can-do

NHS
Cornwall and Isles of Scilly

Cornwall Neurological Services Review:
Taking Stock and Moving Forward – a Stakeholder Event
Notes of a meeting held at the Headland Hotel, Newquay, Cornwall, on 16th February 2010 from 10.30-15.30

Present: A list of all those who were present can be found in **Appendix 1**

Programme Item	What was said
Welcome & Intro	Roger Weatherly, Chair of CAN-DO, welcomed everyone to the day and gave the general housekeeping. Key points from his opening comments were: • He defined the meaning of 'stakeholder', explaining that as this was a stakeholder event, it might help people to place themselves. One dictionary puts it: "A person, group, or organisation that has direct or indirect stake in an organisation because it can affect or be affected by that organisation's actions, objectives, and policies." • He emphasised that everyone in attendance was 'united, active, committed and concerned' in this cause – to see ongoing improvements to neurology services that the people using those services may have a better quality of life as a result. • He gave some background to the project, highlighting the launch event which took place on November 15th at Epiphany House, and noted that this event would be focussed on the results of the neurological services audit and the subsequent outcomes that might be aimed for.
The PCT's perspective	Andrew Kemp, NCS Project Officer, Cornwall presented on 'An overview of NCS: What is it, and what does this review means to Cornwall?' Key points from his presentation were: • That NCS is a partnership of the MS Society, MND Association and Parkinson's UK working together to ensure a broad commitment to effective commissioning. • NCS provides consultancy to health and social care services • NCS places service-users at the heart of neurological commissioning • NCS consults with service users and carers in a variety of different ways, many of which have been used to involve people affected by a neurological condition during this review: – Local branches – Email, phone, social networking sites, online forums

- Condition-specific work streams
- Radio interviews
- Newspaper adverts
- Newsletters, leaflets & flyers
- One to one interviews
- User reference groups

- He outlined the project objectives and anticipated outcomes, both of which can be found in **Appendix 2.**

Opportunities for Shaping Services in Cornwall

Deborah Commissioning Manager - Long-term Neurological Conditions, presented on the 'Opportunities for Shaping Services in Cornwall'

- She outlined the changes that the NHS would be undergoing in the coming years, and highlighted this project, in partnership with CANDO as a positive way of progressing services in line with the NHS's 'nothing about me, without me' focus.
- She highlighted a quote as a strapline to the day's event: "Problems can become opportunities when the right people come together" (Bishop Robert South, 1634-1719)
- She noted that the PCT is holding a number of meetings to look at the changes in the NHS, details of which can be found at http://www.cornwallandislesofscilly.nhs.uk/CornwallAndIslesOfScillyPCT/GettingInvolved/ChangeintheNHSpublicmeetings.aspx
- The meetings are for those who want to find out what all of the changes mean for them and to make sure your views are understood. All venues are accessible. For more information or to speak to someone directly, please call 01726 627895 or email neal.chambers@ciospct.cornwall.nhs.uk

The Audit – what we found

Sue Thomas, Chief Executive of NCS, presented on 'The Audit – what we found'.

- The neurological services across Cornwall and the Isles of Scilly were audited using the Quality Neurology tool, which measures health and social care services against the National Service Framework for Long Term Conditions.
- She outlined what had been found in both the clinicians, and the service user and carer's aspects of the audit, highlighting key areas as well as noting that there are areas of good practice.
- It was noted that the service user and carer perspectives had been gathered in a variety of ways:
  - Focus groups held in Truro, Falmouth, Redruth, Penzance, Bude, Isles of Scillly, St Ives, Liskeard, Lanhydrock, Ladock
  - Facebook
  - Paper questionnaire

- Online survey
- One to one interviews, both in person and over the phone

A full summary of all that Sue reported on can be found in **Appendix 3**. More information about the Quality Neurology Audit Tool, and the NSF for Long Term Conditions can be found on our website at www.csupport.org.uk

Looking at services differently

A range of presentations took place which showcased different types of services which are being offered in new and innovative ways.

- The Renew Exercise Programme presented by Professor Helen Dawes gave a comprehensive evaluation of an exercise programme which has been being piloted across Cornwall as a form of maintenance exercise for people with differing mobility difficulties.

- NeuroResponse**, '**combining technology, humanity and quality to deliver a patient-centred service' looked at how technology can be used to make better use of specialist nurse time, to ensure patients can speak to a qualified specialist whenever they feel they need to, to support the better integration of services, and to essentially deliver a service which allows people living with a neurological condition to get the best possible support.

- Neurology Hubs were explored by Shelley Roberts and Steve Horne of the James Parkinson Centre, a charity which has been delivering 'hubs' for people with Parkinson's on a regular basis, where people affected by Parkinson's and professionals working with them, come together for a day of learning, support, and socialising coupled with an opportunity for exercise and to speak with a specialist who understands the condition.

- Exercise for Mobility was presented on by Lillian Quinn and Janet McCulley, both of whom are living with Parkinson's and have set up this exercise group as a result of a Renew Programme which they were part of in the Bude area. They have set the group up entirely without support, using a Lottery Fund grant to cover costs, and have over 100 people on their database. They hoped that this example would serve as an inspiration to all those present.

Copies of each presentation can be requested from Charlie Peel, (details at end).

Discussion: What matters most to you?

A facilitated discussion was held to consider working priorities for the future, based on the results of the audit and people's personal experiences. The overall discussion was chaired by Steve Paget, Chair of Disability Cornwall.

Arts for Health Cornwall drew on the discussions held around the room to create a 'CANB-DO Island' Utopia, which depicted the services that people wanted to see in a different way.

Pictures of the maps created by Arts for Health Cornwall are available to view at www.csupport.org.uk, or can be requested from Charlie Peel (details at end)

Feedback

The map which Arts for Health Cornwall had created was viewed to aid thoughts on the overall room's priorities.

Each table around the room then fed back the top three priority points which had come out of their discussion.

There were a number of common themes which emerged, including:

- Information – it exists but is scattered all over the place; there needs to be a central place that people can access information in the format that they need.
- Communication across health and social care with all people accessing the same set of records – one set of records per person which everyone accesses and edits; and 'hubs' where professionals all sit in the same office to allow personal communication between them, particularly for MDTs.
- Technology to support services at a local level such as NeuroResponse
- Learning from current good practice and extending it, such as:
  - Further exercise groups in isolated areas such as the exercise group in Bude which has stemmed from the Renew programme.
  - Extending the James Parkinson;s Hubs out across all of neurology.

A full list of the priority points from each table is available to view in **Appendix 4**.

Next Steps & Close

Deborah Matthews outlined the next steps for the project:

- A report will be prepared using data from the audit and that gathered at this event.
- This report will go to CANDO for sign-off, and then to the Board and the PEC (a senior group) to be agreed to.
- The plan is to share this report as widely as possible, including with social services to ensure that everyone works together in taking it's recommendations forward.

- The report will set out priorities into short-term, medium term and long-term, and these will be considered and begun to be actioned over the next 6 months.
- Many thanks to everyone for attending the meeting.
- Notes of the day will be circulated to everyone in due course, and information about the groups will be circulated to all.

Appendix 1

Cornwall and Isles of Scilly

Name	Title / Organisation / Experience of Condition
Adrian Smith	MS Support Officer (South Cornwall Branch)
Alan Drake	Head of Commissioning - Long Term Conditions
Ali Rowe	affected by Fibromyalgia
Alison May	Carers' Support Service Worker
Amanda Hudson	
Andrew Kemp	NCS Project Officer / Service Development Officer, MS Society
Anne Denmead	caring for someone with Parkinson's
Anne Phillips	Carers' Support Service Worker
Annette Pope	Rehab Occupational Therapist
Anthea Pritchard	affected by trigeminal neuralgia
Barbara Bale	Multiple Sclerosis Specialist Nurse
Becky Full	Renew Programme Worker
Bernard Fielder	caring for someone with Parkinson's
Bernard Salisbury	living with Parkinson's
Bill Pashley	living with MS
Carol Wilson	OT and Clinical Champion Chronic Fatigue / ME
Charlie Peel	Administrator
Chris Bennett	Area Manager: West
Dave Denmead	Volunteer Educator for Pd, Cornwall
David Griffiths	affected by Huntingdon's
Deborah Matthews	Commissioning Manager - Long Term Conditions
Eddie Bailey	SW Coordinator for CMT
Elizabeth Paget	caring for someone with a spinal injury
Fiona Hudson	
Frances Colliver (Mrs)	Headway Cornwall
Geoff King	Influence & Service Development Officer
Georgina Willis	Specialist Speech & language Therapist

MS Multiple Sclerosis Society

mnda motor neurone disease association

PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

Cornwall and Isles of Scilly

Appendix 1

Name	Title / Organisation / Experience of Condition
Gill	Arts for Health Cornwall
Gillian Fielder	living with Parkinson's
Guy Stanton	Hospital Business Manager, Genus Pharmacueticals
Helen Dawes (Prof)	Oxford Brookes University
Helen Tite	Renew Programme Lead
Jackie Baker	caring for someone with Parkinson's
Jane Wright	living with Charcot-Marie Tooth
Janet McCulley	Exercise for Mobility lead; living with Parkinson's
Jeffrey Baker	living with Parkinson's
Jeremy Preedy	caring for someone with Huntingdon's
John Beckett	Chair - local branch of Dystonia UK
John Hilder	living with Aphasia
John Tyler	caring for someone with MS
Jon Goodman	affected by Epilepsy
Jonathan Gardner	Business Manager: Neurology, UCLH
Judy Reed	affected by MS
Julia Hilder	caring for someone with Aphasia
Julie Frost	DeNDRoN Research Nurse
Julie Smith	County Occupational Therapy Lead (Rehab)
Karen Retchford	living with Chronic Fatigue
Lilian Quinn	Exercise for Mobility lead; living with Parkinson's
Lindsay Haydock- Clemo	Independent Living Adviser
Liz Barnes	Director
Liz Roberts	Regional Business Unit Manager
Lollie Brewer	Arts for Health Cornwall
Lorraine Long	Centre Manager
Lucy Lyons	MS Specialist Nurse for NeuroResponse

Appendix 1

Cornwall and Isles of Scilly

Name	Title / Organisation / Experience of Condition
Lynne Osbourne	Parkinson's Specialist Nurse
Lynne Young	Advisor, ASBAH
Maggie Meyers	
Majory Bristow	Personal Assistant
Margaret Ray	Head of Speech & Language Therapy
Marie Hudson	Community Matron
Marlene Stevens	affected by MS
Mary Jane Hunter	Information and Support Worker - Cornwall
Maureen Woodhouse	caring for someone with Parkinson's
Melanie Brown	ILME Department Manager
Neville Read	affected by MS
Nigel Hudson	The James Parkinson Centre
Nikki Glasson	Marketing / Administration: Wired Cornwall
Peter Clifford	living with Parkinson's
Ray Woodhouse	living with Parkinson's
Rev Dr Peter Long	
Richards Stevens	MS Support Worker
Roger Weatherley	Vice-chair of CANDO
Sandra Douglas	Therapies
Sarah	Arts for Health Cornwall
Sarah Conniffe-Jones	Physiotherapist
Sarah Jewell	Community Rehab OT
Sharon Riley	
Sheila Harvey-George	EPP coordinator & rotary member
Steve Nicholls	Project Manager
Steve Paget	Chairman Disability Cornwall
Lynne Osbourne	Parkinson's Specialist Nurse

Appendix 1

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Name	Title / Organisation / Experience of Condition
Steven Horne	The James Parkinson Centre
Sue Thomas	Chief Executive of NCS
Susan Bence	living with MS
Sylvia Clifford	caring for someone with Parkinson's
Tamsin Coade	Neuromuscular Care Advisor
Terrence McCulley	
Theresa Court	Disability Cornwall
Tom Pritchard	
Val Wells	Regional Coordinator SW
Victoria Green	Clinical Neuropsychologist
Steven Horne	The James Parkinson Centre
Sue Thomas	Chief Executive of NCS
Susan Bence	living with MS
Sylvia Clifford	caring for someone with Parkinson's
Tamsin Coade	Neuromuscular Care Advisor
Terrence McCulley	
Theresa Court	Disability Cornwall
Tom Pritchard	
Val Wells	Regional Coordinator SW
Victoria Green	Clinical Neuropsychologist

Appendix 2

Cornwall and Isles of Scilly

Andrew Kemp, NCS Project Officer for Cornwall and the Isles of Scilly, and Service Development Officer for the MS Society in the South West, outlined the objectives and outcomes of the project as part of his presentation.

Objectives:

- Supporting CAN-DO in ensuring good representation across neurological service user groups, as well as local providers e.g. GPs
- Undertake a joint strategic needs assessment with Cornwall public health department
- Audit current services using the Quality Neurology audit tool against the NSF for Long Term Conditions and the NICE guidelines, and review via the neurological network
- In partnership with the local authority review provision of existing services with a view to identifying spend and wastage, commissioning more user-friendly and flexible local services, as well as exploring options for joint-funding
- 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

Outcomes:

- Within available resources, ensure a more outcome-focused approach to service commissioning, with an emphasis on personal outcomes and goals
- More choice and control over the support that individuals need and the manner in which it is received, with an emphasis on improved, cost-effective services and better outcomes for individuals and carers
- Appropriate, effective and timely responses to health and social care needs through effective service commissioning
- Ensure that all people with a long-term neurological condition and their carers have access to integrated community-based services, underpinned by quality information to inform their choices & decisions
- Ensure that the personalisation agenda is advanced within Cornwall so that people are able to exercise choice and control over the services they receive and the way in which they are delivered

Appendix 3

Cornwall and Isles of Scilly

Sue Thomas, Chief Executive of NCS, fed back to the room the key findings of the audit of health and social care services for people living with a neurological condition. Results were gathered from professionals and from service users and carers.

Quality Requirement 1: A person centred service

Not met overall. EBM 4 ('access to information') is part met

- Patchy services across Cornwall and lack of joined up working.
- No integrated assessments between health and social care; lack of integration between health teams.
- Different (IT) systems and forms, lack of communication between teams and inconsistencies about writing in patient-held notes / summaries.
- Often multiple care plans for home visits, causing confusion for both patient and care professionals
- Where specialist nurses exist, they act as the single point of contact for information and advice but those patients with rare conditions have no named person.
- End of life planning done in acute setting and with community matrons, BUT not always known of due to lack of joint care plan and who owns it / co-ordinates it.
- Good practice in MND services but this is not mirrored for other conditions
- People with complex needs either use community matron for GP as point of contact, but this is not clear to other professionals.
- There are problems with:
  - transitions from child to adult health services
  - repatriation of ABI and Spinal injury pts
- Lacking neuro-psychological support and support for neuro-muscular conditions.
- There was some confusion about the health and social care interface and difficulties accessing social care systems again cited as a problem
- Info about services is available…
- but there's a lot of information that might be confusing to service users, mainly due to the growth of / changes in services in different areas.
- Information could be provided in a variety of languages and formats.
- A long-term conditions portal in the primary care trust has a variety of literature on managing neurological conditions.
- Concerns about:

- info available for wider social issues ie employment, transport and leisure
- expressed about the availability of information on the internet, and patients raised expectations.
- Good practice in the cancer information hubs should be replicated for long-term conditions
- Self-management programs are available, but not always accessible due to geography and travel issues.
- Most sessions set up by specialist nurses or third sector,
- Pressures on specialist nursing mean that fewer are being organised than in previous years
-

- Areas of good practice exist where there are integrated therapists in health and social care
- Therapy care plans on acute wards and Parkinson's services offer a personal care plan for patients to complete and return to their Parkinson's team.
- New neurology care advisors were cited as being an answer for information and advice
- New appointment of neuro-muscular specialist for whole of peninsular cited as being a start on addressing this.

QR 1: Service user & carers views:

- Not enough information offered by general health and social care professionals
- Mostly, information is from
  - Third sector
  - internet
  - by word of mouth
  - peer support
  - local branches of charitable bodies
- No one point of access recognised by service users -info access is fragmented between health and social care
- Specialist Practitioners are seen as good source of information and signposting
- "I was handed a book [at diagnosis]. It was just assumed that I already knew about it"
- [Of GP's providing info] "Mine just says, 'I expect you know more than I do'."
- Large number of participants not aware of what constituted a care plan and if they had one

- Some had care plans but they had not been updated for a long period despite changes in circumstances.
- Some people complained care plans were not followed.
- Minority with a care plan thought they were active and were regularly reviewed.
- 84.1% of survey respondents did not have a care plan (this was echoed when at a focus group only 2 of 10 people had heard of a care plan)
- "I haven't got a care plan. I've got a letter… saying that I've been discharged…
- I've been discharged so many times. Ataxia's degenerative and I keep having to get in touch with them to ask for help"
- "I've had a review, but not a care plan… How can you have a review of a plan that you don't have?"
- 65% carers not offered an assessment
- Some had been assessed but "nothing had come of it"
- Few had active care plans that were regularly reviewed

- Those caring for people with particular conditions eg. epilepsy were concerned that insufficient information was given on first aid in seizures, drug concordance, and other key areas
- "I do everything… do I really have a choice?"

Quality Requirement 2: Early recognition, prompt diagnosis and treatment

Part met overall: EBM 2 ('diagnostic services') is met; all other areas are part met

- Patients and GPs access specialist neurological advice quickly via specialist nurses, where they exist.
  - ABI specialists are limited and often out of county - there is no brain injury care pathway.
- Due to pressures on staff, follow-up monitoring appointments are often not routinely made (as per guidelines)
  - rely on service users to contact staff if they have a change in symptoms or circumstances.
  - Parkinson's patients have regular follow-ups
  - Speech and language therapy shortages meant that patients were often not followed up
- GPs (involved in audit) believe ability to obtain rapid specialist advice about urgent clinical problems was good.
- Medicines management is good, and meets guideline.

QR 2: Service user & carers views:

- Main issues raised were around lack of information at diagnosis
  - 40% offered information on condition at diagnosis
  - 20% offered information about support organisations
- Where specialist practitioners exist, they are the best way of getting into and navigating the system
- Some people have direct access to neurologist
- Some see the GP as main point of access, although general feeling was that GP's do not understand long term neurological conditions.

Quality Requirement 3: Emergency and acute management

Not met overall, with no EBMs met.

- Transfer to specialist centres: head injuries are a major issue, both
  - provision of specialist places
  - funding
- Major repatriation issues back to a home base in the county when the patient is discharged from a specialist centre. Problems include:
  - Organising benefits for patients when they are repatriated,
  - the speed at which care packages can be set up,
  - specialist drugs are problematical.
  -
  - Spinal injury network has been looking at this lately to help speedy distribution of information.
- Funding issues for equipment.
- Problems with lead times.
- Brain injury patients often left in limbo as mental health teams won't take them on.
- Limited or no Neuropsychiatry access

- Major worry about the future of the neurology ward/beds.
- Staff with neurological expertise will see patients on the wards but they may be spread around the hospital

Quality Requirement 4: Early and specialist rehabilitation

Not met overall: with all the evidence-based markers being part met

- No transitional living unit or service for patients between neuro-rehab and independent living, or who still have rehab potential but wouldn't suit a nursing home placement. (Currently patients have to be referred out of county.)

- The need to discharge patients from in-patient units is at times going against optimal rehabilitation – conflict noted by acute staff recognised; problems with resources.
- A lack of goal planning between disciplines in the acute unit.
- Problems addressing the needs of all the disciplines when being assessed for wheelchairs/seating.
- Conflict in the acute unit:
  - between therapy and nursing tasks regards resources.
  - Therapy care staff could be working to the independence of the patient, while nursing staff find it quicker to do things for the patient.
- Clear therapy-specific goals. Family and carers are involved as appropriate, where they wish to be included and can be present during therapy programmes.
- Problems on discharge to the community re:
  - timeliness of picking up the rehab program
  - and at the intensity that was supplied in the acute unit.
- Major problems with placing patients with ABI / vegetative state / severe behavioural problems.
- Very limited case management, even for complex cases. This means there are difficulties:
  - communicating with professionals
  - coordinating holistic and inter-professional care
  - setting up a formal process for review
  - ensuring a goal-orientated approach

- No specialist nurse management for traumatic brain injury which could bring benefits
- No defined pathway for functional neurological problems

QR 4: Service user & carers views:

- Where specialist practitioners exist, they are best way of getting into and navigating the system.
- Some have direct access to neurologist.
- Some see the GP as main point of access, although general feeling was that GP's do not understand long term neurological conditions.
- General consensus that those who shout loudest – get a better service!

Quality Requirement 5: community and rehabilitation support

Not met overall; only EBM 3 was ('provision of community rehab') part met

Physical…

- No centralised multi-disciplinary team.
- Neuro-physio has own discreet case load depending upon need.
- Self referral an option.
- Therapy remit is 6 sessions / 6 weeks for community physio & OT.
- There can be a six week wait for rehabilitation therapy
- There is a new low-rehabilitation team.
- Continence service supports people throughout their journey
- Exercise industry offer free 20 week courses.
- The Merlin Centre takes the bottleneck of patients from neuro-physios.
- GP referral scheme to leisure centres.
- SALT see patients for episode of care
- Voluntary sector is evaluated differently to NHS services - not seen as a service.
- Joined up services could help provision e.g. partnership and collaborative working between NHS, social care and the third sector.

Mental…

- Lack of neuro-psychology in the community can be a barrier.
- Most psychological support is being done by existing staff on limited training
- Major problem in getting patients with LTNCs who have cognitive or mental health issues seen by mental health services/community psychiatric nurses even for pre existing mental health problems
- Both primary and secondary mental health services can turn down referrals on the basis of organic damage
- No neuropsychiatry available in-county. Those with complex presentations do not have specialist assessment for medication and understanding of their difficulties

Across the board…

- Health and social care professionals do work together, but there is no formal link, no pathways - it is reliant on individuals and personalities.

QR 5: Service user and carer views:

- People felt supported if they had specialist practitioner – but stated these were overworked and could not supply services to level of need at all times.
- Poor understanding of what services were available to support independence:
  - 68% use 3rd sector for advice (ongoing 56%)
  - 41% internet (42%)
  - 30% GP (34%)
  - 24% Neurologist (41%)
  - 23% Health and Social care worker (29%)
- "Some specialists volunteer their own time to give support to us – it's not something that they're paid for. It's on top of their jobs."
- Community rehab was thought to be difficult to access for those trying to stay in work as programmes as always in office hours
- Current rehab and support was thought to be good, but there isn't enough of it easily available -
- Marie Therese House: good but too far away for many people
- Heavy workshop: good but limited access
- Merlin Centre: good, but limited access
- Millerton Court in Launceston: good for those with Huntington's
- Physiotherapy / Hydrotherapy reduced and alternatives not as good
- Not enough work is being done on partnerships with 3rd sector to develop exercise and rehab groups that can be supported by specialist neuro-practitioners
- Gym settings not appropriate for some groups and not always wheelchair friendly

Quality Requirements 6: vocational rehabilitation

Not met overall; with all EBMs being part met

- Universally agreed that there is a real gap in services to keep people in work.
  - Occasional assessments take place in the heavy workshop.
  - Other vocational assessments take place dependent on the professionals experience and then knowing what services exist.
  - Some third sector organisations support the occasional assessment.
- Links to job centre plus could be better.
- Support and guidance on returning to work can be very ad hoc.
- A band 7 0T is employed for vocational rehab.
-

- The heavy workshop has limitations on the number of people in wheelchairs that can be accommodated
- Access to vocational rehabilitation varies across the peninsula due to the geography and transport issues.
- The complexity of benefits systems and lack of knowledge is hampering staff in supporting patients with issues of employment.

QR 6: Service user and carer views:

- Universal lack of feeling unsupported in vocational aspects of their conditions
- 55% people given up work because of their condition
- Access to Work Scheme has been helpful for some
- Cornwall CC cited as supportive employers
- Variable experiences with Job Centre Plus
- "I do lots of voluntary work, but that's not seen as work. No-one's offered to help me find work."
- "…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 work can you really do?"

Quality Requirement 7: providing equipment and accommodation

Part met overall; with EMB 1&2 ('access to assistive technology') as met, and only EBM 4 ('joint funding of specialist assistive technology provision') not met

- Integrated community equipment store, exclusive of beds, alarms.
- Problems getting hold of respiratory related equipment. (Purchase or hire for the individual.)
- Authorisation for any specialist items can take a long time - detrimental to the patients well-being and extremely ineffective in the case of MND.
- Adult social care:
  - Rails take a while to arrive
  - Handy person service is available
  - It can be difficult to obtain funding for some equipment (ie alarm mats)
- Can no longer access specialist cutlery/cups etc
- Possum and communication aids are excluded from statutory equipment.
- No single point of contact for service users for their equipment / wheelchair needs.
- Service not joined up – different sites mean difficulties in

  - integrating all patient's needs
  - providing a comprehensive assessment.
- Wheelchair service works well in the community but not as well in residential/nursing homes. Undermining of progress in rehab due to unsuitable seating - barriers created by wheelchair.

- The more specialist you get, the more limitations you come across.
- Not all equipment is regularly followed up relying on the service user to contact their health or social care professional if they think their needs have changed.
- Specialist chairs difficult to get quickly - have to build a case for the commissioners.
- Ability to fast track patients at end of life allowing them to die at home with appropriate equipment.
- There is a limited stock of adapted housing in Cornwall.

QR 7: Service user and carer views:

- Simple items are quick and easy to obtain
- Wheelchairs improving but only for standard chairs
- Major problems regards specialist equipment with:
  - Waiting times
  - Availability – such as specialist seating and wheelchairs
  - Accessing communications equipment
- Ambiguities over who's responsibility it is for maintenance and servicing of ‘one off’ specialist equipment
- Lack of regular review and follow up on equipment needs
- Lack of information and multiple points of contact for equipment between health and social care – joint store and specialist equipment.
- Lack of affordable adapted housing in Cornwall
- Problems with home adaptations regards:
  - Means testing for it
  - length of time waiting
- 3rd Sector ‘bailing out’ NHS by funding specialist equipment because of
  - it taking people living with the condition too long to access
  - It is not being funded despite being both needed and assessed as such!
- “There are so many different people involved… especially different departments… it makes it even harder”

Appendix 3

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Quality Requirement 8: providing personal care and support

Part met overall; with EBM 3 ('joint h&sc programmes of care to enable people to remain as independent as possible') met; and EMB 4 ('equitable access to services and assessments') not met

- Extra care housing in Liskeard, Redruth & Tregony
-
- One housing association offers 2 year tenancy for a single person - patchy.
- No specialist transitional living for those with brain injuries.
- Preferences are taken into consideration but time is an issue particularly in rural areas.

- No age-appropriate options through residential care for people with ABI
- Turnover of agency staff means that h&sc professionals cannot ensure that all staff are trained appropriately,
  - pressures on health and social care staff mean that training is a luxury!
- Integrated discharge team @ RCHT - health & social care
- Problems with patients having cognitive issues and initiating ongoing rehab.
- Various voluntary organisations can do training
  - One group deliver 1 hour training sessions in care homes
- STEPS re-enablement package of care started 6 weeks ago,
  - Current trial running in Caradon
- Anyone with complex need is screened for healthcare funding
  - can be time consuming
  - Unusual for people to have the money themselves
- Cornwall Social Services are allocated on a substantial or critical need

QR 8: Service user and carer views:

- Transitions from child to adult and adult to elderly care problematic.
- ABI patients felt abandoned
- Care staff often not enabling and do not support independence.
- "one professional's telling you how to do things for yourself, and another rushes in to do it for you… it's confusing and not all that helpful!"

Benefits:

- Information minefield!
- 3rd Sector & Local support groups invaluable

- Word of mouth and peer support invaluable
- Feel generally unsupported by health and social care system in this area
- "When I turned 60, the benefits system changed; they stopped paying my mortgage and halved my benefits payments. A fantastic lady from adult social care tried to help me, but gave up after 6 months. It took me 18 months of calling them three times a week to get things sorted."
- "How do we know if we're getting the appropriate ones [benefits] for us?"
- Individual Budgets: people feel unsupported and ill-equipped to make informed choices
- Direct payments are slowly being rolled out but it's felt they will
- reduce statutory services' availability
- force prices higher in private sector
- Quality of care services from agencies a major issue and availability of alternatives
- Direct Health Budget only obtained by intense lobbying
- [Most positive thing] "For us it's Direct Payments, without a doubt. We've been on them for 10 years and it's transformed the way we live."

Quality Requirement 9: palliative care

Not met overall; 2/3 EBMs = part met, and EBM 1 ('specialist palliative MDT's') was not met

- Not universal coverage for good palliative and EOLC in neurology
- MNDA pilot programme in Devon & Cornwall - joint neurology & palliative care specialists.
- MND/PSP Macmillan involvement in community.
  - Palliative care helpline
- Main point of contact often community nurses, district nurses, specialist nurses
- Team of nurses deliver a programme of care. Pilot scheme - Truro/Falmouth.
- Gold Standards Framework take up is good but not universal.

Quality Requirement 10: supporting families and carers

Part met overall; with EBM 2 ('involving carers in the planning process') as met, EBMs 3 & 4 as part met and 1 & 5 not met

- Carer not always given a choice of the roles they wish to do in caring -
  - this is not always addressed.

  - It is assumed that carers will take on roles, whether or not they are asked to
- Social care does offer carers assessments, but these are not always accepted
  - Carers are offered review assessments
- Specialist practitioners include carers in the acquisition of skills to support the individual with the condition as a matter of course.
  - District nurses support carers who have been taught to do a procedure
- There are carer support workers across the county
- Dementia nurses don't see patients in the community
- GPs tend to see carers more than the service user
- The rapid assessment team (RATS) is available to deal with emergency situations
- Carer's Support Network - quality of information on cognitive problems is quite basic due to the lack of neuropsychiatry
- Programmes of respite care would help carers

QR 10: Service user and carer views:

- Do H&SC work together general consensus – No!
  - Do not share information.
  - Can work to opposing needs
  - Not joined up
  - Services being reduced and having to pay for more services, such as foot care
- Lack of carers assessments

- Lack of information
- Carers feel undervalued

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

Not met overall; with EBMs 3 & 4 ('effective consultation with the person re their management' and 'specialist neurosciences involved in advising generalist staff') as part met

- Referral to usual neurological team is only usually through the carer's prompting
- Aim of OPAL team is to see all neurological patients admitted to health and social care settings.
  - However teams are normally not informed when problem is not related to their neurological condition at present.

- For planned admissions, pre-assessments are routinely done at Marie Therese House / Derriford Hospital
- Improvement needed with lone disability patients.
  - Usually reliant on the patient telling you what is going to happen
  - Can be condition specific
- Catheterisation can cause issues.
- The integrated discharge team will normally check with the usual neurological team prior to patients being discharged.
- Staff will go onto wards and advice staff if invited.

QR 11: Service user and carer views:

- Neuro condition not taken into account when admitted for co-morbidities.
- Pre-assessment information is often not acted on.
- Hospital staff are not considered enabling, and induce dependence.
- Drugs on time is a huge issue for Parkinson's
- 40% of people that had been admitted to hospital (47) did not feel they were listened to
- 51% general staff did not seek help from a neurology specialist professional
- "When my husband went in, I put his pills into little plastic bags – I labelled up the right pills in the right bags and wrote the times on them… he got them all on time."

Specific to the Scilly's: Service user and carer views:

- Small community so continuity of care good
- Issues with hospital appointments and transport (early appointments)
- On island transport free to over 60's
- Vocational rehabilitation – discrimination

Appendix 4

can-do

NHS Cornwall and Isles of Scilly

Following discussion on individual tables, and the creation of the 'CANDO Island' visual representation map of ideas, aims and utopian service provision, each table fed back it's top 3 priorities for change , action or development as a result of the audit.

Table 1

- Information – it exists but is scattered all over the place; there needs to be a central place that people can access information in the format that they need.
- Communication – the value of clinical hubs where MDTs are all housed within one office, and where both health and social care professionals make use of the same offices also – even if people are often not in the office and hot desk when they are, it increases communication and integrated working
- Partnership – scope partners across all areas of work and take into account ongoing work elsewhere which may need to be linked into. This should include health and social care, voluntary sector and service users and carers

Table 2

- Direct Payments for health – patients could vote with their feet; if people want something, they will choose to buy it.
- Communication across health and social care with all people accessing the same set of records – one set of records per person which everyone accesses and edits
- Self-referral – patients have direct access to services saving GP appointments and cutting out the need for the GP to see someone in order to refer them to something they know they need

Table 3

- Further exercise groups in isolated areas such as the exercise group in Bude which has stemmed from the Renew programme.
- Joined up notes / single records across all areas – the hospital, community, GPs, etc with all people involved in one person's care using the same notes.
- Hubs for MDTs

Table 4

- Accessibility of services and information across all neurological conditions – an online database of information which can be

retrieved in different ways (including via phone where someone accesses it online on that person's behalf)

- Keyworkers and case management – this individual would assist in communication across professionals ensuring consistency for the individual they represented and helping integrate working
- Identify a budget – all of these ideas are wonderful but the funds need to be established first!

Table 5

- Communication across all people involved in a service – professionals, voluntary sector, patients, etc
- Extend the James Parkinson Centre's hub meetings to encompass all of neurology
- Neuro IT communications models such as NeuroResponse – these seem very effective

Table 6

- MDTs – bring everything together in a one-stop shop, including information so that the right information and services can be received at the right time for each individual
- Specialists should be given the information and knowledge to signpost effectively – increase training or the information they have access to.

Table 7

'We echo everyone else's key thoughts'

- Raise the profile of neurology – 'brand neuro' vs 'brand cancer'
- Ripple effect – spread standardised services throughout the county and strive for equity
- 'Access Tourism' should be linked with to encourage better pathways, more wheelchair friendly surfaces such as no cobbles, etc

Table 8

- Technology to support services at a local level such as NeuroResponse
- Preservation of excellence – there is a lot of good practice around the county, and these standards of good practice should be used as models to learn from and expand
- Social and physical needs should be taken into account

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