

Key Headlines: the Neurology Services Audit

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
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- 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.
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- 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 OT is employed for vocational rehab.
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- 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 EMB 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”

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
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- 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