia	0.370%	1850
Acquired Brain Injury	0.183%	915
Acquired Spinal Cord Injury	0.070%	350
Ataxia	0.010%	50
Cerebral Palsy	0.170%	850
Charcot Marie Tooth disease	0.038%	190
Dementia & Early Onset Dementia	1.180%	5900
Dystonia	0.062%	310
Encephalitis	0.396%	1980
Epilepsy	0.770%	3850
Essential Tremor	0.500%	2500
Huntingdon's disease	0.016%	80
Hydrocephalus	0.010%	50
Migraine	13.220%	66100
Motor neurone disease	0.016%	80
Multiple sclerosis	0.180%	900
Muscular Dystrophy	0.050%	250
Myasthenia Gravis	0.016%	80
Narcolepsy	0.160%	800
Neurofibromatosis	0.039%	195
Parkinson's disease	0.198%	990
Post Polio Syndrome	0.396%	1980
Progressive Supranuclear Palsy	0.006%	30
Spina Bifida	0.023%	115
Stroke	0.495%	2475
Syringomyelia	0.008%	40
Tourette's Syndrome	0.050%	250
Transverse Myelitis	0.001%	5
Trigeminal neuralgia		0
Tuberous sclerosis	0.013%	65
Others:		195

* Published numbers / 60500000 GB population or taken from organisational websites

** Uses prevalence in correspondence with population size.

Population of Cornwall and Isles of Scilly: 500,000.

4. Department of Health (2005) The National Service Framework for Long Term Neurological Conditions HMSO London

4. Methodology used in undertaking this review

4.1 The National Service Framework

Service quality standards for neurology are contained within the National Service Framework (NSF) for Long Term Neurological Conditions and are referred to as Quality Requirements (QRs) (Box 2). Published in March 2005, the NSF is a key tool for delivering the government's strategy to support people with long-term neurological conditions. Key themes within the NSF are: independent living; care planned around the needs and choices of the individual; easier, timely access to services; and joint working across health, social care and the voluntary sector.

The QRs are designed to place all individuals with a long-term neurological condition centrally within health and social care so that the services provided are efficient, supportive and appropriate throughout the continuum of the condition, from diagnosis to end of life.

Box 2. The Quality Requirements of the National Service Framework

Quality Requirement 1:	a person centred service
Quality Requirement 2:	early recognition, prompt diagnosis and treatment
Quality Requirement 3:	emergency and acute management
Quality Requirement 4:	early and specialist rehabilitation
Quality Requirement 5:	community rehabilitation and support
Quality Requirement 6:	vocational rehabilitation
Quality Requirement 7:	providing equipment and accommodation
Quality Requirement 8:	providing personal care and support
Quality Requirement 9:	palliative care
Quality Requirement 10:	supporting family and carers
Quality Requirement 11:	caring for people with neurological conditions in hospital or other health and social care settings.

The QRs of the NSF were audited using a validated audit tool: Quality Neurology (QN)⁵. Each QR has been broken down into evidence-based markers which are measured (see appendix 1). QN requires 100% compliance of each evidence-based marker for that overall marker to be deemed 'Met'.

5. The Quality Neurology tool was created collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK, with support from York University Research and Social Policy Unit, and funding assistance from the Department of Health.

All evidence-based markers of a QR are required to be 'Met' before the overall QR can be deemed to 'Met'. It is recognised that the tool sets a very high standard for compliance.

The full QN process, in addition to completion of the audit tool through professional's consensus opinion and available evidence, also takes into account the views of service users and carers. These are gathered via focus groups, questionnaires, online discussion forums, semi-structured interviews – both face-to-face and over the telephone – and using existing service user groups, to gather the 'lived reality' of those that experience health and social care services. Service users who are consulted are predominantly those who are currently using, or recently discharged from receiving, services and therefore have a view on the services as they are currently being provided. The results from the audit and the focus groups are then synthesised into a gap analysis and an action plan for service consolidation, improvement and development.

4.2 The NHS Outcomes Framework

In addition to the NSF, and also very relevant to commissioning in neurology, there are a number of frameworks either recently written, currently being written, or in their early consultations.

The NHS Outcomes Framework has been published in its first iteration very recently, and is expected to be an evolving framework which will change over the coming two years as the new NHS structure emerges. The first version of this Outcomes Framework sets out the outcomes and corresponding indicators that will be used to hold the NHS Commissioning Board to account in the future.

The Framework has 5 areas of focus:

1. Preventing people from dying prematurely;
2. Enhancing quality of life for people with long term conditions;
3. Helping people to recover from episodes of ill health or following injury;
4. Ensuring that people have a positive experience of care;
5. Treating and caring for people in a safe environment and protecting them from avoidable harm.

Each area of the framework follows a similar structure:

- A single or small number of overarching indicator(s), which will allow the Secretary of State for Health to track the progress of the NHS as a whole in delivering outcomes across the breadth of activity covered by that area;

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- A small set of improvement areas where the NHS Commissioning Board will be tasked with delivering better outcomes because the evidence suggests that significant improvement or health gain is possible; and
- A supporting suite of NICE Quality Standards setting out what high quality care looks like for a particular pathway of care.

All 5 areas of focus have significance for people living with a neurological condition, and will be taken into account as the Framework continues to form. However, of most immediately clear relevance to neurology is the second area: 'Enhancing quality of life for people with long term conditions' for which the overarching indicator of: 'Health-related quality of life for people with long term conditions' is identified.

The Improvement Areas in relation to this are:

1. That people with a neurological condition will feel supported to manage their condition. The indicator for this outcome ('Proportion of people feeling supported to manage their condition') measures how well the NHS as a whole is doing in supporting people to look after themselves and handle the consequences of their conditions.
2. Functional ability. The indicator for this outcome ('Employment of people with long-term conditions') measures the extent to which people in Cornwall living with long-term neurological conditions are able to live as normal a life as possible by looking at their levels of employment.
3. Time spent in hospital because of the condition(s). This outcome is concerned with how successfully the NHS manages the condition(s) through looking at unnecessary hospital admissions.
4. For adults with long-term conditions, there is a far wider range of conditions that cause emergency admissions and so 'Unplanned hospitalisation for chronic ambulatory care-sensitive conditions' is also included. Prior to full implementation of the NHS Outcomes Framework, work will be undertaken to identify the most appropriate definition for this indicator.
5. Those with mental illness: to ensure that mental illness is not excluded due to an overriding focus on physical health. In seeking to capture the quality of life for this group, the indicator 'Employment of people with mental illness' has been selected as this provides an insight into how individuals are able to manage their condition.
6. Carers: to recognise the vital role they play in supporting people with a neurological condition.

In the future each Improvement Area will state a means of measuring whether the outcome is being achieved, or note a method of measurement that would need to be in place.

The Cornwall and Isles of Scilly Audit and its Outcomes

1. Gathering the data in Cornwall & Isles of Scilly PCT

Data for this audit was gathered from both a professional and service user perspective. The professional audit data was gathered over two full days during January 2011. One session was held in Truro for the South of Cornwall (covering services from The Royal Cornwall Hospital) and one in Plymouth for the North of Cornwall (as, due to the geography of Cornwall, some services are delivered in Plymouth at Derriford Hospital). The sessions were well attended by a wide range of staff from health and social care as well as private providers and some patient-led and voluntary sector service providers.

Patient input was gathered via a series of eleven focus groups across Cornwall during December (2010), and January and February (2011). These groups were held at various places around the county to gain a full representation of experiences locally and to maximise people's ability to attend a group without necessitating lengthy travel.

The locations were:

- Bude
- Falmouth
- Ladock
- Lanhydrock
- Liskeard
- Penzance
- Redruth
- St Ives
- St Mary's, Isles of Scilly
- Truro



Local press such as the West Briton, social networking forums and online communities (such as Facebook and Twitter), and website discussion forums were also used to raise awareness and gather comments, whilst e-mails and letters from service users contributed to provide more detail of their experience of services across Cornwall and the Isles of Scilly. Individual semi-structured interviews conducted both face-to-face and via telephone contributed to the results, as did two online surveys and matched paper questionnaires; one for service users and one for carers. In total almost 1000 people contributed to the audit via one of these methods. The conditions they represent are in Box 3.

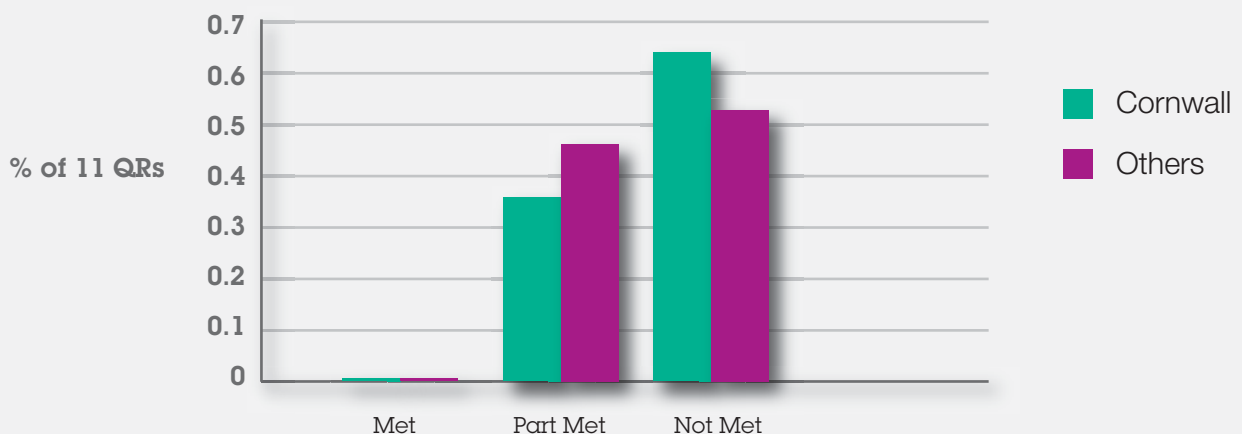
2. An Overview of the Outcomes

2.1 Quality Requirements

In keeping with the 2010 national findings for implementation of the NSF⁷, out of the 11 Quality Requirements, Cornwall and the Isles of Scilly did not fully 'Meet' any of them; four QRs achieved a 'Part Met' and seven QRs were 'Not Met'. As previously stated, the QN tool requires 100% compliance for a QR to be deemed as 'Met'. It also requires that there are no 'Not Met' criteria in any QR evidence-based marker and at least one 'Met' criteria for the QR or evidenced-based marker to be deemed 'Part Met'. Thus, it is very difficult to achieve 'Met' criteria for the overall QR and the majority are likely to be 'Part Met' or 'Not Met' overall. Looking more closely at the scorings of the evidence-based markers provides a better insight into specific aspects of services and how they are scoring.

The below graphs demonstrate Cornwall and the Isles of Scilly's score from the Quality Neurology tool as against an average gained from a mixed sample of other areas. In terms of overall Quality Requirements, Cornwall shows a slightly lower than average score.

Total QRs

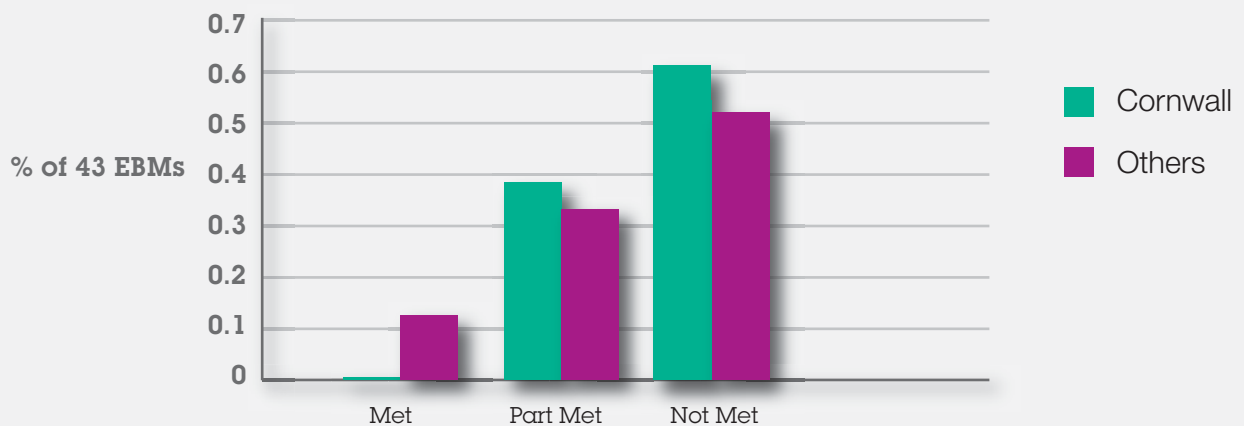


7. Neurological Commissioning Support (2010) 'Halfway through – are we halfway there? A mid-term review of the National Service Framework for Long Term Neurological Conditions' (NCS: London)

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This can be seen through the scores when broken down into evidence-based markers although it is clear that there is not a significant difference between Cornwall and the sample's average score.

Total % of EBMs



Those QRs that achieved 'Part Met' were:

- QR2 'Early recognition',
- QR7 'Providing equipment and accommodation',
- QR8 'Providing personal care and support',
- QR10 'Supporting families and carers'.

The remaining QRs which were scored 'Not Met' are:

- QR1 'A person centred service',
- QR3 'Emergency and acute management',
- QR4 'Early and specialist rehabilitation',
- QR5 'Community and rehabilitation support',
- QR6 'Vocational rehabilitation',
- QR9 'Palliative care',
- QR11 'Caring for people with a neurological condition in hospital or other health and social care setting'.

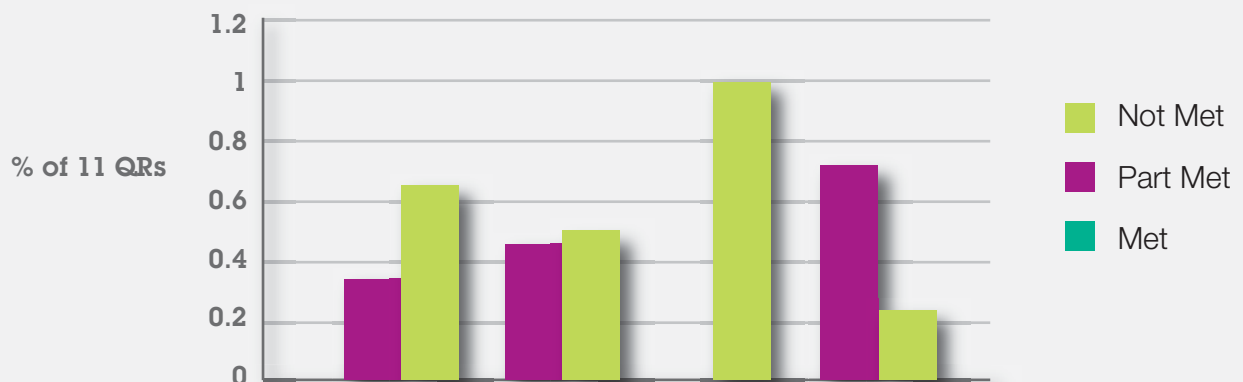
Total Quality Requirements

The below graph shows the overall number of Quality Requirements for which Cornwall scored 'Met', 'Part Met' or 'Not Met' across all 11 QRs.



By way of benchmark comparison, the below graph demonstrates Cornwall's results against 3 other health and social care areas of a similar population size and geographical layout. It can be seen that, amongst these three sites, Cornwall and the Isles of Scilly achieve a reasonably average score from the QN tool.

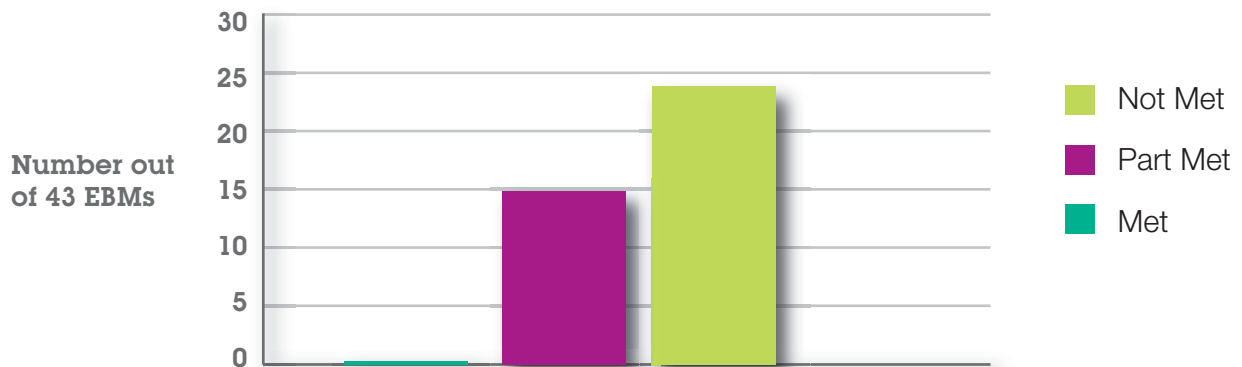
Total QRs against comparators



2.2 Evidence-based markers

Out of a total of 43 possible evidence-based markers across the NSF, the tool found none to be fully 'Met', whilst 17 were 'Part Met' and the remaining 26 were 'Not Met'. It should be noted that many of the EBMs criteria were all 'Part Met', and as the tool requires none to be 'Not Met' and at least one to be 'Met' to obtain a 'Part Met' score for the Quality Requirement overall, many were close to this. This will become clearer in the detail of the results.

Total Evidence based markers



One sample site whose geography is of a very similar nature to Cornwall has been used to create a detailed comparison of scores against Cornwall and the Isles of Scilly. The below grids demonstrate how each Quality Requirement and its underlying evidence-based markers were scored, comparing Cornwall and the Isles of Scilly against this matched area elsewhere.

QR1	Cornwall	Comp PCT
EBM1	Not Met	Not Met
EBM2	Not Met	Not Met
EBM3	Not Met	Not Met
EBM4	Part Met	Part Met
EBM5	Not Met	Part Met

QR2	Cornwall	Comp PCT
EBM1	Part Met	Part Met
EBM2	Met	Not Met
EBM3	Part Met	Not Met
EBM4	Part Met	Part Met
EBM5	Part Met	Not Met

QR4	Cornwall	Comp PCT
EBM1	Not Met	Not Met
EBM2	Not Met	Not Met
EBM3	Not Met	Part Met

QR5	Cornwall	Comp PCT
EBM1	Not Met	Part Met
EBM2	Not Met	Part Met
EBM3	Part Met	Met

QR7	Cornwall	Comp PCT
EBM1	Part Met	Not Met
EBM2	Part Met	Part Met
EBM3	Part Met	Part Met
EBM4	Not Met	Part Met
EBM5	Part Met	Part Met

QR8	Cornwall	Comp PCT
EBM1	Not Met	Not Met
EBM2	Part Met	Not Met
EBM3	Met	Part Met
EBM4	Not Met	Not Met

QR10	Cornwall	Comp PCT
EBM1	Not Met	Not Met
EBM2	Met	Not Met
EBM3	Part Met	Not Met
EBM4	Part Met	Not Met
EBM5	Not Met	Part Met

QR8	Cornwall	Comp PCT
EBM1	Not Met	Not Met
EBM2	Not Met	Not Met
EBM3	Part Met	Part Met
EBM4	Part Met	Not Met

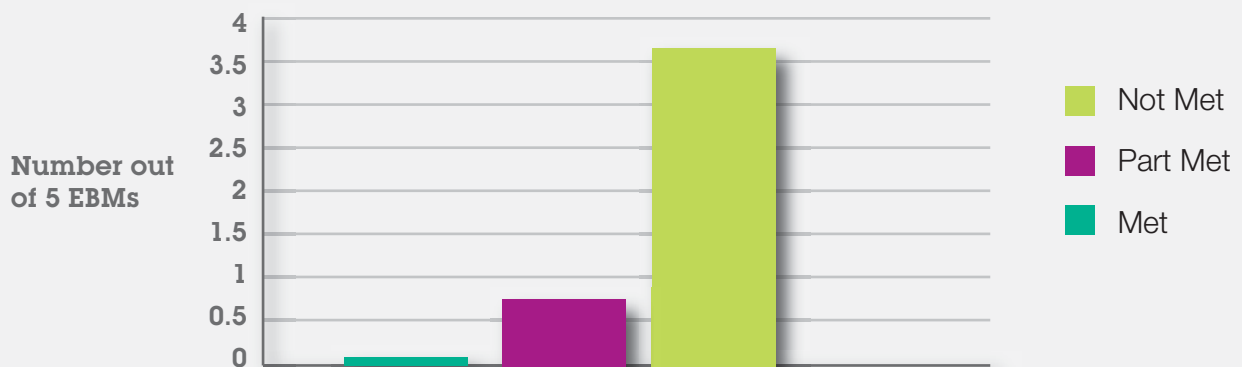
Comp PCT = Comparison Site

In-Depth Analysis

Quality Requirement 1: A person centred service

People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

Evidence based markers **QR1**



● **PART MET:** 'Local arrangements for providing information ensure that: people receive timely, quality assured, culturally appropriate information in a range of formats' (EBM 4) achieved a 'Part Met' result. Much of the information that individuals require exists for different conditions, in accessible formats with an option of translations available but despite its availability, professionals explained that very few of them had any training in delivering information and felt that the information they did provide was not able to be coordinated. They specifically cited a lack of a central care plan as the chief problem with this. This feeling was substantiated by service users, who found difficulty in accessing information about services and predominantly used the Internet, voluntary sector organisations and peer support for information about their condition and the services available to support them.

Good Practice and Integrated Care

Integrated teams and information

The Cornwall CFS/ME Local Multi-Disciplinary Team is a clinical service for adults in Cornwall with Chronic Fatigue Syndrome or Myalgic Encephalopathy and demonstrates a good integrated working model. The service sees people from the age of 16 onwards. All patients are seen in medical or therapy clinics in community hospitals from Stratton, Liskeard, Bodmin, St. Austell, Falmouth, Camborne and Redruth, Helston, and Poltair (Penzance).

The team comprises a Clinical Immunologist, a GP with a special interest, a clinical health psychologist, a consultant grade occupational therapist (OT) and three advanced OTs. The OT team provide evidence-based approaches to symptom improvement and management, and comprehensive physical and mental health rehabilitation and re-alignment skills either at community hospital clinics or in the patient's own home. The OTs are assigned to one geographical area and attached informally to the corresponding local hospitals' Integrated Therapy Service, thereby working as part of a larger rehabilitation team supporting patients and sharing knowledge. They also link into MESH, a service user group that supports local people with CFS/ME through advice and information. More information on MESH is available on its website: www.meshcornwall.org

Additionally:

- Areas of good practice exist where there are integrated therapists in health and social care who are using the same documentation.
- Therapy plans are available on some acute wards at Royal Cornwall Hospital and the Parkinson's services offer a personal care plan for patients to complete and return to their Parkinson's team.
- Specialist nurses and practitioners often act as case coordinators for their patients, acting as a single point of contact, and alleviating some of the confusion felt by service users and carers regarding where to go for information and support.
- Community matrons are trialling "Toughbooks", robust laptops connected to the internet via electronic dongles to get immediate and up-to-date information wherever they are.

There was an overall desire from patients to be self sufficient and independent. Self management courses can support this but the geography of Cornwall and the transport infrastructure has adversely affected the take-up of self-care courses offered, with attendance dwindling over the years and leading to a reduction in the provision of courses. Of those service users and carers who had attended such courses, there was a great deal of enthusiasm, particularly for the Expert Patient Programme, and a desire to develop greater availability of self help resources.

Good Practice and Innovative Steps – Self-Management Programmes

The James Parkinson Centre, a local charity for people living with Parkinson's, runs Hubs where people with Parkinson's can gather together for a day of socialising and learning. The Hubs are also attended by specialist Parkinson's nurses and other professionals with an interest in the condition.

Every Hub is a full day including maintenance exercises, learning about a topic of interest, refreshments and lunch. It gives the opportunity to gain advice and even referrals from the professionals present. More information can be found on its website at: www.jamesparkinsoncentre.org.uk

Similar meetings are also organised by the local branches of Parkinson's UK.



Next Steps

- How can we raise the profile of neurology services across Cornwall and the Isles of Scilly PCT?
- How can we improve information and person-centred care?
- How can we ensure everyone has a care plan?

Short term objectives

1. Designate a clinical lead for neurology in Cornwall so that there is strategic leadership locally, and develop a neurology clinical network.
2. Hold a Neurology Awareness Event for service users and professionals to raise the profile of neurology across the county.
3. Appoint two Neurological Care Advisers who can act as a central contact point for people diagnosed with neurological conditions for signposting. (This development was suggested in 2008⁸) These posts have just been filled and should help address many of the issues raised, providing the posts fulfil their objectives.
4. Ensure information is in one central place accessed through one telephone service or website
 - Develop an online database of information which can be retrieved in different ways including via phone and through printed material for those who do not have internet access.
 - For example a local service directory for health and social care practitioners, service users and carers could ensure information was disseminated widely.
5. Make neurology information on the PCT web portal more explicit and ensure people know that this is available.

Medium term objectives

1. Extend initiatives like the James Parkinson Centre Hubs to all neurological conditions. Extensions to the Hubs should mirror the newly forming health and social care HUBs and average two new neurology Hub areas annually.
2. Cornwall is a Whole System Demonstrator site using IT systems to provide services to local people. This initiative could be extended to include neurology so that services are more inclusive.
3. Implement NeuroResponse services⁹ which could supplement current services to patients and provide professional advice to GPs.
4. Ensure there are integrated care plans for all individuals living with a neurological condition, and their carers.

8. Neurology care business case Marie Therese House, 2008.

9. NeuroResponse service, Queens Square, UCLH

Long term objectives

1. Create a system whereby electronic records are available to all staff.
2. Facilitate the development of integrated team working through extended education.
3. Extend the personalisation agenda so that service users are more in control of the services they want to receive.

Lived Experience

What people living with neurological conditions, and their carers, had to say about getting information in Cornwall:

- 'I get all mine from the MS Society. No-one knows anything about MS really; nothing can be done and there's so many different ways that people experience it.'
- 'For Huntingdon's, it's different for everyone; there's no one way that it goes and we've had one heck of a journey so far. It's been very limiting without information'.
- 'I don't know. I saw my GP once and he referred me. We all know that doctors get given information packs from Parkinson's UK to give out to newly diagnosed people in Cornwall but I don't know what happens because they don't seem to get handed out.'
- 'Nowhere!' [Echoed by three people]. 'It's very difficult to get information.'
- 'I was handed a book [at diagnosis]. It was assumed that I already knew about it.'
- [Of general practitioners providing information] 'Mine just says, "I expect you know more than I do".'
- 'I've had a review, but not a care plan... How can you have a review of the plan that you don't have?'
- 'I've been discharged so many times. Ataxia's degenerative and I keep having to get in touch with them to ask for help.'

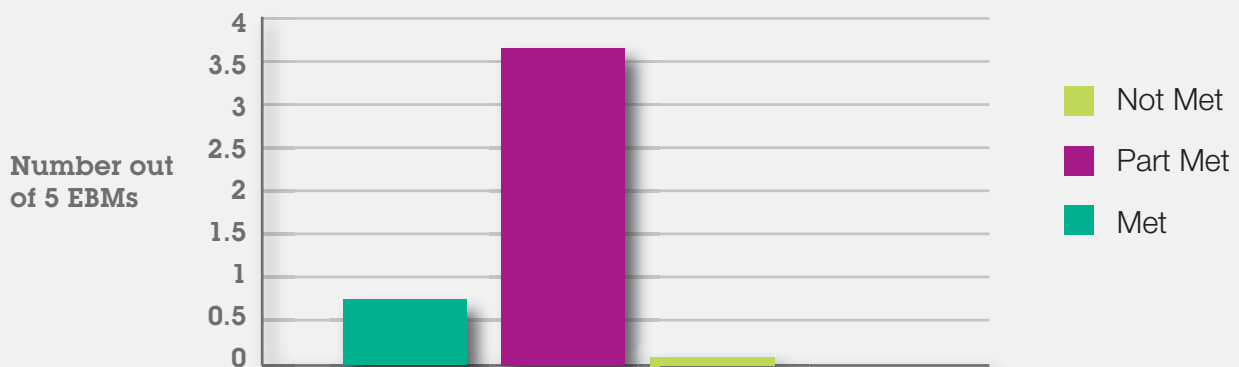


Putting service users at the heart of neurology commissioning

Quality Requirement 2: Early recognition, prompt diagnosis and treatment

People suspected of having a neurological condition are to have access to specialist neurological expertise for an accurate diagnosis and treatment is close to home as possible.

Evidence based markers QR2



● **MET:** 'Diagnostic services are effectively designed and have sufficient capacity to enable prompt diagnosis'. It was felt by professionals that this evidence-based marker was 'Met', and all services were considered to meet NICE guidance and other relevant national guidance on standards. There was, however, no evidence available to support this assertion at the time of the audit.

● **PART MET:** The remaining four evidence-based markers were considered 'Part Met'.

Good Practice and Innovative Steps – Waiting Times

Staff felt that national waiting time directives have improved the speed in which patients can access specialist consultations so that people suspected of a neurological condition do obtain a prompt diagnosis.

The Map of Medicine and the communication routes from GPs to consultants had contributed to improving this standard.

There were issues about timeliness and access to some treatments and medication especially where patients had to go out of county for diagnosis, tests and other services. This was seen to be of particular significance for patients with acquired brain injury (ABI).

Due to pressures on staff, follow-up monitoring appointments are often not routinely made (as per guidelines) although it was thought that patients living with Parkinson's received regular follow up appointments and there had been initiatives developed to expand capacity within the specialist Parkinson's team through nurse specialists and pharmacists.

Speech and language therapy shortages mean that follow-ups in Parkinson's are especially difficult. Generally, services rely on service users or their carers to contact staff if they have a change in symptoms or circumstances.

Good Practice and Innovative Steps – Access to Medication for Parkinson's

There is a local Medicines Usage Review programme ongoing in Parkinson's patients where individuals can receive a Medicines Usage Review in a pharmacy rather than having to have hospital appointments.

Paul Hughes and Lorraine Long (both pharmacists) run their own Parkinson's clinics in the community and have been instrumental in setting up training for other pharmacists across Cornwall.

Lived Experience

what people living with neurological conditions, and their carers, have to say:

'I received my diagnosis from the neurologist in a letter. Luckily I had been pre-warned about this by my GP who had received my MRI results and had requested to see me.'

'My GP thought my hand tremor wasn't Parkinson's. I insisted on a consultant appointment which he gave me to 'put my mind at rest'. The neurologist diagnosed Parkinson's.'

'Her GP had advised that her condition was "all in her head" although he has come round now she had been to a consultant for a diagnosis.'

'A positive predictive test confirmed the diagnosis ten years prior to my symptoms developing.'

Next Steps

- How can we ensure that all people living with a neurological condition across the county are identified?
- How can we ensure each individual has a care pathway to follow?
- How can we ensure that all staff are competent to handle neurology patients?
- How can we ensure that patients receive the services that will give the best possible outcomes?

Short term objectives

1. Ensure GPs and frontline staff are fully aware of the symptoms and problems people with neurological conditions experience through regular education; and develop educational course for GP's.
2. Set up a countywide 'condition a month' update.
3. Implement a generic pathway for neurological conditions agreed across agencies.
4. Ensure patients are aware that they can have a copy letter of their consultant appointments if requested.

Medium term objectives

1. Audit a generic pathway for neurological conditions, linking in, where possible, to the Map of Medicine¹⁰.
2. Explore the possibility of IT solutions for neurological monitoring and advice using Whole System Demonstrator¹¹.
3. Improve access to ongoing specialist advice and neurological support for individuals with rarer neurological conditions. (This may require joint commissioning arrangements with border PCT's / GP consortia).
4. Look at extending the Medicine's Usage Review programme out to other conditions.

Long term objectives

1. Develop a population-based register of people with neurological conditions to inform clinicians and commissioners about service requirements.

10. <http://www.mapofmedicine.com>

11. Department of Health (2009) Whole System Demonstrator an overview of Telecare and telehealth http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100947.pdf (accessed 13.03.11)

Quality Requirement 3: Emergency and acute management

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

This section was not scored during the completion of the professional audit as it was felt that there were insufficient people present who represented the emergency and acute teams. Thus all of the evidence-based markers and therefore the overarching Quality Requirement were scored as 'Not Met'.

Subsequent discussions with consultants in acute care and rehabilitation have confirmed that this QR would achieve a 'Part Met' score, but that to comply with NICE Guidelines, transfer to a Spinal Cord Injuries Centre, and Specialist Neuroscience Centre for acquired brain injury (ABI), is sometimes required. Cornwall has an air ambulance in operation to expedite transfers.

The main problems highlighted in relation to meeting this QR were regarding rehabilitation and repatriation following injury. There was a lack of positive outcomes when individuals had been out of county for treatment and / or rehabilitation. Major problems were also cited in repatriating patients with ABI into the community from out of county in terms of accommodation, ongoing treatment, the organisation of care packages and their funding. This same group of people also reported an inability to access mental health services.

Good Practice and Innovative Steps – Support for people with ABI

The ARNI project is a fitness programme for people with acquired brain injury and stroke developed in collaboration by Headway Cornwall, a voluntary sector organisation for people with ABI, and NHS Cornwall and Isles of Scilly.

The self-recovery programme, created by Dr Tom Balchin who himself lives with an ABI resulting from stroke, teaches each individual how to rediscover lost strength, balance and movement by functional task-related practice with the ultimate objective of achieving maximum self-reliance.

The project is delivered by trained instructors who run series of 12 week-long programmes in various locations across the county.

Putting service users at the heart of neurology commissioning

Concern was voiced about the problems that arise when people with neurological conditions are spread around an acute hospital. Particular areas of concern included: patients' treatment on a general ward, rehabilitation, ongoing rehabilitation as part of the discharge programme, and staff time wasted in accessing patients in multiple locations. Concern was also expressed regarding the lack of advice for people with epilepsy in terms of risk management and seizures.

Lived Experience

What people living with a neurological condition, and their carers, had to say:

'It was very difficult. I ended up on a general ward and the staff just didn't understand.'

'I was transferred to an old people's home. It just wasn't suitable for me.'

'No one told me about the risks associated with having epilepsy – taking my tablets and keeping well. I'm like any other teenager; I want to go out and have fun with my mates. I was shocked rigid when I found out I might die through not taking my tablets when I went out on a bender.'



Next Steps

How can we ensure that individuals receive appropriate emergency and acute management if required?

- How can we ensure that all staff are competent to manage neurological conditions or know where to access advice from specialist neurology staff?
- How can we ensure that risk assessment strategies are in place for all people living with epilepsy?
- How can we reduce the number of emergency admissions caused by seizure?

Short term objectives

1. Ensure there are sufficient numbers of volunteers trained to roll out the ARNI project for people with acquired brain injury.
2. Develop a spinal cord injury support group to promote a peer support 'buddy' system throughout Cornwall & Isles of Scilly.
3. Focus on providing targeted neurology education for staff in the Royal Cornwall Hospital Trust and Cornwall & Isles of Scilly PCT.

Medium term objectives

1. Investigate the full range of neurological conditions that can be supported across Cornwall and the Isles of Scilly, such as post-acute spinal repatriations, long-term ventilation and highly specialist in-patient treatments.
2. Set up a project around epilepsy education and risk assessment to better manage seizures.*

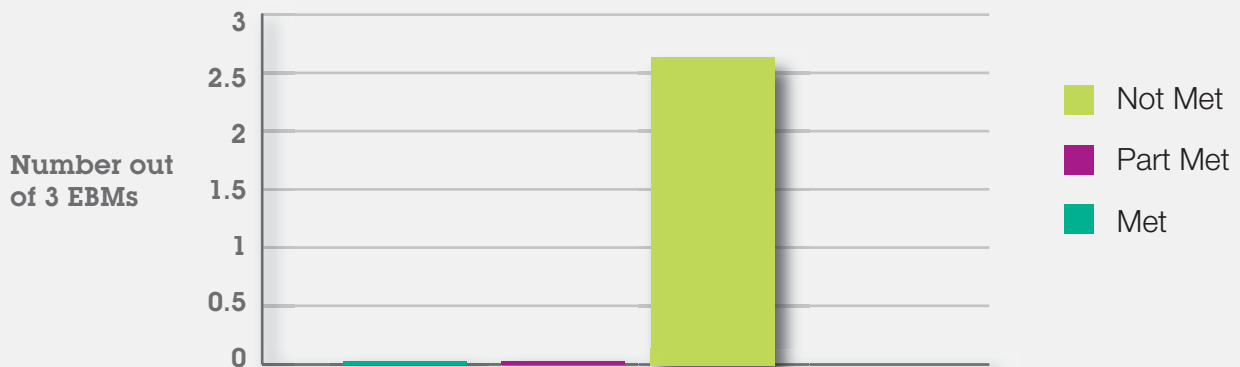
*NHS Outcomes Framework

This aim fits within the NHS Outcomes Framework: 'Preventing people from dying prematurely' - that people with a neurological condition will feel supported to manage their condition. The indicator for this outcome ('proportion of people feeling supported to manage their condition') measures how well the NHS as a whole is doing in supporting people to look after themselves and handle the consequences of their conditions; in this case, epilepsy.

Quality Requirement 4: Early and specialist rehabilitation

People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high-quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

Evidence based markers QR4



● PART MET ● (NOT MET): All of the evidence-based markers within QR 4 were scored as 'Not Met'. However all of the elements of each evidence-based marker were 'Part Met' and so we have marked the overall score here as 'Part Met' to reflect this and to demonstrate how closely it falls short of the mark. (The tool requires at least one element to be 'Met' in order for the evidence-based marker to become 'Part Met'.)

Good Practice and Innovative Steps – Access to Medication for Parkinson's

Marie Therese House, a rehabilitation centre located in Hayle, was cited by both professionals and service users as a good example of integrated services. Since 1983, Marie Therese House has been caring for patients with neurological problems, resulting from conditions such as MS, stroke, spinal and brain injury, Huntingdon's disease, motor neurone disease and cerebral palsy.

Some issues were voiced concerning optimal rehabilitation as against rehabilitation in order to “clear a bed”. It was also felt that there was not always common goal-planning between the disciplines and the provision of some equipment was not coordinated in terms of the 30 rehabilitation process. There were also difficulties around the timeliness of including families in the process, and the expectation of the involvement of families in the rehabilitation process.

Geographical issues meant that access was felt to be patchy. Finding appropriate spaces for people with severe behavioural difficulties, vegetative states, and severe spinal or head injuries was considered to be exceedingly problematic.

Lived Experience

What people living with a neurological condition, and their carers, had to say:

‘I really value my weekly rehab at Marie Therese House. They keep me going and give me the will to live, which I lose on occasions.’

‘Headway is the only service I get. Headway does the best it can with the least support that it gets.’

‘Lots of people with MS go to Hayle to Marie Therese House. It’s very good for MS...’
‘...they’re good for any neurological condition, I think...’
‘...I know they specialise in MND there.’



Next Steps

- How can we ensure that individuals have appropriate access to rehabilitation?
- How can we ensure that each newly forming health and social care HUB across Cornwall has access to rehabilitation facilities?

Short term objectives

1. Ensure each individual has a current care plan and that goal-planning is explicit.
2. Review how individuals access integrated health and social care discharge teams within hospital settings to ensure all people with a long-term neurological condition are able to access discharge planning procedures from the point of admission to hospital.
3. Review how individuals can access rehabilitation within the community.

Medium term objectives

1. Explore development of specialist outpatient rehabilitation services so that there is equity of access across Cornwall and the Isles of Scilly.
2. Further develop local provision of self-care and self-management.
3. Explore what opportunities exist to improve mental health and neuro-psychology services for people with neurological conditions.

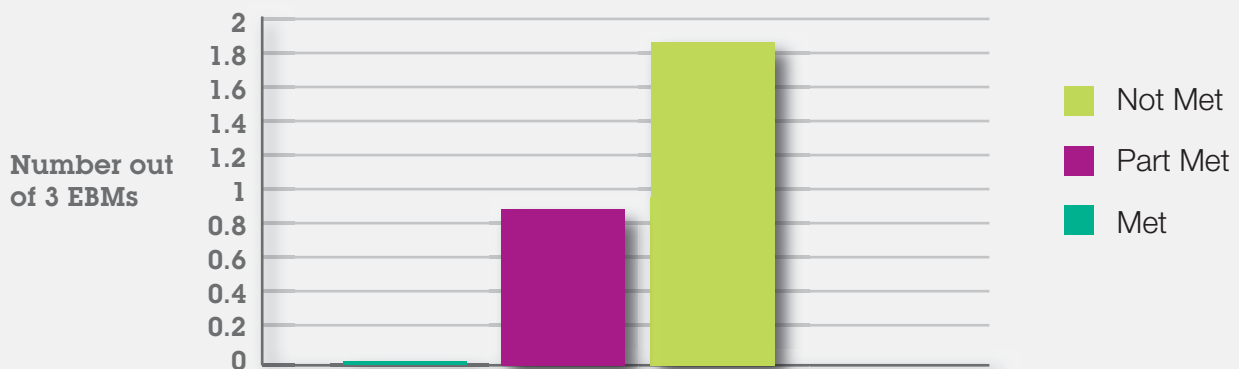
NHS Outcomes Framework

These steps fit with the NHS Outcomes Framework indicator that 'people with a neurological condition will feel supported to manage their condition.' The indicator for this outcome ('proportion of people feeling supported to manage their condition') measures how well the NHS as a whole is doing in supporting people to look after themselves and handle the consequences of their conditions.

Quality Requirement 5: community and rehabilitation support

People with long-term neurological conditions living at home have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

Evidence based markers QR5



● MET ● (PART MET): One of the evidence-based markers in this section was broken down into subsections, with almost all of the subsections being 'Met'. Providers of community rehabilitation and support services support people and their family to: 'Live with a long-term neurological condition'; 'Develop knowledge and skills to manage their condition'; and 'Provide proactive intervention, where relevant, to maintain function and prevent deterioration as the condition progresses' were all cited as 'Met'. However, the sub marker, 'Achieve a sense of wellbeing and make long-term psychological adjustments to altered personal, family, employment and social circumstances' was 'Part Met' which resulted in the EBM only achieving 'Part Met' overall.

What hindered this EBM from achieving a 'Met' status was the lack of formal psychological services across the conditions. The lack of neuropsychological services in the community was considered a barrier to good services and whilst experienced specialist nurses and other practitioners have been providing some psychological support, they are not formally commissioned to do so.

Good Practice Community - Rehabilitation Services

The Merlin Centre near St Austell is a rehabilitation centre founded and run by charitable donations. Throughout the audit process, it was frequently cited by professionals and service users as a 'wonderful facility'. Initially set up in 2001 to cater for people living with MS, the centre has extended support to people with a range of neurological conditions, including Parkinson's, fibromyalgia, chronic fatigue / ME and ataxia.

- **NOT MET:** Of the other EBMs within this requirement, availability of services, rather than lack of them, was the major reason for a lower score. The statutory 'six sessions' applied to both physiotherapy and occupational therapy was felt to be a major block to ongoing rehabilitation, and it was thought that flexibility on this quota would help to rehabilitate people more effectively.

Speech and language therapy is available to people according to clinical need and the service provided is considered to be of a good quality. However, there are insufficient staff resources to meet the needs of all those who would benefit from this service..

Good Practice and Innovative Steps – Exercise Programmes

RENEW

RENEW aims, through the provision of an exercise training programme, to build exercise skills and confidence thus empowering individuals with neurological conditions to achieve a physically active lifestyle for health and wellbeing benefits. Utilising existing community resources, it enables individuals to either self-refer or be referred to the 20 week progressive course of weekly low-impact exercises, posture and stretching exercises and training on healthy living and relaxation techniques (see appendix 3).

Exercising 4 Mobility

This exercise group was started in Bude by local individuals following their own completion of a RENEW exercise course. Classes are free but a £1 weekly donation covers refreshments and buys extra equipment. The initiative has been supported by the East Cornwall Local Action Group Small Grants Communities Scheme.

Professionals thought that health and social care services worked together, although not necessarily in a disciplined and coordinated way. The lack of integration with other mental health services into the neurology service was considered to be a barrier to delivering a holistic service. It was thought that a centralised multi-disciplinary team for neurology would allow for the progression and development of services.

Lived Experience

What people living with neurological conditions, and their carers, have to say:

'Lack of counselling is a huge issue for Huntington's disease.'

'There's a real need for continued exercise – that's why I go to the Merlin Centre.'
'I've been offered it [rehabilitation], but they wouldn't explain what it is to me... They kept passing the buck, so I didn't have it.'

'There is a lack of physiotherapy and few are neurologically trained. It is very expensive to arrange privately.'

'Speech and language therapy is available for Parkinson's but people have to ask for it and nobody comes and tells you.'

'To access speech and language therapy, they had to say that I was having trouble swallowing, not having trouble speaking, which was the actual problem, because I didn't fit the referral criteria.'

'Exercise programmes are always in work hours!'

'There is no regular physiotherapy at Marie Therese House. There have been plans that trained physiotherapists that are available at local hospitals, and some people go to MTH from as far away as Wadebridge.'

'The Merlin Centre is the most positive service I've come across – I just wish it was nearer.'



Next Steps

- How can we meet people's psychological needs and support people across the full range of emotional challenges that neurological conditions can bring?
- How can we provide exercise programmes to enable people to maintain their mobility as well as possible?
- How can we support people living with more rare neurological conditions?
- How can we ensure that patients and families which require specialist

Short term objectives

1. Explore how the 6 weeks of rehabilitation on offer can be annualised into assessment and review rehabilitation, supported by ongoing therapy and exercise within each health and social care HUB.
2. Consider how a centralised neurology team would allow for the development of services, particularly for rarer neurological conditions; and in particular focus on a joint project between health and social care to provide community support.
3. Consider how the current RENEW programme could be shortened to 12 weeks to act as an introductory taster course to build skills and confidence with participants. Attendees could then be encouraged to join ongoing weekly exercise sessions possibly provided by, or linked into, other existing support groups.
4. Explore how this could develop within each health and social care HUB area including an evening exercise group for those still at work.
5. Develop a centrally organised booking system for accessible exercise programme venues, which will also support social services.
6. Explore the provision of assistive exercise.
7. Ensure that joint commissioning arrangements are put in place to commission specialist facilities like Millerton Court at Launceston for conditions affecting lower numbers of people, such as Huntingdon's.

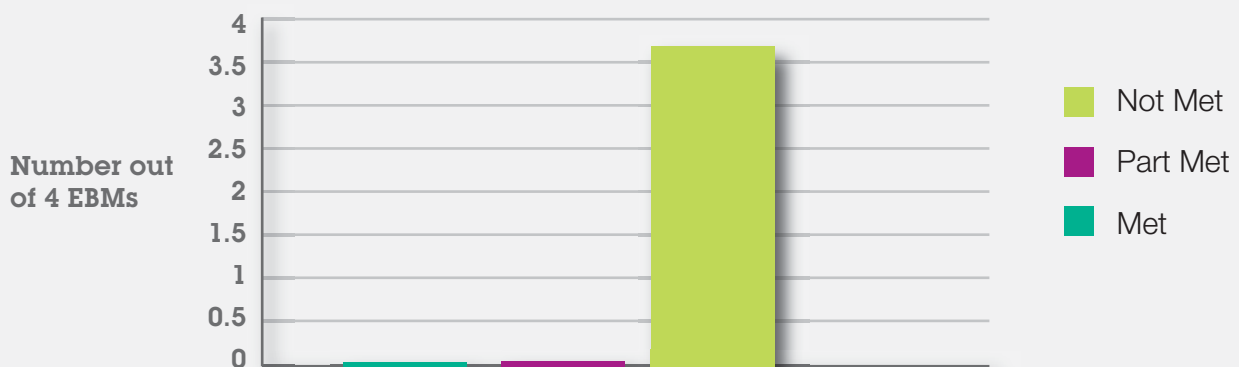
Medium term objectives

1. Explore how there can be better access to mental health and neuropsychology services – a key priority for individuals if they are to be supported appropriately.
2. Provide proactive intervention to maintain function and prevent deterioration as conditions progress.
3. Ensure there are sufficient specialists with neurology expertise to provide education and training for the generalist workforce.

Quality Requirement 6: vocational rehabilitation

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remaining work and access other occupational and educational opportunities.

Evidence based markers QR6



● **NOT MET:** None of the evidence based markers for this scored 'Met' or 'Part Met', although some elements of individual evidence-based markers were 'Part Met'.

Good Practice and Innovative Steps – Support through Creativity

Arts for Health Cornwall aims to support people with neurological conditions by 'getting creative'. It involves individuals in all sorts of art-forms including music, dance, design, crafts, visual arts, theatre, writing and singing.

Different art-forms affect health and well-being in different ways, so it carefully plans each project to suit the particular needs, hopes and wishes of the group of the people involved. It also uses the arts to change healthcare buildings, creating more inviting and relaxing environments for the people that use them.

To find out more, visit its website at www.artsforhealthcornwall.org.uk

Arts for Health Cornwall attended the stakeholder event on 16th February 2011 and facilitated to creation of the collage maps which visualise people's experiences of, and hopes for, health and social care services. Photographs of these maps have been included in this report.

Putting service users at the heart of neurology commissioning

Health and social care professionals felt there was a major gap in provision of vocational services enabling people with long-term neurological conditions to remain in work. It was also felt by those participating in the audit that people with long-term conditions often left it too late to seek help to remain in work, for fear of bullying at the very act of disclosing the nature of their condition to colleagues or employers.

It was also considered by those participating in the audit that experienced staff were more likely to consider vocational options and use their knowledge of local services to signpost people to the best help available. However this relied on the individual's own initiative rather than it being a comprehensive service and therefore it was not equitable across the county. It was thought that the increasing complexity of the benefits and welfare system often puts people off considering vocational rehabilitation, alternative employment or education opportunities.

Good Practice and Innovative Steps – Local charities and Support Systems

The Dracaena Centre in Falmouth offers a range of services to its immediate community across Falmouth and Penryn, as well as those outside the area. Amongst the services available are benefits and employment support, and a number of courses to assist people in accessing work. The centre works in partnership across all sectors to benefit the local community, currently delivering a number of accredited courses including Passport to Work, Information Computer Technology and a range of NVQs.

Cornwall Neighbourhoods for Change is a small charity which also offers employment advice.



Sections of a collage map representing people's current experience of services, created at a stakeholder event on 16.02.11

Lived Experience

What people living with neurological conditions, and their carers, have to say:

'I had no rehabilitation for work and the Job Centre told me there was nothing they could do for me. I had a supportive boss who did a transitional return to work for me. My job was reconfigured and that's been a life saver. I held a management position which I could not do now but I'm not ready to be written off yet. I now do a valuable job, it's just not as demanding.'

'I left employment because I kept falling over and there was a lack of sympathy from my colleagues – I felt pressured to leave.'

'I had received no help from my employer when I was diagnosed and, as my condition worsened, I received support from the Access to Work service, which I found very helpful. Now my employer uses the service. Initially, my employer had attempted to get me to take early retirement but I got support from a solicitor and mounted a successful challenge.'

'They want the services and it seems like your quality of life can only be improved if you go to work. I do lots of voluntary work, but that is not seen as work. No one has offered to help me find real work.'

'We've tried (at the Merlin Centre) to support people, but we've not got far with employment. We do have people coming in to help with the benefits system, and we also have 40 volunteers.'

'My husband was made redundant because family members had Huntington's disease, so they upped his pension, which has stopped us accessing things through the NHS.'

'I'd have liked to carry on in work – but when you can't drive, you can't walk and you're losing the use of your hands, what can you really do?'

'There is nothing as an alternative employment!' (Three people echoed this).

'I had to retire - I felt that, as a teacher, I just wasn't doing a good job any more; I was falling asleep in my classes – I think my students thought I was a bit daft. To keep my pension though,

'I had to literally stop working – I got a letter to tell me not to go in for one more day or it would affect my pension!'

'The Job Centre was of no help to me whatsoever.'

'We've had lots of help from the Access to Work scheme.'

Putting service users at the heart of neurology commissioning

Next Steps

- How can we better support people to remain in work after a diagnosis?
- How can we best support people to get back into work in a way which suits their needs?
- How can we support both service users and employers to find working arrangements that are beneficial to both and take into account the needs of both parties?
- How can we ensure that people understand, and can access, the advisory and financial support they are entitled to?

Short term objectives

An urgent piece of work needs to be developed between all agencies to ensure all people with neurological conditions are provided with:

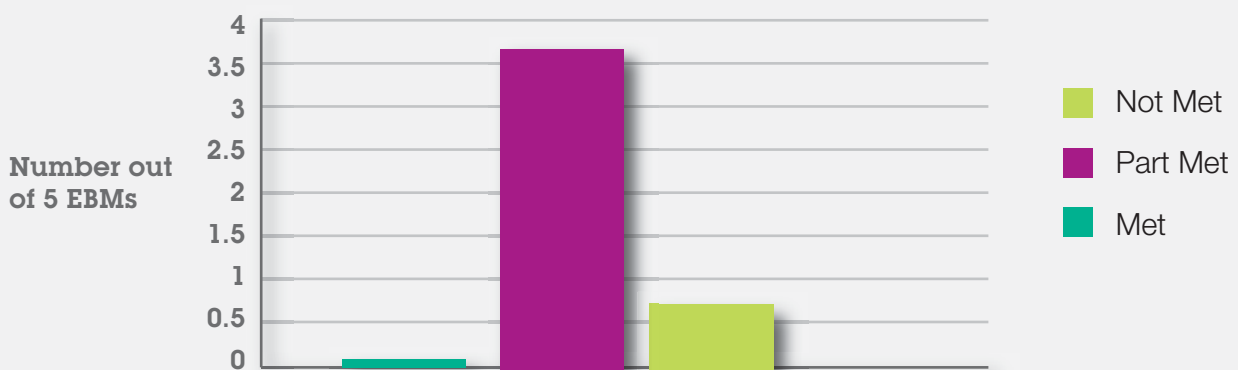
1. Vocational assessment,
2. Support and guidance on returning to, or remaining in, work,
3. Withdrawing from work,
4. The benefits processes



Quality Requirement 7: providing equipment and accommodation

People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help with their care; maintain their health and improve their quality of life.'

Evidence based markers QR7



● **PART MET:** This Quality Requirement scored highly in 80% of the evidence-based markers, achieving a 'Part Met' across four of the five EBMs.

● **NOT MET:** The areas which did not score well were cause for serious concern amongst professionals and service users alike. The joint equipment store was lauded for its efficiency. However, communication aids, POSSUM equipment and some specialist seating are not dealt with in the same way. Frustration was expressed by both staff and service users regarding requests for funding and additional forms – to be submitted to both local statutory services and the voluntary sector – which lengthen the application process, often to the detriment of the patient's health.

Good Practice and Innovative Steps – Accessing Equipment

Cornwall County Council has partnered with the national charity Disabled Living Foundation (DLF) to provide a quick and easy to use, online guided advice service called AskSARA which will assist anyone who finds that they have difficulties with everyday tasks. This tool can be found on the County Council website, at www.cornwall.gov.uk

Putting service users at the heart of neurology commissioning

There was confusion amongst professional staff concerning access to basic equipment for daily living such as adapted cutlery, which some believe they could no longer get, whilst others could obtain it from a standard social services pack.

Some assessments for specialist equipment have to be sent out of county to be considered and it was felt by professionals that this process is potentially more costly than training staff to process the assessments 'in-house'. It was also felt that, regarding general assessments, it would be useful to have all of a patient's needs in one comprehensive integrated assessment with further improvement being achieved by housing all relevant staff on one site.

There is a Mobility Centre at the Royal Cornwall Hospital Trust which was considered positive. It was felt that the wheelchair service works well in the community, although less well in residential and nursing homes. There have been major improvements in accessibility of specialist wheelchairs and all hoped that the current NHS budget cuts would not see the situation revert back to excessive waits for chairs.

The limited availability of adapted housing within Cornwall was acknowledged, but staff were aware that the issue has already been taken on board, and has begun to be addressed by Cornwall County Council.



Part of a collage map representing people's current experience of services, created at a stakeholder event on 16.02.11

Lived Experience

what people living with neurological conditions, and their carers, have to say:

'It's been pretty good. When they come to adaptations – it takes a bit before they come to the house – but once they are there they get it all done. One person came over, took a look at what we had been told we should have, thought we should have something else better so he went off to Truro the same day and came back with what he thought we needed.'

'I was assessed for bath aids and initially denied suction grab rails, which I went out and bought. Some weeks later I was told I could have them! There followed a protracted period of poor communication when council staff kept phoning me up asking when they could install the rails despite me having told them several times I bought them myself because they told me they couldn't be supplied!'

'I can't say I ever hear complaints about that [access to equipment], but if people need expensive pieces of equipment, over £1000 for a chair or whatever, we [the local branch] buy it for them. The standard state chairs don't cut it.'

'We've not had to wait for anything. We needed a walker and they brought us one; we needed a wheelchair so they gave us an old one to use while a specially made one came. It only took four weeks. We got a specialist moving table, bed levers, all sorts, even a thing for the car. We had to go to collect it ourselves, but they put it in – it straps her in and stops her from falling on me while we're driving. They were all very reasonable to get.'

'We have a terrific loaning centre at Bodmin for equipment.'



Next Steps

- How can we ensure there is a ripple effect in standardising information and equipment services across Cornwall?
- How can we ensure that there is preservation of excellence and that where good models exist, we learn from them and expand them accordingly?

Short term objectives

1. Identify the processes for obtaining all equipment to ensure that these are clear to both health and social care staff and service users.
2. Make details of the online equipment and advice tool explicit on the Cornwall County Council website.
3. Provide a pre-assessment form for service users to check whether, as a result of meanstesting, they are likely to need to buy their own equipment.
4. Where specialist assessments are currently done out of country, explore the feasibility of training local staff to undertake assessments.
5. Explore the possibility of the provision of specialist seating by a one-stop shop provider.
6. Promote the use of a single assessment process to ensure integrated care.

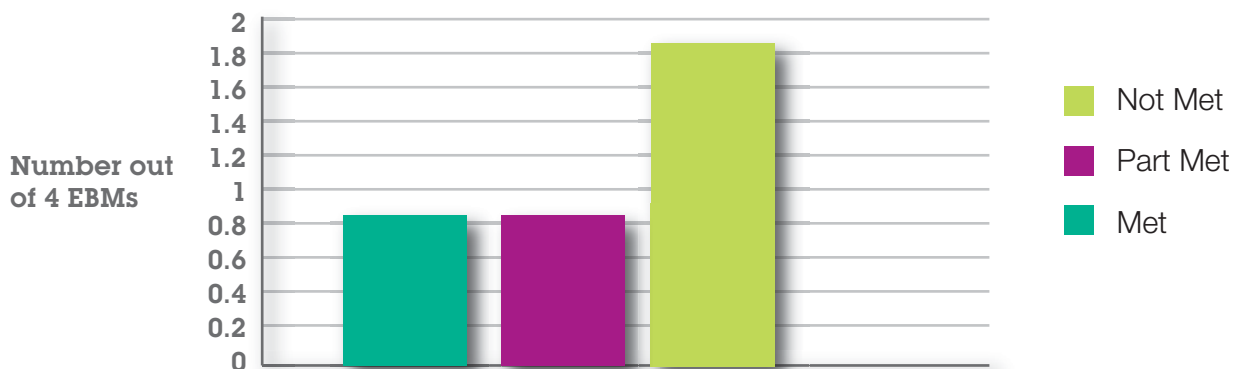
Medium term objectives

1. Monitor wheelchair assessment and delivery times to ensure good practice is maintained.
2. Monitor the work being undertaken by Cornwall County Council in relation to adapted housing.

Quality Requirement 8: providing personal care and support

Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

Evidence based markers QR8



● **MET:** 'Health and social care services work together to provide programmes of care that help a person remain as independent as possible as their condition progresses' (EBM 3) was 'Met', supported by evidence of an integrated health and social care discharge team at the Royal Cornwall Hospital Trust. However, it was recognised that some people might have cognitive issues where initiating ongoing rehabilitation could be problematic.



Good Practice and Innovative Steps – Maintaining independence through technology

The Whole System Demonstrator (WSD) programme is operating in Cornwall and looks at how technology can help people manage their own health while maintaining their independence through telehealth and telecare. This works especially well in isolated areas with poor transport facilities.

Telecare uses a combination of alarms, sensors and other equipment to help people live independently. This is achieved by monitoring activity changes over time and raising a call for help in an emergency situation, such as a fall. Telecare is not intended to replace human contact but is designed to support people living alone. For instance, a sensor can monitor when a person gets out of bed at night, raising an alarm if they do not return within a certain period, which may indicate a fall.

Telehealth uses equipment to monitor a person's health in their own home, enabling them to check vital signs such as blood pressure. These measures are then automatically transmitted to clinicians who are able to check the person without them leaving their own home. Daily readings can be monitored to reveal trends that could indicate a deterioration in condition. The use of telehealth equipment can avoid an individual making frequent visits to a surgery, as information such as blood pressure can be sent via the telephone line to the nurse or GP who will be able to monitor the user's progress from their desk at the surgery.

- **PART MET:** 'Care in all settings is provided by appropriately trained nursing, therapy and care staff with experience in managing long-term conditions' (EBM 2) scored 'Part Met'. It was noted that the high turnover of community care staff and agency staff meant that very few were trained with the result that health and social care professionals were unable to maintain an adequate standard of training.

Good Practice and Innovative Steps – Individuals use their lived experiences to support others

Due to high staff turnover within the care home sector, staff are not always familiar with managing people with Parkinson's. Parkinson's UK has several local branches within Cornwall where service users act as voluntary education officers, delivering Parkinson's education courses to care home staff.

This model allows staff to see first-hand how the condition can affect someone as well as providing a valuable education service from the voluntary sector.

● **NOT MET:** Evidence-based markers 1 and 4 were 'Not Met' due to a lack of age appropriate care homes and adapted housing in Cornwall, and no specific transitional living arrangements for those patients with acquired brain injury. Most professionals believed that patients could only receive support if they were found to have 'substantial' or 'critical' need. There was little take-up of personal budgets with some anxiety amongst service users and carers that these would be forced upon them against their will. However, those individuals who were already in receipt of one were very positive about them, with one person saying of himself and his wife that they 'changed our lives utterly.'

Lived Experience

what people living with neurological conditions, and their carers, have to say:

'I live with my parents and people don't want to know about me they only want to know about my parents.'

'No one goes through with you what different benefits are available and what you might be entitled to.'

'CAB [Citizen's Advice Bureau] in Truro have been really good, they're trying to get my husband's disability allowance upgraded. But you have to know where to go.'

'Well, it's complicated with us. My wife is means tested but I'm not, and she doesn't earn, so we can access the services. She's now on continuing healthcare so we don't have to pay for the respite, though we used to.'



Putting service users at the heart of neurology commissioning

Next Steps

- How can we ensure people are better supported to remain as independent as possible at home?
- How can we ensure that people with an acquired brain injury receive the necessary support to move back into the community and regain their independence?
- How can we encourage people to take control of their own services through the choice offered by personal budgets?

Short term objectives

1. Identify the process for obtaining all equipment and make this explicit to both health and social care.
2. Provide service users with more advice about personal budgets.
3. Map age-appropriate care homes and adapted housing in Cornwall.

Medium term objectives

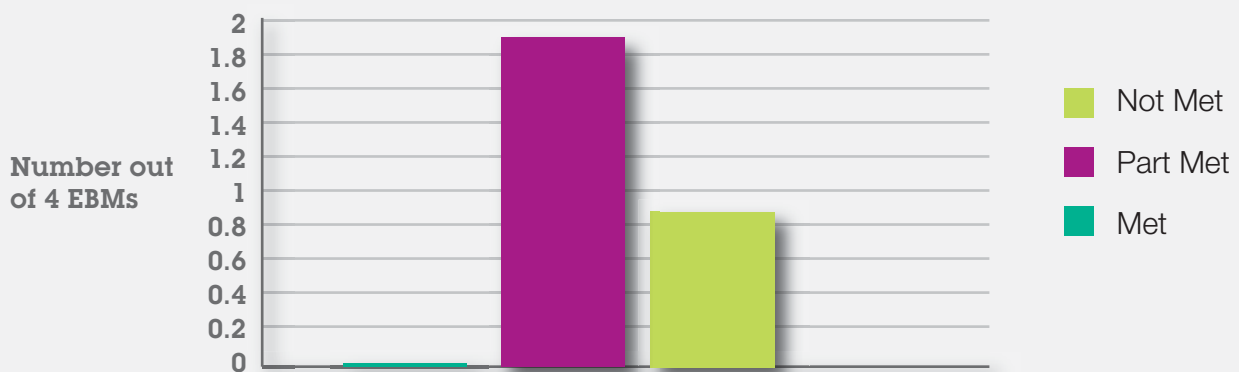
1. Explore extra provision of transitional living arrangements for those patients with acquired brain injury and spinal cord injury.



Quality Requirement 9: palliative care

People in the latter stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

Evidence based markers QR9



● **PART MET:** 2 of the 3 evidence-based markers scored 'Part Met', and of the remaining EBM which was 'Not Met' overall, all the elements were ranked 'Part Met'. This demonstrates that this entire Quality Requirement is very close to achieving a 'Part Met' score overall.

Good Practice and Innovative Steps – Palliative Care Support

There is a pilot programme currently underway in Devon & Cornwall for joint neurology and palliative care services for people with motor neurone disease. This is funded by the MND Association.

In North Cornwall, Macmillan nurses are involved in the care of people with MND and Progressive Supranuclear Palsy.

There is a palliative care helpline at Marie Therese House and the centres in St Austell and Hayle were both cited as offering good support.

Putting service users at the heart of neurology commissioning

Next Steps

- How can we ensure that dying is considered as a part of living?

Short term objectives

1. Hold an End of Life Care in Neurology conference to raise awareness locally.
2. Hold a Dying Matters event suitable for all people with neurological conditions so that issues like advanced decisions including Advance Care Planning can be discussed.
3. Establish numbers of people accessing palliative and end of life care from specialist services in Cornwall.
4. Explore the possibility of specific advance decisions documentation for people with a longterm neurological condition.

Medium term objectives

1. Ensure the Gold Standards Framework is fully accessible to people with neurological conditions
2. Provide ongoing training, particularly to care homes, on managing a person's end of life care needs for living with a neurological condition.

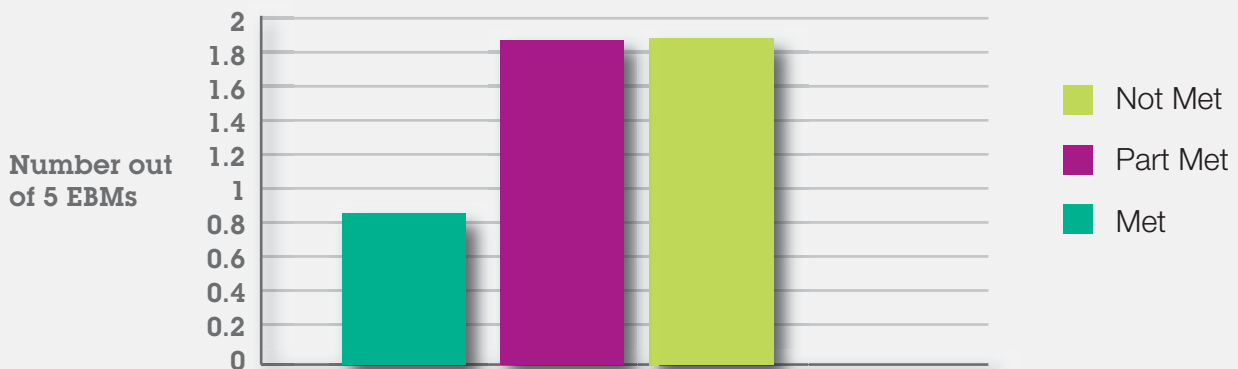


A collage map representing people's current experience of services, created at a stakeholder event on 16.02.11

Quality Requirement 10: supporting families and carers

Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

Evidence based markers QR10



● **MET:** ‘Involving carers as part of the planning process’ (EBM 2) was scored as ‘Met’ with the assertion that specialist practitioners do this as a matter of course. However, it was noted that it is assumed that family members, particularly spouses, will take on the role of carer, whether or not they are asked to do it. This was echoed by family carers, many of whom felt that they had no choice in the level of care they provided.

Good Practice and Innovative Steps – Carer Support Workers

Cornwall Rural Community Council provides carer support workers, mental health carers’ support workers and dementia carers’ support workers. There are also carer support groups across the county and support for young carers.

● **PART MET:** Evidence-based markers 3 and 4 were ‘Part Met’ with the rapid assessment teams that are being rolled out supporting these EBMs. Although there are no obvious ethnic minorities in Cornwall, a named individual has been tasked with addressing any issues regards ethnicity and diversity.

Good Practice and Innovative Steps – Rapid Assessment Teams

Rapid Assessment Teams (RATs) in each district of Cornwall offer services that can last up to 6 weeks depending on need. These teams comprise professionals from Adult Care and Support and the NHS. Anyone can make a referral to the RATs if they believe that this may prevent a person's imminent admission to hospital or into care, although most referrals come from health care professionals.

The aims of the teams are to:

- Provide fast, intensive support and care to avoid a possible hospital admission;
- Facilitate an early discharge from hospital;
- Prevent a marked deterioration in a person's health and well-being – this is carried out within a person's home, or local community.

To do this, the teams may do some or all of the following:

- Arrange short-term care-intensive packages, including night-sitting;
- Provide physiotherapy or occupational therapy programmes at the person's own home;
- Provide intensive nursing support within the person's own home, in addition to the existing District Nursing teams;
- Rapidly deliver specialised equipment to the patient's home.

In the carer feedback from the focus groups and the online surveys and questionnaires, 65.3% of respondents had not had a carer's assessment. District Nurses provide support to carers who have been taught to undertake a procedure but 63.2% of carers responding said they had never been offered any training to help them in their caring role.

Most of those contributing to the audit felt that programmes of respite care would help provide more support to carers. GPs noted that they tended to see carers more often than the person with the condition when explanation about new symptoms was required.

There is a carers' support network in Cornwall, although it was felt that information on cognitive problems is poor due to the lack of neurological psychology support. It was also asserted that dementia nurses do not see people in the community.

Good Practice and Innovative Steps – Memory Cafes

There are numerous Dementia Memory Cafes running across the whole county, including on the Isles of Scilly, attended by people with various neurological conditions, where their memory has been affected. The cafes use:

- Reminiscence sessions;
- Reminiscence training;
- Loans service of Memory Boxes for reminiscing and other activities.

Memory Boxes are packed with stimulating social history objects, photographs and other resources from the 1930s onwards. The Pictures to Share collection is now available as part of the Memory Boxes and photos from the past are also available from the Cornwall Photo Image Bank website:

<http://www.cornwallphotoimagebank.org.uk/>

A Cornwall Memory Cafe Network Newsletter is also available.

Lived Experience

what people living with neurological conditions, and their carers, have to say:

'I'm not sure if the paid carers ever all got together though. I'm not sure that there was ever that much continuity between them; if someone didn't turn up then there was no-one else to turn up instead of them – she'd just go without her lunch that day.'

'I don't have an assessment like you said – a carer's assessment – I didn't know there was one.'

'Respite care is a big thing for carers, some get it and some don't.'

'I get on one day a month; it's neither here nor there. I had an assessment as a carer and it was negative and pre-programmed. They let me have one day a month where they send my wife to Age Concern - and I can't do it - as she has anxieties of being left and she fits, it's placing a huge demand on me and it's very upsetting for her but they won't listen.'



Next Steps

- How can we provide information and check people are getting the services they need?
- How can we make sense of the growth of services and changes in some areas which is causing confusion of information?

Short term objectives

1. Ensure the production and distribution of more explicit information about what carer support services are available and ensure that both professionals and carers receive this. This is an urgent priority.
2. Map and highlight all respite services in a neurology service directory which is then made available to information helplines and services across Cornwall and the Isles of Scilly, and online for those individuals with access to the internet.
3. Ensure that carers are informed of their right to a carer's assessment and encourage them to ask for this.
4. Ensure the communication of information regarding carer benefits and how personal budgets could assist needs.

Medium term objectives

1. Undertake an audit to find out how many people caring for someone living with a neurological condition have accessed support, such as carers' groups, a carer's assessment, respite care, and such.

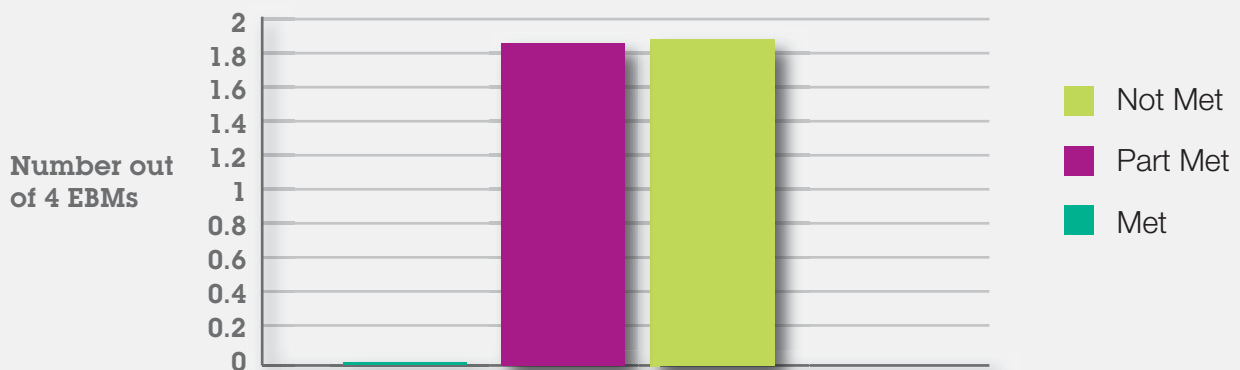
NHS Outcomes Framework

Work in this area will meet indicators in the NHS Outcomes Framework indicator: 'Carers: to recognise the vital role they play in supporting people with a neurological condition.'

Quality Requirement 11: caring for people with a neurological condition in hospital or other health and social care settings

People with long-term neurological conditions are to have their specific and neurological needs met while receiving care for other reasons in any health or social care setting.

Evidence based markers QR11



● **PART MET:** Evidence-based markers 3 and 4 scored 'Part Met'. Training of staff in general hospitals and other care settings was carried out, although increasing pressure on staff workload has meant that professionals felt it was not being done as thoroughly and frequently as required.

● **NOT MET:** Evidence-based markers 1 and 2 were 'Not Met'. There were concerns about patients with long-term neurological conditions being admitted to hospital or other care settings for co-morbidities. There appeared to be limited pre-admission assessments, and where these were carried out, they were often not followed up.

On admission, patients were not always given the equipment they needed and many service users felt that their needs regarding their neurological condition were not necessarily recognised or taken into consideration, specifically with regard to access to medication on time, something which is a particular problem for people living with Parkinson's.

Good Practice and Innovative Steps – Get It on Time

Parkinson's UK have been running a campaign called 'Get It On Time' for people with Parkinson's who are admitted to hospitals or care home facilities, to try and educate hospital staff as to the importance of patients being able to access their drugs at the times they need them.

Lived Experience

what people living with neurological conditions, and their carers, have to say:

'It's so bad; I want to create my own notes to take around with me!'

'Of the professionals, there's a young dentist in Camborne who's wonderful – she steps outside her role to get people referred.'

I did it all, I put these pills into little plastic bags, I labelled up all the right pills in the right bags and wrote the times on them, and the nurses were really grateful. The next time he went in, I wrote a list of which pills he needed at which times; both times he was in he got his medication on time, they were great!'

'I was told that the nurses had to be trained to understand that people with Parkinson's disease needed their medication on time and at regular intervals..... but she still didn't get them on time.'

'I've said I'm not prepared to do medication changes at home any more: the side-effects are too terrifying. The Peninsula Hospital knew nothing about it when I phoned for support. From now on the changes can happen during respite or at Millerton where there are trained people to deal with it. At one stage he was there for two months to sort out a medication that hadn't worked out. If they'd talk it all through in the first place it wouldn't have happened it would have been one week whilst the change took place. Money wasted!'



Next Steps

- How can we support staff to understand the needs of people living with a neurological condition when admitted into hospital for reasons other than their condition?
- How can we ensure that people receive their medication on time when in hospital?

Short term objectives

1. Develop a means for hospital and care home staff to know where to access advice when someone with a neurological condition is admitted.
2. Facilitate a Parkinson's UK 'Get it On Time' campaign within hospitals across Cornwall and the Isles of Scilly.
3. Ensure specialist teams run the Get it On Time audit following the campaign.
4. Ensure that emergency guidelines for the treatment for all elective and emergency Parkinson's admissions are made explicit.

NHS Outcomes Framework

Work in this area will meet indicators in the NHS Outcomes Framework indicator: 'Treating and caring for people in a safe environment and protecting them from avoidable harm.'

The Isles of Scilly

Respondents from the Isles of Scilly contributed to the audit of health and social care services and therefore the overall results detailed thus far, but the audit also highlighted some issues that are unique to the Isles; these are covered separately here.

In particular, service users felt there was good continuity of care from local health services. However there is inequity of neurology service provision on the islands; difficulties include accessing the mainland for a range of services such as outpatient appointments and access to vocational support. It was noted that a particular issue involved the booking of hospital appointments on the mainland, which some people living on the Scilly's find difficult to keep as appointments are not always dovetailed with transport timetables. It was noted that additional difficulties do also arise from inclement weather conditions, which cannot be helped.

Putting service users at the heart of neurology commissioning

It was stated that access to information was limited by the unreliable access that local people had to internet facilities. Many people affected by a neurological condition on the islands live in temporary accommodation and it was suggested that this group of people had particular difficulties in using telephonic internet connections as the service was not available, as a rule, in these temporary residences.

People living with a neurological condition on the Scilly's would specifically like opportunities to attend neurological support groups and to have access to regular exercise.

Next Steps

- How can we make allowances for transport difficulties so that outpatient appointments might be kept more easily?
- How can we help increase access to information for those on the islands?
- How can we use good practice in Cornwall to ensure that people living

Short term objectives

1. Develop a Scilly neurology support group.
2. Ensure outpatient appointment times are made later in the day to assist with helicopter transfers to the mainland.
3. Ensure facilities such as transport and exercise groups which are currently available on the islands are accessible to all age groups.
4. Explore the possibility of computer and internet access for people with a long-term neurological condition.

Medium term objectives

1. Trial 'my clinic' outpatient appointments via Whole System Demonstrator.

Conclusion

Neurological Commissioning Support undertook this audit of services for people living with a neurological condition across Cornwall and the Isles of Scilly, not to be negative or to highlight deficiencies but to try and achieve the service changes that local people living with a neurological condition feel would maximise their independence and quality of life. The audit is not solely about discovering what is happening at a grassroots level, but about utilising that information to stimulate informed and meaningful service change, and we feel that NHS Cornwall and the Isles of Scilly should be applauded for taking this step to examine its neurology services.

Considerable time and effort now need to be invested in providing the Primary Care Trust, newly forming GP Consortia and County Council with support and facilitation so that services can be redesigned in order to improve efficiency, cost-effectiveness and to meet the quality standards service users deserve. Many of the ideas generated in this review and highlighted at the subsequent stakeholder event, address quality, innovation, productivity and prevention (QIPP) objectives.

Although much work has been done, there is still a long way to go to address the identified work streams within this project and we are aware that change cannot take place overnight. We hope that through continued engagement with service users, joint working across health, social care and the voluntary sector, and the newly forming GP commissioning consortia, that this report will be the ongoing mechanism for real service change to take place. In the coming weeks, the work streams will be developed to take forward many of the issues raised and a progress report will be issued to all stakeholders at six-monthly intervals.

APPENDICES

Appendix 1

1. Quality Neurology

Quality neurology was developed collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK. The tool was match funded by the Department of Health and had support from the Social Policy Research Unit at York University. Validation of the tool took place between April 2007 and December 2009 following which a report was submitted to the Department of Health Long-Term Research Initiative Programme. The Department of Health subsequently acknowledges:

'The Department of Health contributed to the initial development of the audit tool and is pleased to see it progressing. It is keen that any further development, or adoption, of the tool continues to be led by Quality Neurology and its partners, ensuring that service users and their carers are at the centre of the process.'

The Quality Neurology audit tool breaks down the evidence-based markers (EBMs) for each of the 11 Quality Requirements of the National Service Framework for Long-Term (Neurological) Conditions into auditable statements. Services can evaluate themselves as 'met', 'part met' or 'not met' against each criterion of the evidence-based marker. The tool then gives them a red, amber, green (RAG) score against that criterion.

The sum of the criteria drives the overall score for the evidence base marker which in turn drives the overall score for the Quality Requirement. It must be emphasised that the answers are reached by a consensus method through open discussion thus ensuring that the audit is not undertaken from a single individual's point of view.

The evidence-based markers of good practice for the Quality Requirements are shown in appendix 2.

Appendix 2

Evidence Based Markers for the Quality Requirements

Quality Requirement 1: A person centred service

EBM1: There is timely integrated assessment involving all relevant agencies leading to individual care plans which:

- Cover current and anticipated it needs (including health, social, emotional and cultural needs);
- Are held by the person and regularly evaluated and reviewed with them by the clinical team. Review is based on clinical need, including self assessment (see QR2): and
- Ensure that staff has access to all relevant records and background information about the person's condition, test results and previous consultations.

- EBM2: arrangements are in place to ensure that:
- All people with long-term neurological conditions have a main point of contact for advice and information.
- People with complex needs who require skilled input from a number of professionals have a named individual (e.g. a care coordinator, Case manager or community matron) who is responsible for coordinating the input from all relevant agencies and producing a care plan.

EBM3: The care assessment and planning process ensures that appropriate services are available to provide support for life transitions and to enable people with long-term neurological conditions to receive continuity of care (e.g. when they transfer to adult health or social care services or across geographical boundaries, or following a change in circumstances such as the death of a carer).

EBM4: local arrangements for providing information in sure that:

- People receive timely, quality assured, culturally appropriate information in a range of formats on:
- All relevant aspects of service provision;
- The condition and how best to manage it;
- Wider social inclusion issues (e.g. employment and transport).
- Health and social care professionals, people with long-term neurological conditions and carers receive appropriate training on effective ways to provide and use information. Assessment of information needs is part of the review and any interaction with health and social services.

EBM5: people with long-term neurological conditions and their carers can access education and self-management programs, tailored to their individual needs and these are available at different stages of the condition.

Quality Requirement 2: Early recognition, prompt diagnosis and treatment.

EBM1: there is improved access to specialist neurological expertise through:

- Training for frontline staff to improve recognition of neurological symptoms
- Shared protocols for referral for further specialist assessment so that people receive appropriate priority within locally agreed target times.
- The guidelines on the management of genetic disorders include referral to genetic services.
- Multidisciplinary neurology clinics run in hospital and community settings where possible:
- Communication routes for GPs to obtain a rapid specialist neurological advice about urgent clinical problems.

EBM2: Diagnostic services are effectively designed and have sufficient capacity to enable prompt diagnosis. Services should be delivered according to NICE guidelines and take account of agreed national guidance and protocols for delivering diagnoses, using staff trained in delivering 'bad news'.

EBM3: there is improved access to appropriate treatments and:

- Treatment available to people includes all those approved by NICE.
- Early integrated assessment and care planning ensure timely access to treatment and to multidisciplinary support, if necessary before diagnosis is confirmed.
- Individuals receive the appropriate information before starting medication to enable informed choice and are supported to manage side-effects or any other problems they may be having.

EBM4: Or people with long-term neurological conditions have prompt access to ongoing specialist neurological advice and treatment. Specialist nurses and practitioners with specific knowledge of long-term neurological conditions are available to support people in the community.

EBM5: There is improved access to treatment review that ensures:

- Processes are in place to provide review and monitoring of treatment appropriate to individual need;
- People taking medicines on a long-term basis have access to regular medication reviews to enable them to get the most out of treatment. To some people, especially those taking three or more medicines, it may be appropriate to have a face to face the review.

Quality Requirement 3: Emergency and acute management.

EBM1: acute and emergency management of sudden onset of neurological conditions complies with NICE guidelines and takes into account the nationally agreed standards and guidelines.

EBM2: local hospitals except in people with a neurosurgical or neurological emergency have appropriate resources to treat, manage and review individuals presenting with a sudden onset of neurological condition, including

- Trained staff/teams (A&E, medical assessment, acute medical, neurological) to ensure that people with acute neurological symptoms receive prompt neurological assessment;
- Appropriate facilities and links to a specialist in neuroscience centre and spinal cord injuries Centre for prompt expert opinion if necessary;

- Protocols of care agreed with specialist spinal cord injury, neuroscience and neuro rehabilitation centres.

EBM3: There are protocols in place which comply with NICE guidelines on head injury and take account of nationally agreed standards and guidelines, the people with acquired brain injury not admitted to hospital.

EBM4: transfer to specialist centres is available when needed, and:

- Specialist neuroscience centres and spinal cord injury centres have the capacity, staff and facilities to accept prompt transfer of people who need more specialist management and to conform to national standards,
- Protocols are in place to support prompt transfer of people to district all local services when specialist intervention is no longer needed.

EBM5: Local hospitals admit people transferred from specialist neuroscience centres to suitable wards or facilities where any necessary ongoing neurological care, supervision or rehabilitation can be appropriately provided, involving senior specialist medical staff and other staff with neurological expertise.

Quality Requirement 4: Early and specialist rehabilitation.

EBM1: rehabilitation is provided which complies with NICE guidelines and takes account of other nationally accepted guidance

EBM2: there is improved access to rehabilitation and:

- Rehabilitation is provided:
 - Early,
 - At high intensity appropriate to need,
 - By a co-ordinated interdisciplinary team,
 - In an appropriate specialist setting, and
 - On an on going all the accessible basis to people with changing needs,
 - With specialist equipment (including wheelchairs and seating support systems) where required,
- Trained rehabilitation, nursing or allied health professional staff support people to apply the skills acquired during therapy sessions in routine daily living activities,
- The person, their family and the rehabilitation team all work towards the same agreed goals,
- Inpatient rehabilitation programs are followed by ongoing rehabilitation and support in the community for those who need them.

EBM3: Seamless transition of care is provided through:

- Integrated working with other healthcare professionals/teams,
- In reaching/outreach arrangements between:
 - Specialist neuro-rehabilitation and acute care services; and
 - In patient and community-based specialist neuro-rehabilitation services.

EBM4: Specialist rehabilitation services are provided to meet the needs of people with very severe and complex disabilities, including:

- Profound and complex disabilities (e.g. vegetative or low awareness states, high or complete spinal cord injury or severe brain injuries);
- Severe cognitive and behavioural problems needing a structured environment;
- Other long-term medical problems needing intervention.

Quality Requirement 5: Community rehabilitation and support.

EBM1: there is improved access to community rehabilitation through:

- Flexible, individualised programs and community rehabilitation and support which are focused on individual goals beyond a basic daily care and to promote participation in a full range of life roles;
- Interventions provided according to individual need may include:
 - Rehabilitation and support centred on the person's home and environment,
 - Holistic outpatient or day rehabilitation programs.

EBM2: local multidisciplinary rehabilitation and support are provided in the community by professionals with the right skills and experience, and:

- Involve health and social services working together;
- Include access to specialist neurological expertise (e.g. neuro rehabilitation, neuropsychology) to address the full range of practical and emotional challenges;
- Are available in the longer term based on clinical need.

EBM3: providers of community rehabilitation and support services support people and their family members and carers to:

- Live with a long-term neurological condition;
- Develop knowledge and skills to manage their condition;
- Achieve a sense of well-being and make long-term psychological adjustments to altered personal, family and social circumstances;
- Provide proactive intervention, where relevant, to maintain function and prevent deterioration as the condition progresses.

Quality Requirement 6: Vocational rehabilitation.

EBM1: coordinated a multi agency vocational rehabilitation is provided which takes account of agreed national guidance and best practice

EBM2: local rehabilitation services are provided at which:

- Address the occasional needs during review of a person's integrated care plan and as part of any rehabilitation programme:
- Work with other agencies to provide:
 - Vocational assessment:
 - Support and guidance on returning to all remaining in work;
 - Support and advice on withdrawing from work;
- Refer people with neurological conditions who have more complex occupational needs to specialist the occasional services

EBM3: specialist the occasional services are provided for people with neurological conditions to address more complex problems in remaining in the all returning to work or alternative occupation including:

- Specialist vocational assessment and counselling;
- Interventions that job retention, including workplace support;
- Specific vocational rehabilitation or work preparation programs;
- Alternative occupational and educational opportunities;
- Specialist resources for advice for local services.

EBM4: specialist vocational rehabilitation services routinely evaluate and monitor long-term occasional outcomes, including the reasons for failure to remain in employment.

Quality Requirement 7: Providing equipment and accommodation.

EBM1: Assistive technology/equipment is provided and maintained in accordance with nationally agreed standards and guidelines.

EBM2: people with long-term neurological conditions have access to integrated community and specialist assistive technology/equipment services which work closely with neurology and rehabilitation services to provide,

- Specialist assessment and advice to help them select the most appropriate assistive technology/equipment for their needs and lifestyles;
- Support in using direct payments the equipment and vouchers for wheelchairs;

Putting service users at the heart of neurology commissioning

- Assistive technology/equipment to maintain their health, help with their care, and support independence;
- More specialist equipment on temporary loan or trial;
- Systems for tracking and recycling equipment to increase cost efficiency or temporary provision;
- Regular and ongoing review of their assistive technology needs, especially in response to changing need, including the needs of their carers, where appropriate.

EBM3: Assistive technology/equipment needs are documented in a person's integrated care plan.

EBM4: there are specific arrangements the joint funding of specialist assistive technology provision (e.g. communication aids electric standing frames and special seating aids).

EBM5: social services work closely with housing/accommodation and Supporting People services to provide timely, suitably adapted or purpose-built accommodation.

Quality Requirement 8: Providing personal care and support.

EBM1: health and social services work together to provide the full range of accommodation, care and support options and facilities to maximise choice, and Where day or residential care or supported living is provided it, they are in suitable settings or people with neurological conditions.

EBM2: care in all settings is provided by appropriately trained nursing, therapy and care staff with experience in managing long-term neurological conditions; and Care staff receives support and advice from community rehabilitation and support providers and other specialist neurological, palliative care and rehabilitation services as appropriate.

EBM3: health and social care services work together to provide programmes of care that help the person to remain as independent as possible as their condition progresses.

EBM4: people with long-term neurological conditions have equitable access to services and assessments based on many health and social care support (with prompt reassessment when needs change), and are supported in the applying for:

- Direct Payments, to increase their control and choice over their care;
- Fully funded NHS continuing care that takes account of the particular needs of long-term neurological conditions, including physical, communication, cognitive, the failure will and emotional problems,

- Adult social care delivered under the Fair Access to Care Services scheme based on need;
- Help from the Supporting People Program which provides housing related support for vulnerable people; and
- Staff administering these assessments and schemes are aware of the particular needs of people with neurological conditions (e.g. for social inclusion, independent living, preventative care).

Quality Requirement 9: Palliative care.

EBM1: specialised numerology, rehabilitation and palliative care multidisciplinary teams and providers work together to provide care for people with advanced long-term neurological conditions.

EBM2: people with advanced long-term neurological conditions have access to specialised and generalised palliative care services which support them in their home or in a specialised setting according to their choice and needs and in line with national best practice guidelines, and Specialised neurological and community rehabilitation services provide support, advice and training for all staff delivering palliative care in the community.

EBM3: staff providing care and support in the later stages of a long-term neurological condition have appropriate training so that:

- Neurologists and neurological rehabilitation teams are trained in palliative care skills.
- All staff providing care for people in the advanced stages of neurological illness is trained in both the management of long-term neurological conditions and palliative care.

Quality Requirement 10: Supporting the family and carers.

EBM1: carers of people with long-term neurological conditions:

- Can choose the extent of their caring role and the kinds of care they provide,
- Are offered an integrated health and social care assessment at diagnosis and all future interactions, together with information that addresses their needs;
- Are offered a written care plan agreed with them and reviewed regularly;
- Have an allocated contact person.

EBM2: Involving carers is part of the planning process so that:

- All carers are treated as partners in care and helped to acquire appropriate skills to support them in their caring role, including how to move and handle the cared for person and how to use equipment to help in daily living.
- Carers are given the opportunity to work in partnership with specialist teams.

Putting service users at the heart of neurology commissioning

EBM3: A range of flexible, responsive and appropriate services is provided for all carers which:

- Deals effectively with emergency situations,
- Can support highly dependent people at short notice;
- Provide appropriate support of the children in the family;
- Provides carers with breaks across a range of settings;
- Is culturally appropriate (e.g. to the needs of black and ethnic communities).

EBM4: Carers who need help to adjust to changes especially of the cognitive or behavioural kind have access to support based (where appropriate) on a whole family approach and delivered (where necessary) on a condition specific basis and in partnership with the voluntary sector; and Current service models are evaluated to inform future good practice.

EBM5: staff working with people with long-term neurological conditions receive care that awareness education and training which involves carers in planning and delivery.

Quality Requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings.

EBM1: whenever the person is managed in a non-neurological setting (e.g. a general hospital wards or care facility).

- The integrated neurological care plan is available for all staff;
- There is a close liaison with their usual neurological care team

EBM2: Arrangements are in place to ensure that neurological needs can be met in all settings:

- Planned admission:
 - There are preadmission interviews to establish any special needs, including equipment provision, communication aids and transport.
- Emergency admission:
 - Protocols are in place for liaison with:
 - A person's community care team; and
 - Any relevant specialist team (e.g. neurosciences centre or SCIC).
- There is evidence of appropriate consultation between teams.

EBM3: There is effective consultation with the person about their management and, where appropriate, involvement of the family/carers who are familiar with the person's care needs; and Interpreters are available for people who need them.

EBM4: specialist neurosciences, rehabilitation and spinal cord injury services are involved,

Appendix 3

The RENEW Programme

In order to address the need for community provision of exercise for people with long-term neurological conditions RENEW was commissioned, as a pilot by the PCT, and provided by a local fitness organisation in 2008. RENEW set out to support and encourage self-care for people with long-term neurological conditions, seeking to find sustainable ongoing everyday exercise that enables people with LTNC to make lifestyle changes which will impact on health and enable people to self-manage their care. RENEW is a 20 week progressive course of low impact exercises, healthy lifestyle advice, relaxation techniques, posture and stretching exercises for people with LTNC.

The overarching aim of RENEW is to, through the provision of an exercise training programme, build exercise skills and confidence to empower individuals with neurological conditions so that they achieve a physically active lifestyle for health and wellbeing benefits. This utilises existing community resources and facilities. The service does not rely on existing NHS rehabilitation services.

Objective of evaluation

To evaluate the effect, process and sustainability of the RENEW programme with a view to determine whether to take it from a pilot stage project and develop it into a regularly commissioned service.

Objective and Aim of the evaluation

Specifically the effect of participating in the RENEW programme, delivered at three separate venues, was audited using the following criteria:

- Mobility and Fitness
- Physical activity levels
- General health and wellbeing
- Service use (GP, emergency care and hospitalisation, clinic visits and medication)

To collate information of:

- Service users and their characteristics
- Direct costs of the programme
- Adherence to the programme
- Participants views of the process, the programme and of sustainability

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Methodology

Evaluation design: Mixed methodology to include an experimental pre/post-test design and quantitative and qualitative process evaluation.

Intervention: RENEW exercise programme

The RENEW programme is a progressive exercise training programme for people with neurological conditions, which sets out to educate and empower participants to achieve an active lifestyle. The exercise programme was developed and provided by the CORE Fitness and Body Studio. The programme is progressive aiming to initially build confidence and then to gradually develop participant's skills to safely exercise.

The programme involved 20 sessions spanning a 26 week period. Sessions were run in the mornings with each session lasting approximately 1 ½ hours. Sessions were run by fitness trainers experience in supporting exercise in people with clinical conditions. Sessions were run in hall settings with exercise equipment (resistance bands, weights, steps and balls) provided by the core. Sessions included a warm up and then gentle strengthening, stretching, balance and core stability exercises and ending with a warm down. Sessions were run as a group activity with exercises adapted in order to meet individuals needs. Exercises were progressed using body position, speed, weight and repetitions. Aerobic/endurance activity was encouraged as part of the class as the programme progressed as allowed within the limits of each exercise facility. Social interaction and support was encouraged within each setting.

Participants

Adults with one or more neurological condition, including stroke were invited to participate. Conditions were not necessarily confirmed by a consultant neurologist. Participants could be referred into the programme through the following routes:

- Self-referral
- Community referral, from a health or social care professional, or other agency or charity e.g. Multiple Sclerosis Society
- GP referral

Referred individuals were then registered onto a course via the PCT commissioner. Participants approaching the PCT commissioner were allocated to one of the three venues as determined by their home location. A maximum of fifteen people could be allocated for each class venue. All venues received the same exercise programme delivered by the same provider 'The CORE' between June and December 2010.

All participants were interviewed by a CORE instructor prior to entry to the programme to determine participants' suitability for safe participation in the course (safe exercise participation [PAR-Q questionnaire¹], neurological condition, other background medical conditions, body function, and attitudes towards exercise). Further details of confidence and attitudes to exercise were discussed.

All assessments and interviews were performed by a researcher (from Oxford Brookes University) independent of the exercise programme provider. Assessments were performed either in person, or by phone.

Assessments

At week 0 entry to the programme (Assessment 1), 8 weeks after the start (Assessment 2), 20 weeks after the start (Assessment 3).

Background Descriptors (Measured at assessment 0)

Disease/condition and time of onset/diagnosis/diagnosing clinician

Medication use (patient reported use)

Age

Barthel index (independence in activities of daily living)^{2, 3}

Employment status (patient reported use)

Equality and Diversity (Cornwall and Skye NHS scale)

Exercise venue

Measures at assessments (0, 1, 2)

Questionnaire self reported acute service use, GP visits and prescribed medication use

Self reported physical activity questionnaire (IPAQ)⁴

The General Health Status questionnaire SF-36⁵

Quality of life measure EQ-5D⁶

Mobility and fitness –(grip strength and Timed up and go)⁷

Physical activity levels (Physical activity for the elderly questionnaire)⁸

Putting service users at the heart of neurology commissioning

Interviews

Semi structured interviews were undertaken with participants and centre managers in the second half of the 20 week programme. Interviews were undertaken with the PCT commissioner and exercise providers after completion of all of the programmes. A total of sixteen interviews with programme participants and one interview each with the PCT commissioner and the CORE providers were conducted. Interviews were carried out in a private corner of the venue, in a quiet room or over the phone as appropriate depending on the venue and availability. Whilst we used slightly different interview schedules for the participants, provider and PCT commissioner, the same key topics were discussed. The topics which are outlined below were identified from previous research findings⁹⁻¹², a background literature review undertaken by the research team, and by drawing upon the providers, participants, research team and commissioner's collective experience and knowledge.

Participant anecdotes of their experiences relating to all aspects of the service were explored. A pre interview plan was used and subjects covered included: booking for the course, delivery of the course, venue, scheduling and timings, transport and access, and both positive aspects and difficulties and problems encountered by participants. In addition the following direct questions, rated using Likert and ordinal scales, were asked:

- How did you hear about the course?
- Have you done a course before?
- How was the booking process?
- What did you think of the Venue?
- Was the time of class good?
- What did you think of attending the class?
- What did you think of the content of class?
- How would you improve sessions?
- How often did you attend?
- How much would you be prepared to pay for the classes to continue?
- Would you do another course?
- Would you take on running a class yourself?

The Provider's views regarding long-term sustainability of programmes considering above findings, resource use and costs were explored. Specifically the following areas were considered: Recruitment in the three centres – expressed interest, actual take up, and resource use to manage recruitment (time) (from commissioners interview and referral records) Management requirements and their sustainability in each of the three centres (i.e. how much effort (time) does it take to organize and run the classes and is this level of effort sustainable) (from provider/centre managers).

Scheduling and timings issues faced. Views re continuation sustainability etc.

Attendance and class content record

Finally information from the provider of session attendance (register) and session content were obtained.

Analysis

The study was an audit of an established service and so did not require ethical approval from an NHS committee. The matter was explored and discussed through the local NHS ethics committee and ethics 'research or audit' documentation. Participants were made aware of the audit, consented to their data being collected and were offered the possibility to opt out of participation with no implications for their care.

Quantitative data analysis

Data analysis was carried out according to a pre-established analysis plan. Descriptive statistics were calculated for demographic characteristics, attendance at centres, components of the Physical Activity Scale for the Elderly, timed up and go (seconds), grip strength left and right (N), health (SF-36) and wellbeing (EQ5D). Participants from the different venues were compared at entry to the programmes on health, wellbeing and independence in activities of daily living measures using a one way ANOVA or Kruskal Wallis test as appropriate. In this before after trial data imputation was not performed on missing data points. Following tests to establish normality and variance several repeated measures ANOVA (polynomial) and a Friedman test for non parametric data were performed on outcome measures grouped together from venues, collected at baseline, week 8 and week 20. Repeated measures contrasts were performed on significant tests. Outcome measures were then plotted in relation to attendance with attendance as the independent variable. Then from curve estimation linear regression was found to best describe the data and was performed to investigate the strength of relationship of attendance to outcome in the markers. All analyses were performed with SPSS version 17.0 (SPSS Chicago, Illinois, USA) alpha was set with a Bonferroni correction via SPSS.

Interview analysis

The data collected from interviews was transcribed verbatim and analysed. Two members of the research team independently analysed the data to identify and categorise major themes using an approach modified from Framework analysis (Ritchie and Spencer). Minor differences were resolved by discussion. Data coding and organisation into conceptual categories and themes was done by hand. Data responses to direct questions were collated and categorised by a member of the research team. Participant's responses to questions on: booking organisation and, location, class content and exercise continuity/sustainability were rated on Likert and ordinal scales and then analysed descriptively.

Discussion of findings

Summary overview

Overall the RENEW programme was well received by participants and their carers and was popular with both the provider and commissioning team. There was good recruitment to the programme in all three centres, despite limited advertising as a result of the evaluation. Participants were recruited with a number of different neurological conditions and a range of impairments to body function, mobility and functioning. As such recruitment to the RENEW programme was consistent with its overall objective and included individuals requiring and appropriate for inclusion in the programme.

The programme was safely delivered to this clinical group, with no reported adverse events or issues regarding the exercise sessions. Individuals benefitted in both body function and health outcome measures and demonstrated a trend to improve in wellbeing measures and to a reduction in hospital appointments. Following participation individuals demonstrated an understanding of and empowerment in managing their own exercise needs. The provider demonstrated empathy, knowledge and understanding of neurological conditions and how to generate confidence to exercise in this clinical group. Exercise sessions were appropriate and included an educational element and appropriate progression. The venues and halls selected for delivering this programme to a mixed audience with varied and complex needs meant that whilst strengthening, coordination, flexibility and core stability training could be included and adapted for all within classes, there were limited aerobic/endurance activities and most activities were delivered at a relatively low intensity. The inclusion of more endurance exercise and the gradual appropriate progression to the inclusion of some higher intensity exercises may provide further benefit for participants. The audit findings are positive regarding the effect of this community exercise service provision, however it was outside the remit of the evaluation to compare the cost/benefit to other service models.

A major challenge for the exercise programme is both in initiating exercise and achieving adequate levels of adherence of at least once a week in a clinical group in a rural area. The programme managed to effectively initiate a number of individuals to exercise. However, whilst in some venues the majority of participants achieved adequate adherence, in other more isolated venues only a minority did. The selection of appropriate venues is critical to achieving adequate adherence to the programme and its sustainability. This theme was echoed by participants, the provider and the commissioning team. The importance of the social support from participating in the course was a common theme reported by individuals and it is worth noting that the Merlin centre which enabled participants to relax together following sessions had notably higher adherence than other venues.

Finally the programme would appear to be potentially sustainable in all the selected venues, with some participants expressing a willingness to run sessions and all participants being willing to pay for the ongoing service. The Merlin centre had the highest adherence rates and general satisfaction levels associated with it and finding other similar venues would appear to be important although not critical to the programmes ongoing success.

Participants

Recruitment to the centres was generally good. The RENEW programme managed to enable people to work through many of the barriers to initiating exercise^{9, 17, 18}. The demographics of participants were similar to other community provision projects¹⁹ and in line with national statistics²⁰ including participants with a range of conditions with the most common MS and the next most common Parkinson's disease. Participants were mainly female (18) and reasonably independent in activities of daily living using aids as required, with all walking independently with an aid except for two individuals who needed the support of a helper to walk. Five of the participants had previously participated in a RENEW course. The group consisted of people with an average age of 57, who were white, British with five participants currently employed, three unemployed and 20 retired. In agreement with this profile, people were most physically active in the home or in social activities. The activity questionnaire confirmed extremely low activity levels (54/400) in the twenty eight participants at entry to the RENEW programme compared to age match older adults (males) mean 154.3/400 (SD 80.4) (females) 137.9/400 (76.7)²¹⁻²³. The low levels of activity confirm previous findings in neurological populations²⁴⁻³⁰. As such this group were at risk of developing secondary conditions of inactivity³¹ and indeed there were a number of co-morbidities within the group associated with inactivity³¹ including osteoporosis, heart disease, bowel cancer and stroke. The demographic profile was similar across the three venues, although all participants at Liskaard/Looe were either unemployed or retired. The participant profile suggests that individuals should benefit from even low levels of exercise, which was confirmed by our findings. In summary the group of participants was representative of people with neurological conditions who are extremely inactive²⁴⁻³⁰ and often present with co-morbidities and find it extremely difficult to access standard exercise referral schemes or facilities due to physical, emotional and social barriers⁹. The successful initiation and delivery of exercise to this complex group in the community setting is a positive and encouraging finding.

Effectiveness of the programme

The RENEW programme was well liked by participants with all commenting that they had enjoyed the programme. This confirms previous findings of exercise studies⁹. There were no reported adverse events with participants achieving body function and health benefits and positive trends in hospital visits and wellbeing. Again these findings of safe community exercise provision are in line with the evidence from other community provision for neurological populations^{11, 19}. Indeed these findings are in line with the general population with physical activity having been shown to contribute to well-being and good health for all^{32, 33} with the risks associated with participating in physical activity at levels that promote health and wellbeing being low³². Whilst some intensive research studies have achieved high levels of exercise frequency over the short term with associated higher levels of benefit, these studies have generally been delivered over a period of less than 12 weeks and there is extremely limited evidence of this form of exercise having been achieved or evaluated in actual service in this clinical group over longer periods^{16, 34-36, 15}. Such short term controlled research studies are prone to overinflate the effects of exercise compared to delivery within an actual service. Indeed in community provision exercise even when transport is supported more than once weekly attendance is rarely achieved^{11, 37}. Considering the previously reported decline in treatment effects after exercise interventions have ended in neurological populations^{38, 39}, the general benefit with only limited exercise frequency and the continued improvements observed over the 20 week period in the RENEW programme is an extremely positive observation. These findings suggest that this model can achieve ongoing benefits with longer-term participation.

Participants reported feeling empowered from participating in the programme. This finding has not previously been explicitly reported in exercise research in neurological populations and is an extremely important finding supporting a mixed educational, motivational and practical approach to exercise implementation in the community¹².

The main challenge of any exercise programme is to achieve adequate levels of attendance for health benefit. The programme achieved better attendance at the Merlin centre (56%) attending weekly for the intervention than other standard exercise referral schemes (44%)⁴⁰, but at Liskeard/Looe it was lower (21%)⁴⁰. Achieving an active lifestyle is an issue for all and this clinical group report greater barriers⁹. Considering this, alongside the challenges of the environment in some centres, the RENEW programme achieved good attendance figures. Looking at the outcome data much of the change would appear to occur relatively early on in the programme, and considering patient and provider views regarding holidays and exercise provisions over the longer-term, the development of the programme into a shortened initial RENEW course (~12 weeks) with the provision of a follow-on exercise session (possibly patient run and with a charge) in these venues would appear to be attractive option.

Certainly recent evidence suggests that, whilst the government guidance is of exercise for 30 minutes 5 times a week, people with neurological conditions can benefit from weekly exercise¹⁹ of as little as 20 minutes exercise a week³⁸.

The evidence is compelling; attaining a physically active lifestyle is associated with health and wellbeing benefits. Clear guidance and support for achieving adequate activity levels for healthy adults and children is now a central health policy in many countries⁴¹. Participation in physical activity has been shown to improve mobility, health and wellbeing in people with long-term neurological conditions (LTNC), with more recent evidence proposing that physical activity may also delay neurological disease processes⁴². Exercise thus offers an exciting opportunity to benefit individuals and reduce health costs in neurological as well as other long-term conditions where exercise on prescription is better established⁴³. This study confirms that suitable community exercise facilities available in most localities in the UK can be utilised for safe exercise delivery. Acknowledging the recommendations of people with neurological conditions^{9, 44, 45, 46-48} and theoretic frameworks to optimise take up and adherence^{8, 9} and the issues of actually achieving regular exercise in a rural setting⁴⁹, the RENEW programme would appear to be an effective model for such provision.

Sustainability

Recruitment was good in all venues and it was generally accepted by both the provider and commissioner that recruitment could be improved with an appropriate marketing and advertising strategy. The programme also managed to convert initial referrals to an initial exercise interview with most (26/28) individuals continuing onto initiating the exercise programme, one of whom did not wish to participate in the audit. Previous research evidence from people with neurological conditions stating overwhelming barriers to exercise initiation and participation due to inadequate knowledge of appropriate exercises⁹⁻¹² should be considered alongside the findings of this audit as they support the success of the programme in empowering individuals to take charge of their own exercise needs⁹. When considering sustainability and recruitment, a system for supporting individuals to attend the initial session would appear to be an important element to a successful exercise programme in people with neurological conditions^{11, 19}. Indeed, services where no explicit link is made have been shown to fail to get participants to initiate exercise^{11, 19}.

In the RENEW programme individuals were carefully introduced to the programme and instructors through personal interviews. This system worked well and supports the role of an introductory exercise course with initial interviews. This role of linking individuals in to exercise programmes was successfully taken on by the CORE, who achieved an excellent record in keeping participants involved following initial recruitment.

Putting service users at the heart of neurology commissioning

These research findings indicate that this system should remain in future services, or that the role could be taken on by a health practitioner working across the district as successfully utilised in other programmes^{10, 11}. However, whichever system is employed it remains clear that knowledge of both neurological conditions and appropriate exercise for neurological conditions would appear to be an important part of this role which was successfully addressed in the RENEW programme⁹. Indeed from the findings of this audit, this model for supporting exercise in neurological conditions would appear to address barriers to exercise initiation^{9, 44, 45, 46-48} although further support mechanisms may need to be implemented to increase exercise adherence.

Indeed we found strong support for the RENEW programme from participants. When considering that a strategic and directed approach by using the Health Promotions LEAP Active Team has been suggested as a means of achieving sustainable ongoing exercise classes, we explored participant's views of achieving ongoing exercise. The findings from this study suggest that attaining ongoing sustainable community exercise programmes is achievable with half of participants expressing a desire to continue immediately following the course, all participants confirmed a willingness to pay £5.00 for sessions with at least one individual in each class stating they would be willing to run a programme at a venue as long as they had appropriate support. The LEAP team may be used to give advice on how to apply for grants and set up an exercises group and could be used to achieve sustainable programmes.

Both participants and the exercise provider suggested that a follow on weekly exercise session, rather than repeated courses, may better address the ongoing physical activity needs of participants following the course. If a weekly exercise class, as an ongoing service, was to be developed in accordance with comments from participants, the provider and the commissioning team. However a system for introducing participants to community exercise, such as employed by the RENEW programme, would appear to be an essential initial part of the process to enable initiation of exercise. The choice of venue for both introductory classes and ongoing sessions requires careful consideration. The ability of individuals to successfully move exercise venues has yet to be established and it may be that courses and follow on classes should be run at the same venue in order to optimise take-up.

Cost implications

In the UK there are three million individuals with over 200 different neurological conditions. They have direct health care costs almost double those for coronary heart disease. Neurological conditions are also associated with aging and as such form an important growing patient group. Physical activity helps maintain health and independence of people as they age, affecting cardiac, musculoskeletal, mental health and other factors that ensure people stay well³¹. There was no previous service in the region enabling community exercise participation for people with neurological conditions prior to the RENEW initiative and everyday physical activity levels were extremely low in people attending the programme. By improving health, wellbeing, quality of life and decreasing the risk of more than six major diseases, activity enablement can significantly benefit people with neurological conditions and offers a cost effective means of achieving important savings³¹. Inactivity currently costs the UK £8.3 billion/year with direct health costs of £1-1.8 billion³¹. Increasing physical activity levels can decrease the risk of developing more than six major diseases and help to maintain and prolong individuals' independence as they age. Individuals with neurological conditions are extremely inactive and the RENEW programme utilises an innovative, relatively cheap sustainable approach that empowers the individual and works across private, voluntary and statutory sectors. Participants of the RENEW programme found benefits in some body function and health measures with positive trends in other health and wellbeing markers. The programme as such has important possible cost saving implications. People with Multiple Sclerosis (MS) and Parkinson's disease (PD) made up the majority of the participants. The costs of treatment for Parkinson's disease (health and social care) have been estimated at between £560,000 and £1.6 million per 100,000 population (i.e. per 160 patients, or an annual cost of between £3,500 and £10,000 per person. Significant cost drivers include the onset of motor fluctuations, psychiatric symptoms, and later institutional care. With an incidence of PD in the UK of 13 per 100,000, and annual cost of £7,000, a delay in symptoms of 6 months could reduce NHS costs by $130 \times 60 = 7800 \times 7000 = £546,00000$. When considering MS two thirds of diagnoses occur in young adults between the ages of 20 and 40, who are at the peak of their career and family development. Because of the early onset, disability and that most people with MS have a normal life span MS imposes considerable cost on individuals, families, the health care system, and society. Total cost per patient is estimated at £17,000 per year, suggesting a total burden to society of around £1.34 billion per year. Informal care accounts for 26% of this total, and direct medical cost only 16%. A cost of approximately £3,400 per patient per year falls on the NHS, and the remainder is borne by patients and their families and carers. The RENEW programme showed positive beneficial effects on these aspects in both people with MS and PD. Whilst the cost effectiveness needs to be confirmed a more detailed quantitative analysis beyond the scope of this audit, the RENEW programme appears to offer both quality of life benefits and cost savings for the individuals, families and the NHS.

Limitations of the audit

The findings of this audit should be considered alongside the following important limitations. The audit was carried out using a pre/post test design with no control group and as such any effects may be considered to lie at the upper of the 95% confidence intervals and give a generally more positive bias to the findings. The audit was carried out within a real exercise provision service with the research team having no control over participant recruitment, enrolment and compliance. Due to initial issues with recruitment, some participants were enrolled late throughout the programme and these individuals could not be included in the analysis, some individuals enrolled at the beginning of the programme and were not able to maintain their engagement throughout leading to dropouts and missing data points. Individuals who failed to make appointments had to be followed up over the phone leading to difficulty in obtaining body function measures. Some individuals were not keen to commit to all measurement time points. The above resulted in a smaller sample size for analysing benefit to individuals, particularly in body function markers. There was no means within the audit to keep track of all dropouts, with these individuals not wishing to complete further measures, this may have influenced the findings. With individuals entering the RENEW program at different time points, this created difficulties for the research team to determine entry and exit points for individuals. This led to a relatively small sample, whom the team had confidence in the integrity of the attendance, entry, exit and measurements being analysed fully. Finally the research team, their presence, interviewing and measuring and any requested controls to the service for research purposes, (such as the recruitment route) may have unduly influenced the programme and its findings.

Policy that RENEW addresses

Achieving a physically active lifestyle has been a central tenet of current UK government policy, however there is minimal maintenance of community physical activity, the majority of people remain inactive, particularly clinical groups, and activity levels reduce with age. This service development is a means of delivering an evidence based intervention to support current government policy to have its desired impact. The Darzi report 2008, supported by the recent Public Health White Paper⁵⁰ encourages voluntary cooperation between the government, private and third sector organizations (NHS, county council and private fitness providers) to improve health outcomes. RENEW provides an accessible physical activity intervention for the aging population and thus impacts on two of the six stated key goals: tackling obesity, and improving mental health. The programme supports the coalition for better health proposed in the Darzi report and the 'Big society' by providing a means for cooperation between the government, private and third sector organizations (NHS, university, county council, and private fitness providers) in improving health outcomes.

Current guidance for community services⁵¹ and rehabilitation⁵² promotes the need to respond to the requirements of people in local communities and provide safe, effective services that are a good experience for patients through the development of community care provider collaborations. The RENEW programme considers the enablement of physical activity for people with neurological conditions in community facilities⁵³. In line with the National Stroke Strategy, RENEW supports people with long-term neurological conditions (LTNC) to achieve an ongoing personalised physical activity care plan working in partnership with local community and voluntary sector organisations to enable sustained inclusion and participation. The RENEW programme provides a means for commissioners and providers to offer personalised care, community rehabilitation and support for a range of conditions (NSF for people with LTC and 2006 NICE Public Health Intervention Guidance). The concept of encouraging self-efficacy and self directed responsibility for health is also in spirit of the Green Paper 'Independence, Wellbeing and choice' also addressed by the RENEW initiative.

Recommendations

A link person, CORE exercise professional or possibly a health practitioner acting across the district linking to classes with introductory interviews as provided in the RENEW programme to initiate potential participants to exercise sessions.

Centrally organised booking and organisation of classes and venues possibly by the provider or by a user group such as CANDO who links to the provider.

The current RENEW programme to be shortened to 12 weeks to act as an introductory taster course to build skills and confidence with participants then encouraged to join ongoing weekly exercise sessions, possibly provided by or linked to the same provider in order to achieve continuity for participants, at the venue with a charge to be introduced. Venues and programmes that optimise recruitment and adherence to be selected. Venues that encourage social support groups to be promoted.

Providers to consider timings of sessions and venues to encourage a more diverse group of participants i.e. those who are working and with different ethnic backgrounds.

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About the partners involved in this review:



CAN-DO is a volunteer patient/carer led Alliance of Organisations for people in Cornwall living with Neurological conditions. They exist to: present a united voice in support of health and welfare; focus on equality of treatment, improvement of services, raising awareness and understanding; provide support for carers; and promote an environment for excellence in neurological health care. **For more information visit www.candoweb.org**



Neurological Commissioning Support Ltd is a joint initiative from the MS Society, MND Association and Parkinson's UK established to support all those planning for, and providing, health and social care services to ensure that people affected by neurological conditions have access to the right services, in the right place, at the right time.

For more information visit www.csupport.org.uk



Cornwall and Isles of Scilly

NHS Cornwall and Isles of Scilly is the primary care trust for the county of Cornwall and the Isles of Scilly. It is their responsibility to buy health and social care services for everyone that lives in the county and islands.

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