Lessons from running a neurology strategic clinical network

Despite a considerable number of reviews, from high level political statements to local initiatives, the pace of service development for people with neurologic conditions remains slow. The Neurological Alliance recent 2017 review of patient experience makes a disheartening read, showing a worsening of many metrics, including an increased proportion of patients needing to see their GP five times or more before a specialised referral was made and a decreasing number who feel involved in making choices, or that their health care professionals work together well “at least some of the time”. Unfortunately, the system does not seem to learn from its mistakes. In 2012, the House of Commons Public Accounts Committee released an important report on services for patients with neurologic conditions. It concluded that the implementation of the National Service Framework for Long Term Conditions has failed, causation including a lack of leadership at a national and local level, poor data, huge postcode variation in expertise, poor integration of health and care and a paucity of quality standards.

Part of the NHS response to this was to appoint a National Clinical Director (NCD) for neurological conditions and establish Strategic Clinical Networks (SCNs) in 2013 to drive local developments. The NCD catalysed many important developments, including the development of the much-needed Neurology Intelligence Network whose “fingertips” publications have been considerably illuminating. However, was it all just a sop to the politicians? In a further 2016 review NHS England reported to the same committee that the NCD would not be reappointed, but instead neurology would be led by a national message and remained invisible is only speculative. If I was a cynic I would suggest it’s rooted in a cultural indifference to people with neurologic disabilities. One of my patients recently asked me why if you have cancer and are trying to get back to work everyone is bending over backwards to help, but his experience (following a stroke leaving him only with mild dysphasia) was to be shown the way to the car park.

Credible proposals to modernise the way neurology is delivered are simple including that:

• The management of common neurologic conditions in primary care could be stronger (in many areas).
• Systematic ownership could be taken at a secondary care level by Neurologists for emergency and urgent care.
• Variation in access and services offered by neuroscience centres and local hospitals could be reduced.
• Outpatient neurological services models need rethinking as they are often unresponsive to need, clogged with unnecessary referrals, and operate on a top heavy one in one out model.
• Management of neurological crises in the community could be strengthened – lack of knowledge/confidence, unresponsiveness all result in waiting for an outpatient appointment or reliance on A&E with subsequent unplanned admission.

This involves people working in a different way, such that more of the precious resource is shifted from outpatients to acute and community settings, interfacing with integrated care systems in the community and building important relationships.
Acute neurology
In London, we undertook an audit examining the delivery of neurology at a secondary care level, finding no hospital offering first line assessment and admission of patients with neurologic conditions by Neurologists. Considering the mass of Neurologists at some regional centres this is notable. UCL Partners undertook an evaluation for us of “hyperacute regional centres” based on the concept of the next day acute medical unit requiring admission were very small, and the concept of the next day acute medical unit round became redundant (there were few neurology patients on it).

The service was reduced, partly through appropriate signposting, (e.g. patients with epilepsy were organised to attend seizure clinics)

- Inpatient transfers to tertiary neuroscience centres were reduced.

The increase in breadth of diagnosis was considerable (30 fold), but perhaps not surprising if the generalists’ differential diagnosis for severe headache is subarachnoid haemorrhage or subarachnoid haemorrhage. It turned out there was no need for a hyperacute neurology unit as the actual numbers requiring admission were very small, and the concept of the next day acute medical unit round became redundant (there were few neurology patients on it).

Integrating care
Outpatient referral rates for adult neurology published by Public Health England reveal staggering variation. In Camden CCG, the rate is 2470 per 100 000 per annum and in Doncaster CCG its 147. Despite this 174 fold variation the rates for unplanned admission are much the same, so you could argue that having considerable outpatient access does not prevent unplanned admission.

This is a key issue for patients with long term conditions where services have traditionally been organised around the secondary and tertiary sector. Other services e.g. therapists, social services often require a separate referral and delayed access to expert advice, particularly at times of crisis.

Explicit coordination and integration improves movement through care pathways by reducing duplication, avoiding suboptimal pathways, and minimising risk. It can also enhance prevention activity and rehabilitation. Better co-ordination reduces emergency admissions to hospital or unscheduled discharge, and improves the provision of information for self-management.

The principles of integration are simple and include:
• Case ascertainment
• Care planning
• Promotion of self-management
• Risk stratification for crisis avoidance
• Community MDT working

Most of this is generic and more than deliverable for patients with neurological conditions, requiring minimal, highly specialised support. Usually the most important person in the MDT is the psychologist. An exemplar has been developed by the Thames Valley SCN who have launched a new commissioning brief to support local commissioners to improve the services provided in community settings to people diagnosed with a long-term neurological condition. Ground breaking work has also come from Bernadette Porter, a Nurse Consultant who has developed a unique telephone based system “Neuroresponse” to guide patients in crisis into appropriate care settings from the outset and avoid the pinball effect where no one in multiple agencies can / will take responsibility. She has also identified urinary tract infection as a major cause of unplanned admission for patients with LTCs and is trialling community intervention (man on a bike) for early diagnosis and prevention of systemic complications (Figure 2).

Common conditions
It’s easy to say that more common conditions could be managed in primary care but being a GP at present must be a great challenge with a huge raft of conditions being pushed out of the secondary care sector. Education is laudable and we and others have produced a series of video casts to guide management of common conditions. These have had thousands of views but I doubt they impact on referral rates in isolation. Referral management alone certainly delivers restriction but is a blunt tool compared to improving communication between primary and secondary care. Talking

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**Figure 1: Principles of integrated care**

**Level 1**
- Complex and case management
- Proactive frequent rapid access interventions

**Level 2**
- Needs led interventions
- Specialist input required

**Level 3**
- Self-care
- Information, education and advice, keeping well initiatives, peer support

**Care plans**
As per defined clinical need, one individual may change between tiers and move within services within the same tier during their journey and over time. Care coordination and self-management must continue throughout.

**Figure 2: Neuroresponse triage pathway**

**URINARY TRACT INFECTIONS**
NEURORESPONSE AND 111 PROVIDE TRIAGE PATHWAY

- **1. COURIER**
  - Courier to collect specimen
- **2. LAB**
  - Receive laboratory results
- **3. TREATMENT**
  - Deliver bespoke antibiotics
- **4. OUTCOMES**
  - Collect outcome measure
- **5. RESEARCH**
  - Signpost to U1I research trials

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to GPs never imbues me with confidence that we (Neurologists)
as a generalisation are great at this. London has a high rate of
neurology referrals to hospital outpatient departments (OPD)
compared to England; 30 of 32 London CCGs have referral rates
greater than the England average. We estimated that 50 to 60
percent of referrals are for common conditions, and 30 percent
of these could have been managed in the community. However
more appropriate models could be within the multispecialty
community provider model which could:
• Improve response time and diagnosis averting the develop-
ment of chronic problems.
• Reduce outpatient appointments for common conditions by
17 percent.
• Encourage rational prescribing, as specialist reviews are likely
to standardise drug usage, cost effective use of available drugs
(generics over branded), counsel on lifestyle impacts on the
condition (e.g. migraine, manage medication overdose headache).
• Reduce ambulance callouts.
• Provide active referral management both into the integrated
system and onward to secondary care.
• Allow dissemination of skills across the primary/secondary
care interface.
• Co-ordinated care between primary and secondary care;
improved collaboration and communication.

The near future
There remain several ongoing mechanisms for improvement. NHS
England have established a National Advisory Group on
Neurologic Conditions. With its leadership aligned with the
neuroscience CRG this looks exciting. The “Right Care” concept
is providing a significant window into local conversations with
commissioners, though its output poses another round of ques-
tions. As its core principle is variability it will not produce a sit-
ing where provision is universally poor. The “Getting it Right First
Time” concept also is seeking to establish a neurological condi-
tions programme, principally working at a secondary care level.
However, the key requirements for commissioners at a local level
to deliver for neuroscience remain absent. We previously lobbied
NHS England to get some development of this but it wasn’t going
to happen. The issue was prioritisation, which is a fair enough
principle though still makes little sense to me on a public health
basis.

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