NHS

Yorkshire and the Humber Strategic Clinical Networks

Neurology E- Bulletin, Feb 2015, issue 1

WELCOME

To the first Neurology SCN e-bulletin, which we hope you find informative
In this issue we focus on:

- ***Meetings and forthcoming events***
- ***Neurology concerns and commissioning changes***
- ***A View from one of our Clinical Leads***
- ***SCN Work programme priorities***
- ***Achievements worth a mention***

Meetings and forthcoming events

Neuro Rehab Strategy Group 25th March 2015
Inaugural SCN Commissioners meeting14th May 2015
Neurology Clinical Experts Group (CEG) 19th May 2015

Neurology concerns and commissioning changes

From April 2015 CCGs will take on more funding responsibility for some neurology services that are currently funded through NHS England's specialised services. The biggest impact will be across outpatient neurology services at the three specialised centres (Leeds, Hull & Sheffield) All GP to Consultant referrals will become the responsibility of the CCG, NHSE will fund any onward outpatient referral from consultant to consultant at these locations.

It is anticipated that outpatient referrals for specialist headache clinics will prove the biggest challenge in terms of costs for CCGs. Despite the fact that the majority of headache cases can be managed in primary care, headache accounts for 33% of all new referrals into neurology (Migraine Trust 2014) This not only demonstrates a waste in terms of monitory value for CCGs it also places a significant demand on limited neurology resources that could be utilised more effectively and impacts on the patients in terms of travel costs and time away from work.

Generally headache conditions fall into two categories:

- *Primary - migraine and tension or cluster type headaches*
- *Secondary- headache following a head or neck injury or resulting from an underlying illness such as a vascular disorder or brain tumour.*

Patients with a primary headache disorders can and should be diagnosed and managed in primary care. The rates of misdiagnosis, mismanagement and inappropriate referrals add to the delays in effectively treating patients and can increase the risk of sufferers developing associated problems such as anxiety and depression.

Another area for concern is the management of Epilepsy

Around five in every 100 people will have an epileptic seizure at some time in their life, of these around four will develop epilepsy (Epilepsy Action 2013) An estimated 114,080 have been wrongly diagnosed as having epilepsy, the cost of misdiagnosis is around £221 Million each year (Epilepsy Action 2013).

The BMJ recently reported that approximately 1.16 per 1000 people with epilepsy die suddenly each year, In 2013 there were 680 deaths from epilepsy among people aged under 75 (973 deaths at all ages) in England and Wales. Sudden death in epilepsy peaks in young adults, particularly men, so a 20 year old with epilepsy has a greater than 1% risk of dying before he reaches 30, before adding other known risks for sudden death (BMJ 2015)

So what does this mean for commissioning?

The Neurology Alliance indicates the following key points in their newly published report "The Invisible Patients"

- *Only 14.7% of CCGs have assessed local costs relating to the*

provision of neurology services

- *Only 20.4% and 26.2% of CCGs respectively have assessed the number of people using neurological services and the prevalence of neurological conditions within their area*
- *Only 33% of CCGs obtain vital feedback from patients in regards to the neurological services they commission*
- *These issues have a significant impact on patients' care, with 58.1% of patients having experienced problems in accessing the services or treatment they need.*

A View from one of our Clinical Lead Dr Helen Ford – Consultant Neurologist from Leeds Teaching Hospital

The Yorkshire and Humber SCN for acute and chronic neurological conditions has established workstreams in the three national priority areas of headache, epilepsy and neuro-rehabilitation. We have an engaged and committed Clinical Expert Group with Lead Clinicians from all of the neurology providers in the region. The neurologists in the CEG have provided invaluable advice about the local context of their neurology services and their own areas of expertise. We have reviewed the first national datasets for neurology which include general outpatient activity data and more detailed data on parts of the epilepsy and headache pathways. Using this preliminary data we have been able to identify local areas of concern related to data collection. The Y&H SCN team are leading a pilot study of the assessment and management of acute headache in the Emergency Department. We plan to scope the current services for headache in the region. We are working with the national team, the West Yorkshire Commissioners and the voluntary sector to improve epilepsy services.

An area of focused work for the Yorkshire and Humber SCN has been reviewing services and developing a comprehensive pathway for people with neuromuscular diseases. These rare conditions are complex and require the input of multiple services. The Champions for this work have been Dr Mark Busby, Bradford, and Dr Chris Mc Dermott, Sheffield.

2014 was an exciting year for people with MS with three new licensed and NICE approved disease-modifying treatments for relapsing remitting MS. The SCN convened a meeting of the MS Specialist leads from our regional prescribing centres with the support of NHSE Specialised Commissioning to discuss the new developments. The treatment pathway for MS is now more complex and we were able to reach consensus on how the new drugs fit in to the patient pathway.

Work programme priorities and SCN actions

Clearly the SCN will focus attention on the big national topics so the key priorities include:

- *Headache management in primary and secondary care*
  The current health care process needs redesigning to:
- *Address the rising burden of primary headache disorders*
- *Reduce misdiagnosis that leads to mismanagement of headache disorders and can result in the development of co-morbidities such as depression and anxiety with a negative impact on quality of life.*
- *Reduce the referral burden on secondary care clinician's, thus reducing waiting times and diverting clinical resources to more complex headaches and other neurological conditions*

The SCN is awaiting approval from the West Yorkshire CCGs to begin a project aimed at improving the system by:

- *Identifying the current best practice pathways for headache management in Primary Care (protocols/process/guidelines)*
- *Increase awareness of signs and symptom management amongst GPs by facilitating GP education*
- *Identify areas (locations/trusts) of good headache practice across the region/nationally*
- *Identify the costs of primary headaches across Yorkshire and The Humber CCGs*
- *Identify the wider societal implications of headaches including the effects on employment*

For commissioners

- *Identify QIPP opportunities which focus on reducing referrals into secondary care and the impact associated with the changes in commissioning of some neurology outpatient clinics*
- *Identify cost effective models of care to support improved use of clinical time in Primary & Secondary Care (freeing capacity in secondary neurology care)*
- *Reduce variation in service delivery across the area*

Epilepsy management

To address the current standard of Epilepsy care as highlighted in NICE quality standards and the National Audit of Seizure Management in Hospitals (NASH1 & 2)

To improve standards of care across Yorkshire and the Humber by:

- *Reducing variation in patients access to services*
- *Reducing delays in the diagnostic process*
- *Enabling better review processes to prevent misdiagnosis & mismanagement*
- *Optimising drug management to reduce side effects, improve seizure control and well being*
- *To align with the development of national commissioning tools for*

epilepsy and support commissioner's to utilise these evidence based approaches

The SCN is awaiting approval from the West Yorkshire CCGs to begin a project aimed at improving the system by:

- *Moving towards a community based model ensuring access to the most appropriate clinician to diagnose and manage care*
- *Improve management of possible seizure presentations in A+E/ED*
- *Developing Fast first seizure pathways (access to specialist's and imaging if needed)*
- *Developing responsive pathways for people who continue to have seizures despite current treatment*
- *Enhancing quality of life for adults with epilepsy, through supported self-management e.g. Training and education and access to timely specialist support*
- *Ensure appropriate transition of the care of young people with epilepsy*
- *Develop (e.g. map of medicine) shared care protocols with GP's to ensure early accurate diagnosis, admission avoidance and early discharge from secondary care*
- *Reducing the number of avoidable deaths from Epilepsy (e.g. risk assessment for care plans)*
- *Aim to improve the numbers of epilepsy patients who are seizure free*

For commissioners

Identifying QIPP opportunities which focus on:

- *Unplanned admissions*
- *Reduced A+E/ED attendances*
- *Reduced inappropriate out-patients follow up*
- *Work force re-alignment including access to nurse specialist input freeing up consultant neurologist time for complex cases*
- *Focus on a community model e.g. alternative follow up methods*
- *Meeting the needs of people with additional needs E.G people with learning disabilities who may require longer appointment times locally*
- *Reduce variation in service delivery across the area*

Community support and neuro-rehabilitation

There is currently a national lack of neurology specific community support and neuro-rehabilitation which is further compromised by:

- *Variation in services in both acute and community care with Stroke taking precedence over all other neuro-rehab (stroke specific posts commissioned)*
- *Skills shortages in neurology and neuro-rehab (low numbers of Neurology Consultants nationally and AHPs spread across many conditions/geography, limited neuro-rehab consultants and consultant posts available, costs associated with specialism vs generalist posts)*
- *Many neurological conditions are of a deteriorating nature and the self management model of supportive care may not easily fit this*

cohort particularly if expected goals are always aimed at maintaining levels of ability rather than managing gradual deterioration and increased dependency which are not positive outcomes or measures of success

- *The complexities associated with neurological conditions can be physical, cognitive or associated with mental health so community support needs to be multi-professional*
- *The patients motivation, strength, fatigue levels and mood can influence the effectiveness of any interventions*
- *The patient's ability to self manage or engage in rehab may be delayed until they are medically stable (stop start process)*
- *Some patients may improve or relapse and support needs to be tailored to these needs. Interventions may be short or continue over many months or years with access back into services when required.*
- *Commissioning responsibility varies nationally and depends on historical contracts between NHSE and providers services in some locations, whereas CCGs have much of the commissioning responsibility in other locations including the Y&H . Current contracts and service specifications are broad with little detail to identify levels of rehab service*
- *The definition of neuro-rehab definition is unclear*

Action

National

Developing neuro-rehab pathways and service specifications to address the complexities

Local update

Scoping report completed for the Y&H identified the gaps and issues in current neuro-rehab provision
SCN Team working with stroke team and services to identify alternative/existing models of rehab that may be suitable to include neurology patients (ESD schemes)
Neuro-rehab steering group looking at how to upskill, increase the rehab workforce (through alternative models of skill mix, sharing/pooling resources e.g. Calderdale Framework)
SCN Team working to support NHSE with promoting and developing plans to take the improvement work forward
Use of SCN Commissioning group to raise the profile of neuro-rehab and inspire the need for large scale change
Development of an SCN joint rehab group with the ODN and specialised commissioning to ensure information is shared and avoid duplication

Achievements worth a mention

The Y&H SCN Neuromuscular Disease pathway has been endorsed by Muscular Dystrophy UK (MD UK) and held up as a best practice model of care nationally. MD UK has circulated the pathway to the other 11 SCNs in England with the aim of obtaining national adoption into practice. The SCN would like to thank the members of the Y&H Neuromuscular Disease pathway group for their support and commitment.
More information about Neuromuscular Disease and Muscular Dystrophy can be found at http://www.muscular-dystrophy.org/
The Y&H SCN NMD pathway can be found on our website and is available to view or download by following this link
http://www.yhscn.nhs.uk/mental-health-clinic/neurology-network/work-priorities/Neuro-Muscular-Disease.php

References

Headache Services in England http://www.migrainetrust.org/assets/x/50478 (BMJ 2015);350:h718 doi: 10.1136/bmj.h718 (Published 10 February 2015) Page 1 .

Epilepsy Action (2013) A Critical Time for Epilepsy in England. www.epilepsy.org.uk

Neurology Alliance "The Invisible Patients" http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report

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