Population health

Monitoring population health in epilepsy: a data dashboard for NHS Wales

Dr Anderson and Dr Martin describe the way the epilepsy data dashboard in Wales can help monitor epilepsy population health in real time and the benefits this could bring.

Summary
Epilepsy teams in Wales have worked in collaboration with information technology specialists to create a 'live' epilepsy data dashboard that monitors metrics of population health across Wales, in relation to epilepsy and seizures. The dashboard provides valuable data on epilepsy outcomes across all of Wales in real time, and this article outlines the background and processes that led to this development, as well as demonstrating the functionality of the dashboard.

Introduction
In recent years, policy documents setting out aspirations for the continued development of neurological services in Wales have been supported by Implementation Groups for the major disease areas. The Neurological Conditions Implementation Groups (NCIGs) comprise of members from all NHS health boards in Wales (and are a mix of a range of clinicians and stakeholders). One such sub-group has been an epilepsy group, made up predominantly of consultant neurologists and epilepsy nurse specialists from epilepsy teams across Wales. In previous years, the epilepsy group has created an all-Wales referral pathway for seizures from primary and secondary care. A later project saw health boards work together on unifying approaches and avoiding duplication in the work to implement the MHRA PREVENT programme for women taking sodium valproate, for example.

The National Epilepsy Dashboard is a project between the Epilepsy NCIG, the Welsh Value in Health Centre, and Digital Health and Care Wales, bringing together three national workstreams in NHS Wales to work collaboratively.

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Epilepsy is a common and unpredictable neurological disorder, which causes significant morbidity and mortality, and accounts for a large proportion of acute hospital admissions for neurological conditions. We sought to use already existing national data sources to create a 'live' data dashboard related to epilepsy. The goal of this was threefold:

1. To help us understand the national picture, particularly around hospital admissions and unscheduled care, for people with epilepsy. This would help us understand the resources being used and how this has changed over time.
2. To provide an easily accessible source of accurate and up-to-date data on epilepsy that can be used in preparing business cases to develop epilepsy services, to respond to Freedom of Information requests, and to explore variance in services and outcomes between different Health Board regions in Wales.
3. To try to further understand the critical issue of epilepsy-related deaths.

Method
The relevant data sources available for the data dashboard included:

1. Admitted Patient Care Data Set (i.e. hospital episode data on admissions, length of stay, critical care stay etc. known as 'Hospital Episode Statistics' in NHS England)
2. Emergency department data
3. ONS Data (deaths due to, or involving, epilepsy)
4. Primary care data (diagnostic coding from QOF and QAIF data)
5. Welsh Ambulance (WAST) data for calls related to 'fit' or 'convulsion'.
   All of these data sources have their limitations, and it can be difficult to interpret the data without an understanding of how and why each data source is collected.

Figure 1. Admissions including a primary diagnosis of epilepsy (all Wales, 2017-22)

Clinicians and data scientists on the project would meet monthly to generate ideas and questions for the dashboard. As a consequence, these developed into discussions about what data to display and how to display it. Between meetings, these ideas would be implemented, and iterative cycles of development over around 12 months led to the finished product. Partway through the project it was decided to duplicate some of the pages for 'non-epileptic attack disorder' as opposed to epilepsy. The dashboard is available for use by all on the NHS Wales IT network, and is hosted at *vbhc.nhs.wales*.

Results
The data dashboard was launched on 6 February 2023. It is built in Microsoft Power BI (*powerbi. microsoft.com*) and displayed in the user's internet browser. It contains important disclaimers about

appropriate use of the data, as well as a glossary, definitions and explanations of the data sources. The dashboard consists of multiple 'pages' displaying different categories of data (usually for the last five years), and importantly this data can be filtered by multiple variables in real time. These filter variables include resident health board and age, for example, meaning individual adult or paediatric teams from respective centres can extract data relevant to just their patient cohort. There is also the ability to filter data by the socioeconomic status of patients based on their home postcode, which correlates with their Welsh Index of Multiple Deprivation (*gov.wales/welsh-index-multiple-deprivation*). *Figure 1* illustrates a typical page, including filters.

While most of this data will display large numbers that examine trends, for example number of admissions per year for 'epilepsy', the dashboard can

Figure 2. Primary cause of death (ONS data) in the cohort of patients who had an epilepsy-related admission to hospital and died soon after (all Wales, 2017-22)
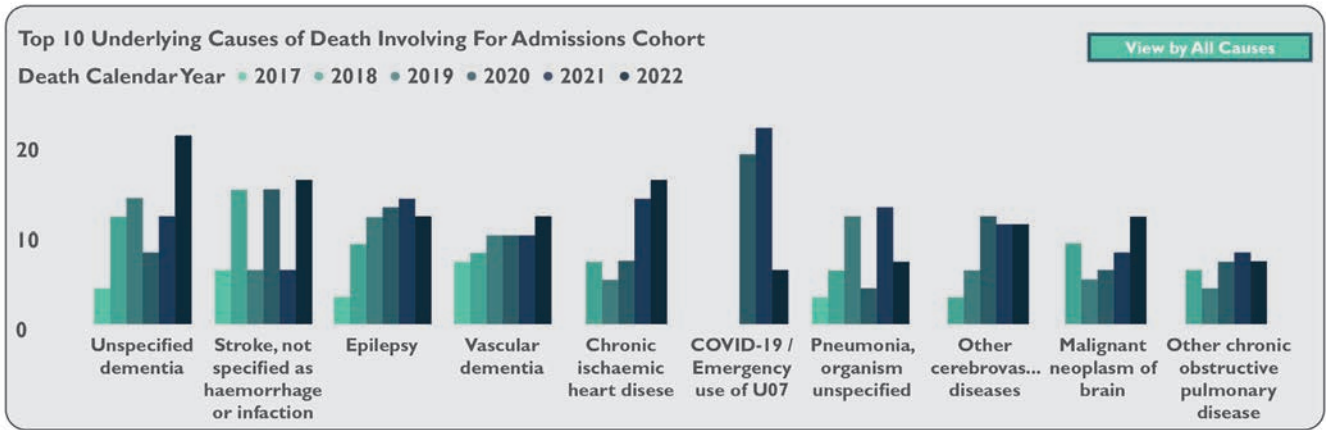
also be used to explore smaller, patient-level data, such as 'frequent flyers'. Through this function, the numbers of patients being admitted three or more times in a year can be calculated, and individual epilepsy teams can then request the NHS numbers for those patients, in order to explore the reasons for frequent

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admission. This is valuable to epilepsy teams as they may not otherwise be aware of these patients if they do not access out-patient services appropriately. This provides an opportunity to work with acute inpatient services and the emergency department to promote better management of these patients. This could be, for example, ensuring they receive neurology input while they are in hospital if there are barriers to their appropriate use of outpatient services. Importantly, unlike the wider dashboard, this patient-level data would only be available on request to appropriate clinicians with responsibility for those patients.

Data on epilepsy-related deaths is available on the dashboard, but as this anonymised data is provided by the Office for National Statistics (ONS) and not the NHS, UK law does not allow epilepsy teams to request the patient-level data. This remains an important dip in learning for epilepsy teams, especially in relation to supporting families and being able to learn lessons from instances of sudden unexpected death in epilepsy (SUDEP). Despite this dashboard, we remain dependent on being directly informed of any potential SUDEP in order to support the family and explore what happened. We can, however, have a much better understanding of numbers of epilepsy-related deaths in patients who have had an epilepsy-related admission to hospital, and also

Figure 3. Number of emergency admissions for epilepsy compared with non-epileptic attacks (all Wales, 2017-21)
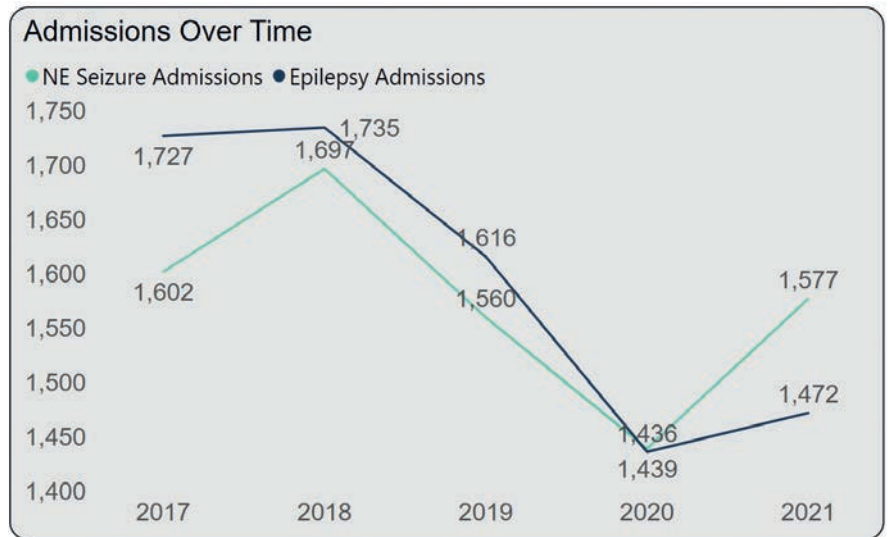
of the underlying primary pathology (e.g. stroke, dementia, tumours) in those patients (*Figure 2*).

Outpatient data is typically not coded well in NHS organisations within Wales, and there is no standardised method of running clinics and setting clinic codes for epilepsy across organisations (unlike inpatient admissions). Moreover, individual epilepsy clinics invariably contain patients with conditions other than epilepsy. As such, trying to incorporate data on outpatient clinic performance in the dashboard has not been successful or reliable.

Other areas where the dashboard has provided valuable insights into epilepsy-related use of resources has included looking at 'out-of-area' patients, and admissions for non-epileptic attack disorder. The dashboard identifies and quantifies geographical scenarios where large volumes of patients are being conveyed or self-presenting to emergency departments outside of their resident health board, due to the

proximity to their home address. This is an important consideration for services, as good lines of communication (and referral pathways) are needed between epilepsy teams and their neighbouring emergency departments. This is key, for example in prompt referral for suspected first seizures. A patient should not suffer delays in their specialist outpatient assessment due to the choice of hospital they presented to. There are, of course, important financial considerations to this data also.

A major insight provided by the dashboard has been the number of inpatient bed-days used for non-epileptic seizures. We used the same setup for emergency admissions involving a primary diagnosis of 'dissociative seizures' (ICD-10 F44.5 and R56.8) as we did for epilepsy (G40 & G41), combined with length of stay. With this, we have been able to calculate the number of bed-days used for both conditions across all of Wales in the last five years (*Figure 3*); approximately 58,700 bed-days a year

across Wales for epilepsy, and 45,100 for non-epileptic seizures. This information demonstrates very clearly that in terms of seizure disorders and use of acute resources, non-epileptic attack disorder needs to be considered alongside epilepsy. Most epilepsy teams will already be aware that diagnosing and managing non-

The dashboard has provided valuable insights into 'out-of-area' patients and admissions for non-epileptic attack disorder

epileptic attack disorder takes a considerable amount of their time. We have been able to demonstrate that for acute medical teams, it is almost on a par with epilepsy. This again is important for Health Boards when

Figure 4. Outcome for 999 calls for 'fit' or 'convulsion' (all Wales, 2018-22, 2018 data incomplete)

Incidences by Resolution
● 2018 ● 2019 ● 2020 ● 2021 ● 2022
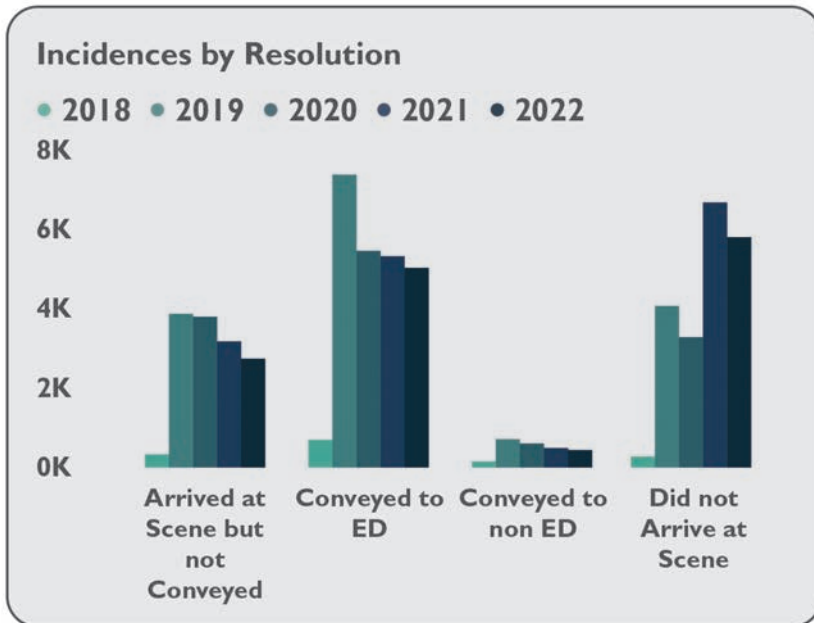
considering what specialist services to develop and commission.

Finally, ambulance data demonstrates the volume of seizure-related calls that are dealt with by paramedics and 999 call handlers, but not brought to hospital. *Figure 4* demonstrates that these incidents ('arrived at scene but not conveyed' and 'did not arrive at scene' respectively) outnumber those where the patient is brought to hospital. Epilepsy teams will not be aware of these incidents unless the patient or GP contacts them retrospectively. In many cases, this doesn't happen, and an opportunity to address seizure control and seizure-related risks (including SUDEP) is missed. This gives a clear indicator of a need to develop links between epilepsy services and local ambulance services.

Conclusion

A collaborative approach between clinicians and information technology specialists can drive rapid developments in data visualisation tools. Data dashboards for epilepsy can be a useful tool to examine regional and national trends in important epilepsy outcomes, ultimately improving patient care. The dashboard also saves clinician time, as data is 'live' (weekly refreshed) and easily accessed. We hope the dashboard will play a pivotal role in making the case for further development of epilepsy services across Wales, as well as for non-epileptic attack disorder.

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