Connected Health Cities

End of Project Report

Clinical Pathway: Epilepsy

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ABSTRACT:

Epilepsy and seizures are the most common neurological reason for emergency presentations at hospital. They represent around 1.5% of emergency admissions nationally, and it is known that there are an equivalent number of Emergency Department (ED) attendances that are discharged without admission. Whilst 1.5% is lower than many of the more high profile conditions (such as heart failure or COPD), many of the seizure admissions are eminently preventable, rather than an expected feature of a declining chronic state, and so there is a huge opportunity to improve care amongst these patients. However, care is poorly coordinated across sectors and organisations.

The first step in understanding the scale of the problem and how patients navigate the healthcare system is to accurately identify the correct cohort of admissions. Whilst there are pre-existing figures available, the vagaries of the coding system mean that these are not always recognised by clinicians as the true case mix. We believe that our method of identification, described below, is currently the most accurate.

Once we have identified the seizures admissions, by combining data from the A&E and outpatient datasets, both before and following the index admission, it is possible to monitor hospital performance and report this back to them as part of a Learning Health System. Moreover, the routine collected hospital data can be used to assess the impact of interventions, such as the Walton Seizure Pathway and the NIHR-funded Care After Presenting with Seizures (CAPS) project and monitoring the effect these interventions have on health inequalities, as outlined below.

Using the geographical data which is present in the data, allows patterns of high referral rates to be identified, and when fed back to local CCGs, we show how this can be used to inform the siting of community outreach clinics. The clinical information held within the data can also be analysed, and we demonstrate how an analysis of CT scans highlights the inadequate coordination in care and leadership, as well as wasted resources and unnecessary radiation exposure to patients.

Our work has been presented and, to varying extents, our methodology has been adopted at a national level by a number of groups including National Neurology Advisory Group, RightCare, Getting It Right First Time, and the NHSE Epilepsy Specialist Commissioning Review.

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Professor Tony Marson

INTRODUCTION:

The model for a Learning Healthcare System for the North West Coast (NWC) pilot was to first establish a Trusted Research Environment (TRE) hosting anonymised hospital administrative data for the whole region. This data was made securely and remotely accessible to a team of university-based data scientists working closely with front line NHS teams. Each of three pathways (Alcohol-related liver disease, Chronic Obstructive Pulmonary Disease and Epilepsy) shared a common core aim – to develop methods to leverage greater insight from currently available datasets and to share this information with the healthcare system. Crucially, the projects were developed 'bottom-up' and iteratively with direct engagement with those delivering care.

The methodologies and results were shared with those delivering care and key players in the local health economy, seeking to bring new approaches to enabling, monitoring and guiding local quality improvement initiatives. The work focused on providing new analytical tools to enhance the health care system's ability to accurately track emergency care pathways, identify variation and its drivers and opportunities for improving care. Having established novel analytical approaches to the use of administrative data, we then explored opportunities to enhance the analytical tools through linkage to other datasets including primary care and by applying emerging alternatives to traditional statistical approaches (e.g. machine learning).

Emergency admissions due to seizures account for around 1.5% of all-cause admissions nationally. They are the most common cause of unscheduled admissions for neurological conditions. Whilst 1.5% may seem a small percentage compared to some other conditions, the fact is that, unlike some other conditions, such as heart failure or COPD, this is a preventable condition and not part of a declining disease rate. A recent paper has estimated that the median cost for each admission is £1,651 with around one-fifth of patients experiencing more than one admission per year, and around half of those admitted have not seen an epilepsy specialist in the previous 12 months. There is, therefore, a huge opportunity to deliver better care.

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METHODS:

In the first phase of the work, the CHC Data Lab at the University of Liverpool developed and tested a new approach to the interrogation of the datasets.

Rather than relying on the traditional methods of looking at a narrow range of epilepsy codes in either the first or all diagnostics positions of emergency admissions, its algorithm uses a clinically-led approach that also utilises codes that can often be associated with a seizure (such as a head injury sustained during a fit) – reflecting the complexity and variability of the emergency presentations of the condition.

The method is summarised as follows:

- Admissions with an epilepsy code (G40x or G41x) in the first position. To be listed first, it is almost certain that the admissions is due to epilepsy
- Admissions with the unexplained convulsion code (R568) in the first position, provided there is also a G40x or G41x code in a subsequent position. Here, the probability that the admission convulsion was due to epilepsy is high; and
- Admissions with selected codes (e.g. syncope and collapse, head injuries, pneumonitis due to inhalation of food and vomit) in the first position, provided there is also a G40x or G41x code in a subsequent position which suggests that epilepsy is the cause of the admission. Here, the probability that the admission was due to epilepsy is high.

The reasoning is that coders code according to the way the notes are set out. In a case of known epilepsy, then it is probable the first doctor seeing the person will observe that a seizure is likely to be an epileptic seizure, and thus the case will have an epilepsy code in first position.

However, if there is not a known history of epilepsy, most staff will be cautious about attribution of a diagnosis they may not be trained to make, and thus other symptoms or the R568 code will appear first. In addition, some seizures are due to alcohol issues, or an acute illness (eg. stroke or head injury) and we would not expect them to be managed on an epilepsy pathway.

This logic has been tested first by examining the lists of cases included and excluded and checking there is face validity to the logic, and second by presenting it to specialists to gain their support. It was not possible to check the case notes of the actual admissions because CHC is working with anonymous data.

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The team created linkages between three NHS datasets (admitted patient care, accident and emergency attendance and outpatient visits), which allowed us to assess if the patients were being referred on to the outpatient clinics.

The National Institute for Health and Care Excellence (NICE) recommends that patients experiencing their first-ever seizure should be referred on to a neurologist and be seen within two weeks of the seizure, although previous work such as the NASH audit shows that this target is very rarely met.

Linking the datasets together and analysing across time, the team was also able to split patients into two groups, namely those who were under active follow-up (seen within the previous 12 months), and those who were not.

Previous work has shown that these two groups appear to receive a vastly different experience in referrals. Quarterly reports were sent to local hospitals to allow them to see how they were performing against key metrics, and how they compared to their peers.

Using the place of residence of the admissions (at Lower Super Output Area (LSOA) level), the team was able to map the area where those admitted live, and identify hotspots that could be areas of focus for interventions.

RESULTS:

The algorithm that the CHC team developed in conjunction with clinical experts identified an extra two-thirds of admissions when compared to just using the primary diagnosis.

Across the patch, this means that any planning based on first position only would be missing an average of 120 patients and 600 bed days at each site.

The CHC team compared the CHC algorithm with those used by both the NHS RightCare and Getting It Right First Time (GIRFT) programmes.

Although RightCare and GIRFT also go beyond the first diagnostic position, the CHC team's analysis showed that just over 40% of its epilepsy cohorts do not have an epilepsy code at any diagnosis point in their defined spell.

Whilst their overall numbers appear to be in line with the CHC method, the fact that they are identifying a substantial number of admissions from patients who do not appear to have an epilepsy-related seizure has implications for planning the corrects services. For instance, the average length of stay of the RightCare and GIRFT cohorts appear to be between 20-30% less than the figure found using the CHC method.

Previous work undertaken by the team had found that within Cheshire & Merseyside, there was a distinct difference in referral rates for patients that were known to the neurology service (ie. had a neurology outpatient appointment in the 12 months prior to their emergency admission – see figure below) and those who were not.

Analysis of the CHC data which covers the whole of the NWC showed that this pattern was evident across the whole patch.

Time to Neurology Appt. following Seizure Admission
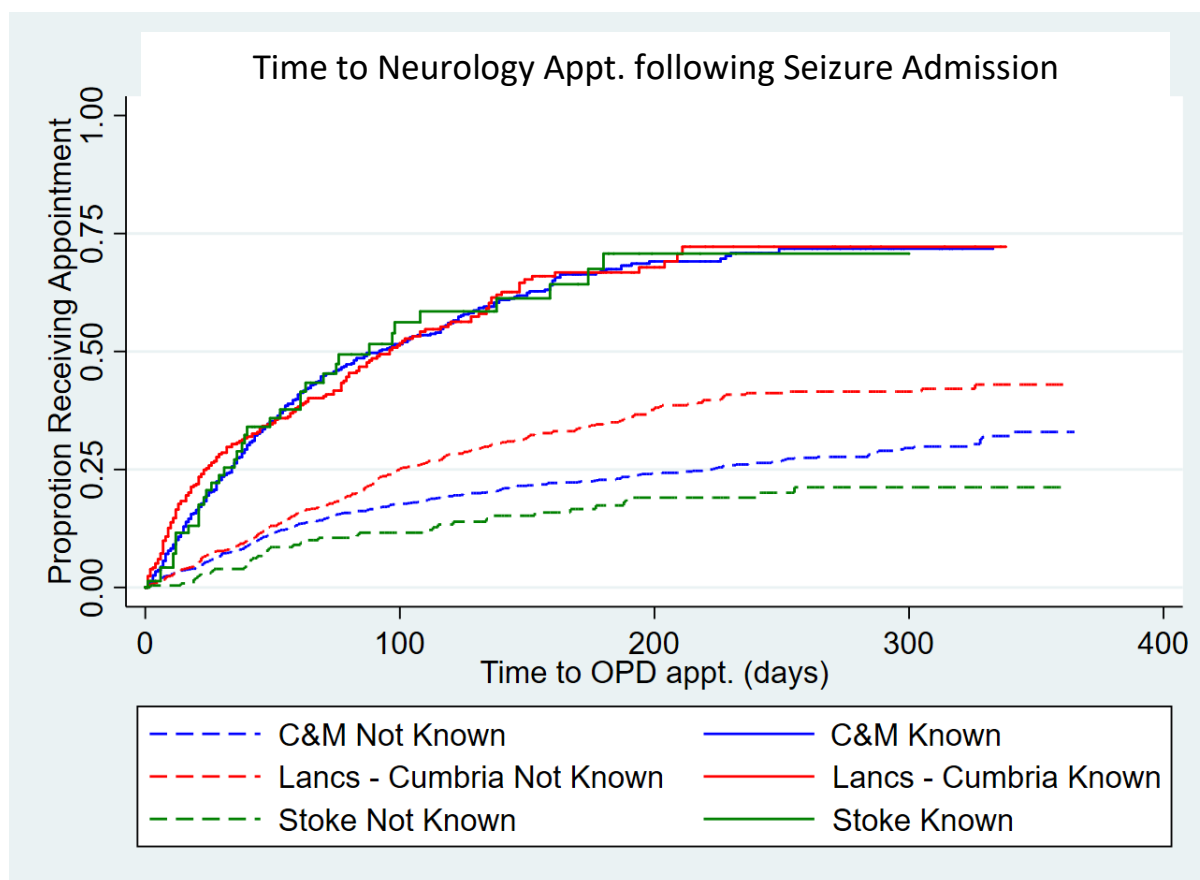
The CHC data also allowed an analysis to be undertaken of the effectiveness of the Walton Centre Seizure Pathway, which was implemented in the secondary care hospitals within Cheshire & Merseyside in 2015, as well as an allied project (Care After Presenting with Seizures, or CAPS) funded by the NIHR CLAHRC NWC.

This showed that since the implementation of the pathway, the rate of admissions which had a neurology outpatient appointment within the following three months had increased (by 28% for those already known to neurologists and 42% for those unknown). This increase was statistically significant.

Analysis also showed that having nurses employed part-time to facilitate referrals resulted in a further increase (105% for the unknown cohort). It also identified that the odds of getting an appointment significantly decreased with both age and increasing deprivation status.

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The issues with age and deprivation were known before the instigation of the pathway, and whilst the pathway has not widened these health inequalities, more work needs to be done to ensure equitability of access.

The fact remains, though, that despite the statistically significant increase in referral rates following the introduction of the seizure pathway, and with the added benefits of dedicated nurses, the referral rates are still much lower than what they should be. There remains a gap between the needs of the population and service provision.

Local area mapping allowed us to see that, within CCGs, admissions were not equally distributed (often closely linked with deprivation). As examples:

- In Greater Preston and Chorley & South Ribble CCGs: <5% of LSOAs accounted for 19.5% of admissions
- In Blackpool CCG: <11% of LSOAs accounted for 26.3% of admissions; and
- In South Sefton CCG: <11% of LSOAs accounted for 31.7% of admissions
- In Southport & Formby CCG: 10% of LSOAs accounted for 36.0% of admissions

The routine data also included information on clinical procedures and allowed an analysis of commuted tomography (CT) scans on patients admitted with a seizure to be performed.

Over a three-year period, just over 30% of patients admitted with a seizure received at least one CT head scan during their hospital spell.

For most, this is an unnecessary investigation, highlighting the inadequate coordination in care and leadership, as well as wasted resources and unnecessary radiation exposure.

Importantly, we also found considerable variability in scanning rates among hospitals, which ranged from 15.4% (medium-sized district general hospital) to 44.3% (large teaching hospital), and cannot be explained by differences in case-mix.

Whilst patients admitted to hospital with seizures may represent a cohort of patients with more complex presentations compared to those who attend the emergency department with simple seizures and are discharged straight home, this rate of scanning is difficult to justify and is likely to represent unnecessary radiation exposure and poor use of resources.

IMPACT:

The CHC team is represented on the National Neurology Advisory Group (NNAG) by Prof Tony Marson.

The NNAG has worked with the Specialised Commissioning team at NHS England to deploy the CHC algorithm across the national data and analyse the results.

As a result of this NNAG has recommended that the CHC algorithm be used for national reporting.

The CHC algorithm was also shared with analysts at RightCare and Prof Marson worked with RightCare on their epilepsy toolkit.

The results of the local area mapping were presented to South Sefton CCG. It is recognised that patients with epilepsy can experience problems with travelling, for instance, due to their condition not allowing them to drive.

This is exacerbated by the fact that the majority of neurology clinics held in Cheshire & Merseyside are sited at a single site, *viz.* The Walton Centre.

The CCG. therefore. used the results of the local area mapping and worked in conjunction with The Walton Centre to instigate community-based epilepsy clinics, run in a local GP surgery by a Walton Centre neurologist.

The GIRFT neurology group had seen the work undertaken by the CHC NWC team on using routine data to identify admissions and calculate referral rates, and now use the three-month referral rate as a key metric on which to measure hospital performance. The Walton Centre is the best performing site in the country on this measure.

CHC worked closely with The Walton Centre Vanguard team to assess the impact of their seizure pathway and implementation of community neurology nurses.

Findings from the project have been presented to a number of groups, for instance, the Association of British Neurologists, the North West Epilepsy Group and meetings of local CCGs.

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The epilepsy pathway work also led to the PED4PED project, funded by MRC/HDRUK, which aims to provide paramedics with access to epilepsy care records form secondary care in order to inform decisions about conveyance and immediate care.

CONCLUSION/DISCUSSION:

- Developed algorithms that reliably identify admissions with epilepsy, which have been adopted nationally
- Identified metrics and produced quarterly reports that inform Trusts of performance
- Identified significant problems with care pathways
- Created the tools for a learning health system to assess the impact of interventions
- Identified geographical variation that has resulted in a trial of community outreach clinics
- Built capacity and health informatics expertise
- Facilitated investment in the CDT and ARC

FUTURE PLANS/SUSTAINABILITY:

In collaboration with the Liverpool City Region, the CHC team is working to create the LCR Civic Data Trust, which will include the next generation of TRE (TRUDE – Trusted Data Environment), bringing together health and social care data from across Cheshire and Mersey.

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