



## Quality Neurology Audit: Surrey A Summary

The audit took place over three days on 27<sup>th</sup>, 28<sup>th</sup> and 29<sup>th</sup> September with the focus groups taking place on the 1<sup>st</sup>, 4<sup>th</sup> and 6<sup>th</sup> October.

The audit, built around the 11 quality requirements (QRs) and the embedded evidence based markers (EBMs) of the National Service Framework (NSF) for Long term Conditions (neurological) was conducted with each day focussing on the services of either the Northwest, Southwest or East of Surrey. This segmentation of Surrey was done in preparation for the forthcoming GP consortia, so as to eventually produce recommendations which will fit into the same localities which they will operate within.

Six focus groups were run and the broad themes from the NSF were explored with all. Two groups were held for each locality, and the results were assessed in accordance with the professional's day which audited the same area of Surrey as the focus group considered.

### Results from Audit:

#### Quality Requirement 1: A Person-Centred Service

##### Integrated assessments

There are no integrated care plans or assessments within the whole of Surrey. Professionals do not have access to all of the information concerning the service user during their interactions. There are IT issues between health and social care, and between secondary and primary care. Community nursing notes are held in the patient's homes and some therapists make entries, but their main records are held within their teams. Patient's records are therefore very fragmented.

##### Named point of contact and specialist posts

Where a specialist nurse is available these act as the main point of contact, gate-keeper and source of information for people with a long-term neurological condition. Specialist nurses across the board have implemented innovative ways of delivering their services, and their posts were felt to be of huge value to both service users and carers, and to other clinicians. Where they do not exist, such as epilepsy, acquired brain injury and motor neurone disease, the GP is first point of contact often, or the neurologist via their secretaries.

##### Care assessment and planning process ensuring appropriate services

Problems with children crossing into adult services and having a bad experience, especially in epilepsy were highlighted. Those going out of the area for educational reasons found it difficult to re-access services as an adult on return to the area. It was a general consensus that there was no clear process or pathway for patients moving through the system, or across geographical boundaries. There was considerable confusion amongst professionals over transitions from adult to older persons care. Some believed it should be the GP who made decisions on what services were needed when a child transferred from children's to adult care, and adult care to elderly care.

### **Timely quality assured culturally appropriate information in a range of formats**

Universally, staff thought it was difficult to find local information, that it was poorly coordinated, not up-to-date, inefficient and often duplicated as staff do not know what information other services give out. Where a specialist nurse exists, information was deemed to be more coordinated and timely. It was universally accepted that the 3rd sector was a good source of information for people with long-term conditions, their carers and professionals. It was universally agreed that employment information is patchy as was information around transport and leisure.

### **Access to education and self-management programs**

Self education programs are not condition-specific and vary across conditions. 3rd sector organisations run courses for the newly diagnosed, and Headway Surrey provide support concerning cognitive and psychological consequences of brain injury. Health professionals queried whether some courses were actually still running or not.

### **Quality Requirement 2: Early Recognition**

The Northwest were unable to answer a lot concerning early recognition as there was no representation of secondary care at the audit. However the Bradley Unit was cited as having good multidisciplinary team working, and there was a multi-disciplinary team specifically for MS. The neurological consultant worked in conjunction with the specialist nurse for Parkinson's disease.

The main concern in the Northwest was lack of specialist practitioners for motor neurone disease, acquired brain injury and epilepsy. The South West also cited gaps in specialists for motor neurone disease, brain injury and epilepsy, and problems with reviewing patients with acquired brain injury. A neurological consultant was present at this audit, and early recognition and diagnosis was deemed to be met in this area.

In Central Surrey and the East there are concerns about joint working with doctors and again the lack of specialist practitioners in the community. Specialist nurses were seen as a point of contact for GPs to obtain specialist neurological advice about urgent clinical problems.

**ACTION** Due to the lack of secondary care practitioners and the majority of the audits, this area needs to be explored further.

### **Quality Requirement 3: Emergency and Acute Management**

Links with the Wolfson Centre in Wandsworth and Stoke Mandeville exist, and protocols are in place for neurosciences, but there is confusion about protocols for ongoing rehabilitation. There are agreed pathways for spinal-cord injury.

In the South West there were concerns about the ongoing needs for rehabilitation for those with acquired brain injury. There was a general concern around capacity to repatriate patients from specialists and tertiary centres. These issues concerned equipment and workforce, including speciality practitioners, and specialist equipment. Lack of beds in the community/secondary care can lead to delays in repatriation. The South West floated the idea that stroke units could become brain injury units and share the expertise.

#### Quality Requirement 4: Early and Specialist Rehabilitation

There was universal concern about the lack of workforce and equipment to fulfil obligations for early and specialist rehabilitation in the community when patients are discharged. A lack of speech and language therapists and psychologists was highlighted in all areas.

Therapists and nurses also cited problems with care agencies not being enabling, and not supporting rehabilitation. Godwin Unit was cited as a good community hospital to involve families in rehabilitation, as was the Bradley Unit. Community staff felt more pressured and were sometimes unable to include the family. It was felt that some families have unrealistic expectations of rehabilitation, and some community staff need more training in dealing with these issues.

In the South East it was felt that stroke dominated the workload and other long-term neurological conditions were missing out on early and specialist rehabilitation.

Concerning seamless transition, it would appear that this is mainly on an informal basis from acute to community. In some instances, acute staff do not liaise with community staff in discharge planning. The non-replacement of the rehabilitation consultant has had a detrimental effect on those patients transferred into the community. Where patients use the Bradley Unit, there is good liaison with community staff prior to discharge.

In the North West and South West, most people with complex needs go outside of Surrey, but some patients may be resident in the Bradley or Godwin Units. In Guildford and Waverley, previous work approximately 18 months ago marked the issues.

Services in Central Surrey do not have access to the Bradley and Godwin Units and limited access to 4 step-down beds in community hospitals. Services are being trialled in Salisbury, Wiltshire.

#### Quality Requirement 5: Community Rehabilitation and Support

Though there are no daily rehabilitation services except for the Bradley Unit, Headway Surrey supply most services for people with acquired brain injury. Inner Surrey support is mainly crisis management. All areas cite a lack of vocational rehabilitation as a problem.

Universally it was deemed that health and social services did work together but on a purely informal basis and often un-coordinated. Neurological psychological services are cited as lacking across the board. There were felt to be skilled deficits especially in East Surrey where the team was generic. The decommissioning of functional electrical stimulation services was noted as problematic, as was the only access to spasticity management being via the Bradley Unit. Ongoing problems with people moving into the area and not being put under a specific consultant, then needing further treatment / orthoses was very problematical.

There appears to be wide variations on how the different rehabilitation teams are commissioned and wide variations in every unit of working and terms of engagement.

#### Quality Requirements 6: Vocational Rehabilitation



There was general confusion amongst health and social staff concerning vocational rehabilitation. There was a lack of understanding of where responsibilities lie in terms of who is responsible for what part of the vocational rehabilitation.

Headway Surrey provide services for people with acquired brain injury and those with access to the Wolfson Centre and to military services can be supported. There were no clear pathways and it appears to rely on the individual's knowledge to signpost service users.

In Central Surrey, employment needs are part of the normal assessment; there are no assessments of readiness to return to work.

### **Quality Requirement 7: Providing Equipment and Accommodation.**

The main problems lay around communication aids and specialist equipment. Much time is wasted in finding funding for communication aids which are not statutorily supplied. Likewise functional electrical stimulation is no longer funded and much time is wasted by health professionals securing funding.

There can be major delays in obtaining specialist equipment due to the slowness of the assessment panel, often meaning that the equipment when provided is rendered inappropriate, as the person's condition has deteriorated - often due to the lack of the equipment they were awaiting.

There were problems with supplying required equipment into nursing homes, leading to the disadvantaging of those people in the nursing home. There were problems of supplying equipment associated with need and not long-term worst-case scenario, as was often the case, thus leading to disabling the service user rather than enabling, by providing equipment beyond their immediate present in anticipation of their deterioration. This appears to be totally budget driven and not patient-centric.

The Millbrook services for supplying statutory equipment were said to be very responsive, with same-day or next day delivery common. However there were problems into trialling equipment before supplying to assess suitability.

Equipment issued from hospitals on discharge was often not followed up or reviewed for ongoing suitability and maintenance. Normal statutory items supplied by Millbrook were reviewed and maintained regularly, but there were concerns around the confusion from maintenance and review of specialised equipment that had been ordered as a one-off.

Staff were not always knowledgeable about waiting times for the delivery of equipment, and adaptations to homes were deemed not in their remit to comment on. There were concerns around the issues of direct payments and capacity of community staff to support service users in assessing their needs and obtaining appropriate equipment.

### **Quality Requirement 8: Providing Personal Care and Support**

Universally there are problems with age-appropriate options for day care with some provision at the working research unit, White Lodge and Leonard Cheshire home. There are major problems with age-appropriate residential care for younger people and service users may have to go out of area.

Some care agency staff are poorly trained and while staff can invest time in training carers the high turnover of care staff puts pressure on capacity and funding is not always available to training.

It is perceived that nursing homes have better standards of care than the care homes. The high turnover of care staff make it difficult for all agencies to work to the same plan and to be enabling, promoting the individual's independence.

Health care staff appear confused over the system of direct payments / individual budgets and the impact this has on the equality of access to services and assessments based on need. It is deemed that people with long-term neurological conditions have poorer access to services and equipment than those with stroke, cancer and other conditions. In the South West there has been a 25% reduction in funding giving rise to problems in providing housing-related support to vulnerable people.

### Quality Requirement 9: Palliative Care

People with MND appear to have better access to services than the other degenerative neurological conditions, but these services are still not optimal as no formal arrangements or triggers exist for expert support and advice.

It would appear that different pathways such as the Gold Standards Framework and the Liverpool Care Pathway are used across Surrey.

There are issues around Parkinson's disease and multiple sclerosis being defined as having palliative care needs. There appears to be no formal procedures for transfer from daily care to palliative care.

In relation to MND there is good team working and development of new guidelines for respiratory care. There is an aim to set up 3 multidisciplinary MS clinics. The Beacon Centre is cited as a good support for palliative care and the Beacon model of care is to be rolled out across Surrey. However there are concerns about palliative care in nursing homes and limited training available to community staff, especially speech and language therapists and dieticians, around supporting palliative needs.

### Quality Requirement 10: Supporting Family and Carers

It is universally accepted that carers do not understand they have a choice concerning the level of care they may wish to give. Carers assessments appear a variable across Surrey and questions were raised about any support to young carers.

There are concerns that written care plans for carers are not regularly reviewed. Care plans for carers, as with care plans for the person with the condition, are not integrated.

In the Northwest, Central and South East, back care advisers will go out to carers for more complex patients and support them in manual handling duties. There are concerns about the high turnover of statutorily supplied carers and their training in the use of equipment and supporting the individual to use aids for activities of daily living.

BLIP, ICE, carers cards, and message in a bottle are used as flexible responses in emergency situations, but questions over whether these cover all situations and how responsive they are arose. Emergency respite beds are limited and carers breaks are patchy. Services are not always culturally and gender appropriate. Helping carers adjust to change is patchy but they are supported by third sector organisations such as Headway Surrey, and the Samson Centre, as well as by the Beacon.

There are significant gaps in psychological support.

Carer or awareness training is available but poorly accessed and not mandatory.

### **Quality Requirement 11: Caring for People with a Neurological Condition in Hospital or Other Health and Social Care Setting**

Because there is no integrated care plan or close liaison with normal neurological teams, patients admitted for non-neurological conditions are at a disadvantage. Free admission assessments are not always communicated to Ward's and information taken in by the individual is often ignored.

There is some preadmission support from the community in Central Surrey but usually teams are not informed of a patient's unplanned admission.

Patients moved around between A&E, MAU and wards often find the free admission information is lost in transit. Similarly these patients may find ineffective consultation about their condition management. This is especially problematical for patients with Parkinson's disease who have a real need to manage their medication on time in order to prevent unnecessarily deterioration whilst in an Acute setting.

There is a network of MS specialist nurses across Surrey, and the Spinal Injuries Association has provided local training and specialist trained staff are now in the community supporting ventilation equipment. However training is underfunded and although 3rd sector organisations offer training, it is difficult for health and social care professionals to attend due to funding and staffing issues.

### **Service user and carer key quotes:**

#### **Quotes: Information**

- “We need to make sure we get information out to people living on their own who do not have a computer or visit the GP so no information is getting to them”.
- “The onus falls on us. I have to find out myself, I have to listen and remember what I hear and have to do it myself. The onus is on me to do it”.
- “Yes it is the voluntary sector and networking rather than from service providers like social services.”
- “Exactly – where do you look and who’s going to guide you? I find there’s nothing. We were put in touch with Headway and that’s been the only assistance we’ve had”.
- “There’s information there but it’s up to you to find it”.
- “It was my next door neighbour who knew about a group and it was them, [the group] who told me stuff. We have the Samson Centre and they help you and give you the information for the MS Nurse”.

- “There’s a lot of the jigsaw there in the NHS, but it’s so fragmented – it’s so difficult to navigate this unwieldy thing; it’s so hard to find your way through that maze”.
- “So it’s knowing who to ask to be referred first of all but getting the information from the information”.
- “you find that the literature that comes from like Epilepsy Action and National Society of Epilepsy is very relevant to, up to date
- information that we need to make our decision as to what we want to do with our treatment”.

### Care Plans:

- “We don’t see them so were not involved.”
- “When \*\*\*\* came out of the hospital, there were people to help us [as we left the hospital] but there’s nothing – this disabled person is put into your life, you have to care for them, you don’t know how, you don’t have help, you don’t have assistance to get the house ready...”
- “They don’t set up the next stage. It’s all about whoever shouts the loudest – what if you don’t have time, or the energy to shout?”
- “In my experience, care and coordination isn’t good. The epilepsy side, we have a (children’s) nurse who’s funded by the NHS; she’s part time and when you’ve only got one person on a part time basis, there’s only so much she can do. She was really helpful at diagnosis but she’s not an ongoing resource”.
- “I find that social services aren’t really adequately trained, they don’t have enough medical knowledge. They’ve done their social services in a general way but when it comes to specialist conditions they’re not adequately trained to see what the needs are of those people with the conditions”.
- “Haven’t had a care plan marked up for me I don’t think ever and neither have my members. Because it’s (epilepsy) an unassuming condition because you don’t know when you’re going to have the seizures”.

### GP’s

- “I get my medication and my visits so no complaints except that there is no information”.
- “Not very (helpful) – they’re generalists not specialists, they don’t see that many of us so they don’t know. You need to educate yourself about your own condition and learn to do the information-finding yourself”.
- “I think that the GPs as well they’re so generalised that unless you go over and say “I would like to see this specialist neurologist
- who deals with my condition.” You get referred to just a general neurologist and you don’t really gain very much from it”.
- “Not very helpful unless you go there with some suggestions and then they will follow up and investigate for you”.
- “ And the same with the GPs if they knew more about the social side rather than just medical”.
- “The only other problem we experience is this change of – going on to generic drugs. And that’s messed up quite a few people with
- the epilepsy and the pharmacy’s actually giving them the generics rather than their usual branded drugs”.

### Getting back into the system

- “I always go back to the MS nurse as she liaises back with any were needed and us her own prescriptions and she tells the neurologist if needed But the GP will also help”.
- “I go to the MS Nurse, who’ll direct me to the right department and alert that dept that I’m going to contact them”.
- “We go to the GP and have to rely on the GP that they’ll send a letter to the right dept. I usually have to chase the GP”.
- “I go through the MS nurse – but it’s very reactive. That’s how the NHS works. They’re not ahead of the game, sending you off for physio or CBT; it’s only when something goes wrong that you try to access an appointment. If you were always in the system it wouldn’t matter, but we’re on the outside looking in; something goes wrong, you wait for your appointment, by the time it’s being addressed you’ve been living with that problem for weeks”.
- “It’s invariably going to my GP because there isn’t a nurse or a neurologist on hand to talk to and putting my thoughts and fears with the GP and hopefully getting some positive reaction from them. But it’s quite iffy again because unless they know me and my condition for quite a long time, so it would be the GP”
- “If I need to see the neurologist it would probably be about three to four weeks time when the condition’s probably past so we just
- reflect on it if I do see the neurologist. But if I could actually access a nurse whether it may be trained generally and be a general
- nurse but with a specialist interest in neurology or epilepsy it would help dramatically because the medication might need to be changed”.
- “Your GP seems to take longer because they write these letters and it takes them, takes ages for the letter to go through the loop”.

### Transport

- “Buses will not go to hospitals and general practitioners which is the main point of transport and why they won’t do it”
- “If the bus breaks down the replacement bus is sometimes not wheelchair accessible it’s the same as train stations around here”.
- “Transport is a big problem and it affects our relationships with our friends and family”.
- “There are lots of us who have no choice in using public transport – we’re not allowed to drive – and if there’s no transport then we can’t do anything”.
- “But the bus cards are good in this area as you can use them before 9.30am, and you can’t do that everywhere, but that’s only if you can get a bus”!
- “I had to stand and explain to a bus driver about my disabled card and you shouldn’t have to do that. In front of a bus load of people. He mutters, ‘they know how to waste their money’ – it really upset me”.

### Wheelchairs.

- “My wheelchair service is the only one that comes to me and is very good”.

- “I was at the wheelchair service last week because I had a brand new wheelchair they didn’t really check much of the seating at all”.
- “In fact when I got this chair I had to keep chasing them saying that I needed a new chair because the wheels kept falling off the other one which is a bit dangerous when you’re in it. And I did – in the end I made a fuss so they then assessed me and the only chair that they could give me I couldn’t lift into my car so I ended up getting vouchers and paying more than that much again to have this one made to my spec so that I could lift it into my car. The car I had then because I couldn’t afford to change the car”.

### Vocational

- “I used to be a factory for people and I enjoyed it and got some money. It was stopped but the people missed it and they now struggle to find something to do”.
- “The only job they offered me it was making tea and coffee and I’m good on computers that don’t offer me that”.
- “I hate claiming all the time. I want a job”.
- “In my last job, after my medical history slipped out, they dismissed me, but on a number of false grounds that they were coming up with. We weren’t given any support...” ..... “I remember your case – I take calls for Epilepsy Action - and even with the charity helping, we couldn’t find anyone to help them as a family”.
- “In my current workplace, there’s a lot that I can’t do now and I’m not getting any support”.
- “I have an access to work grant so that I can get to work, they pay for my taxis – I had to find it, though, my GP didn’t tell me about it – I stumbled across in on the internet. You have to really look to find things out”.
- “I think quite a lot of our (epilepsy) members now have it written into their contracts that if they are unwell then they’re given the time off, probably the rest of the day and they come back to work the next day without any repercussions. So it’s actually acknowledged that they do need that backup”.

### Care Support

- “My dad was my carer and I had a stroke and now I’m in a wheelchair and have to get agency support outside and sometimes live in carer 24/7”
- “In terms of information about you in your condition as you go around agencies not much information is shared or joined up and it’s a problem going over and over the same things again and again”
- “I want to say how lucky your daughter is to have you, how lucky \*\*\*\* is to have me – what about people who don’t have anyone? They’re not able to go online, even people who have carers – when they start, they’re low too – where’s the support?”
- “I agree – all they do is make sure you’re well enough to go home. My husband had to give up work to look after me. They get you better to get you out of hospital, you don’t need their care

anymore but where do you go after that? They gave my husband loads and loads of leaflets, but it was me that had always done all of that. He couldn't go through them, he didn't have time".

- "My wife's never had a care assessment".
- "As far as the NHS is concerned, a good district nurse service is essential, both for regular procedures and for emergencies, so there has to be adequate out of hours cover".
- "I have an exceptionally different case whereas my carer was a dog. I had a seizure alert dog that could alert me before my
- seizures happened 20 minutes before. And also my mother was too old to be my carer, my husband had died. And so I was
- Without a human carer so I got the finances and support for my dog..... It was pushing my social workers to accept
- That this dog actually did look after me. And I went to I think six panels before I could actually get him acknowledged as a carer
- and do all the explanations that was necessary. But it took a lot of effort to get him recognised.
- "What I feel is very unfair on a lot of the elderly carers when they become pensioners that care money is actually taken away from them".
- "I qualify for direct payments..... and I can use it for all sorts of things around the services but it's got to be all regulated".
- "I think for the epilepsy side of it if we do need, if there's a severe case of epilepsy it's acknowledged now that they will send that person up to somewhere like Chalfont St Peter which is a sort of respite home for people with epilepsy and other conditions. And that is the first port of call now. And they don't question how much it will cost the fact it's £1,200 a week to stay there, they are deeming that that is money well spent now and there's no question about it and that's good".

### **Other hospital settings.**

"When I'm in hospital for other things they forget I have a neurological condition."

### **Specialist Practitioners**

- "But we've not got the vital link of the MS Nurse - but they're so overworked, she can't keep up with it all, there's too many people. She does a drop-in clinic but even then she's got so many people. The NHS want to reduce her working hours or give her more people".
- "I think there must be some national shortage of physio. Once my daughter reached school, there was no more physio. They expected teaching assistants and teachers to do the physio in school – it shouldn't be their jobs! If I could push for one thing it would be for more physio".
- "It's the same for the PD Nurse. They're trying to reduce her hours but Parkinson's UK are finding some of it".
- "The importance of the MS practitioner, both as a readily available source of advice and as someone who has contacts within the NHS. Our current practitioner also runs a disability clinic which is very helpful, as MS sufferers have a variety of needs".

- “In the absence of a cure, treatment is essentially of symptoms. The treatment I have found most beneficial and which seems unavailable on the NHS is regular physiotherapy with a therapist specialising in neurological disorders”.
- “One thing that I do find that the NHS does provide and is very beneficial are nurses, specialist nurses”.
- “..... ours (epilepsy) was withdrawn about three years ago and I think \*\*\*\*\* might have told you about it yesterday. But we have
- backing to try and get another specialist nurse put back into her place and they say the funds aren't there and yet they take the burden off the neurologists”.
- “From my knowledge of the past specialist nurses are still important as well though because you do need specialist knowledge in Parkinsons, in MS separately because they are, they might be neurological but they're all very different in terms of their impact with people. So I wouldn't want to see them replaced by expertise, extra expertise in GPs surgeries. I think they need both”.
- “I was going to say trying to get physio is an absolutely endless battle”.

#### **Adaptations.**

- “Community Equipment Board for Surrey and in terms of equipment that's provided to people's homes generally speaking it's reasonable”
- “The problem with it is what they call specials”
- “Yes it's more the actual putting in a change, like changing a tap and shower rooms and things that's the stumbling block more than delivering the goods that you need”.

#### **Social Services:**

- “Social services are phenomenally overworked and their caseloads are enormous”
- “People are seen as money drains... until you've actually lived with it [epilepsy], you don't know what it's like”.