Data-Driven Alerts to Support the Care of People Living With Epilepsy and Provide an Infrastructure for the Development of Real-World Evidence

RWD52

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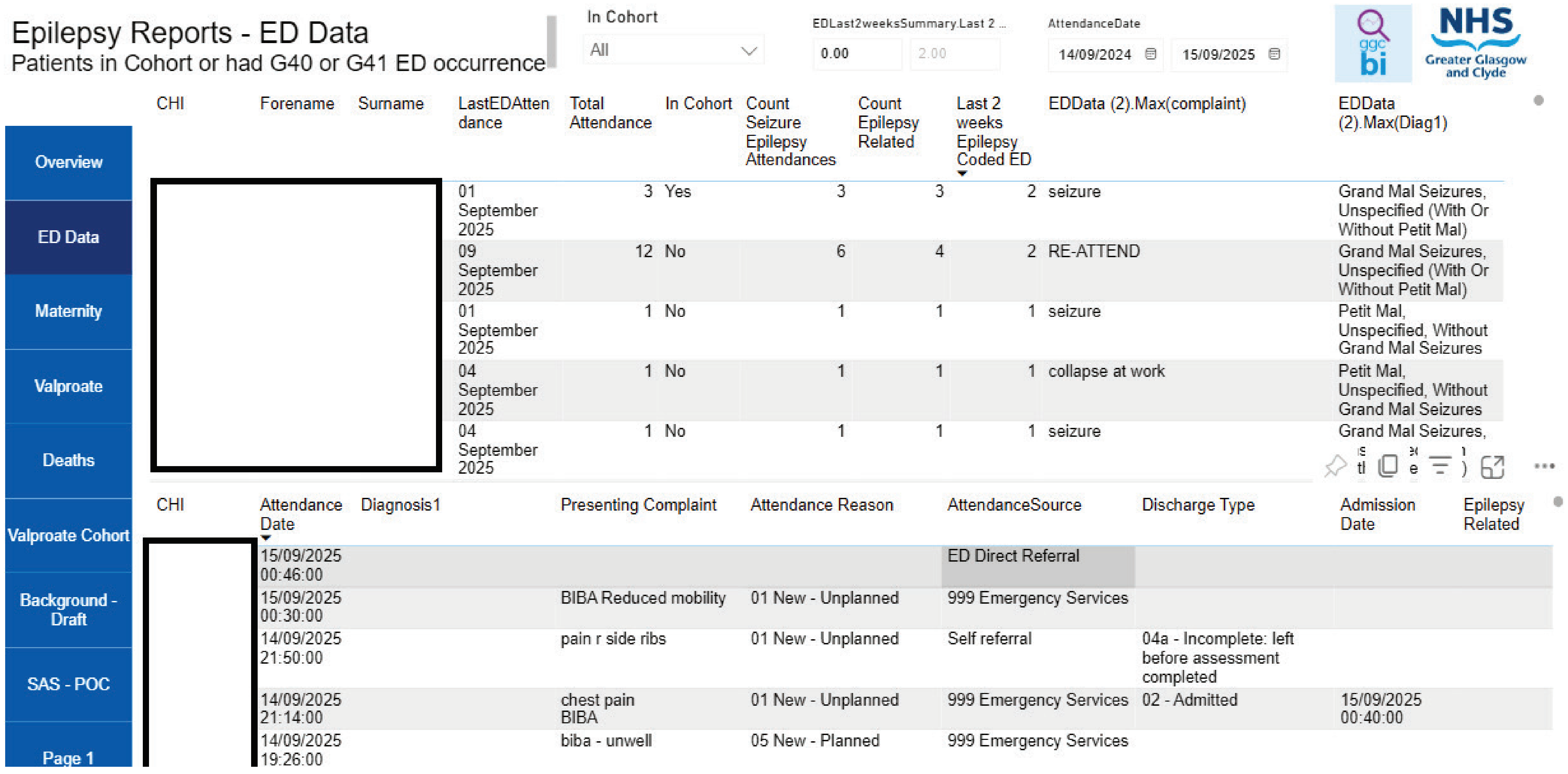
Background

- Within NHS Greater Glasgow and Clyde (NHS GGC), we have created a registry infrastructure comprising an epilepsy patient cohort and data-driven alerts visualised on an Epilepsy Dashboard. [Figure 1]
- This near-live dashboard not only provides an alert to healthcare professionals, allowing timely support following key events, but it also provides an opportunity to collect key variables as part of routine clinical practice.
- Given previous reports highlighting that those attending the emergency department (ED) for an epilepsy-related emergency have a 3-fold increased risk of mortality, our early focus has been to support people living with epilepsy during this high-risk period.
- In the present study, registry data were used to explore epileptic seizure emergencies including patient characteristics, emergency seizure event characteristics and associated outcomes (inpatient admission, readmission and mortality).



Epilepsy Reports - ED Data
Patients in Cohort or had G40 or G41 ED occurrence

In Cohort: All
EDLast2weeksSummary.Last 2 ...: 0.00 – 2.00
AttendanceDate: 14/09/2024 – 15/09/2025

CHI	Forename	Surname	LastEDAttendance	Total Attendance	In Cohort	Count Seizure Epilepsy Attendances	Count Epilepsy Related	Last 2 weeks Epilepsy Coded ED	EDData (2).Max(complaint)	EDData (2).Max(Diag1)
[redacted]	[redacted]	[redacted]	01 September 2025	3	Yes	3	3	2	seizure	Grand Mal Seizures, Unspecified (With Or Without Petit Mal)
[redacted]	[redacted]	[redacted]	09 September 2025	12	No	6	4	2	RE-ATTEND	Grand Mal Seizures, Unspecified (With Or Without Petit Mal)
[redacted]	[redacted]	[redacted]	01 September 2025	1	No	1	1	1	seizure	Petit Mal, Unspecified, Without Grand Mal Seizures
[redacted]	[redacted]	[redacted]	04 September 2025	1	No	1	1	1	collapse at work	Petit Mal, Unspecified, Without Grand Mal Seizures
[redacted]	[redacted]	[redacted]	04 September 2025	1	No	1	1	1	seizure	Grand Mal Seizures,

CHI	Attendance Date	Diagnosis1	Presenting Complaint	Attendance Reason	AttendanceSource	Discharge Type	Admission Date	Epilepsy Related
[redacted]	15/09/2025 00:46:00				ED Direct Referral			
[redacted]	15/09/2025 00:30:00		BIBA Reduced mobility	01 New - Unplanned	999 Emergency Services			
[redacted]	14/09/2025 21:50:00		pain r side ribs	01 New - Unplanned	Self referral	04a - Incomplete: left before assessment completed		
[redacted]	14/09/2025 21:14:00		chest pain BIBA	01 New - Unplanned	999 Emergency Services	02 - Admitted	15/09/2025 00:40:00	
[redacted]	14/09/2025 19:26:00		biba - unwell	05 New - Planned	999 Emergency Services			

Figure 1 – Example screen showing the information presented via the ED screen on the NHS GGC Epilepsy Dashboard

Methods

- Seizure related ED attendances between January 1, 2022, and December 31, 2022 were retrospectively identified through the Epilepsy Dashboard. The first encounter was classified as the index attendance.
- Patients were included if they had at least 12 months of data available prior to the index attendance, met the then-current ILAE definition of epilepsy and were registered with a GP in NHS GGC. Patients were excluded if they were under 16 years old. Figure 2 summarises the inclusion and exclusion process.
- A manual review of electronic health records was performed to extract data relating to epilepsy classification, mental health and substance-related comorbidities, learning disabilities, history of prolonged seizure (PS) and status epilepticus (SE) and historical use of rescue medication.
- Index seizure duration was classified according to the ILAE definitions for PS, SE and seizure cluster (SC). Rescue medication use, need for intubation and on-call neurology input during index event were noted.
- Anti-seizure medication (ASM) adherence data were captured via MAVIS (Medicines Adherence Visualisation Information System), a novel app, and poor adherence was defined as a Medication Possession Ratio < 80%.
- Data were subsequently anonymised and CHI-linked to national routinely collected health data covering demographics, inpatient and day case admissions, outpatient clinic attendance, comorbidities and prescribing. Additional data were obtained from the Scottish Ambulance Service relating to care provided prior to arrival at ED.
- Primary outcomes were inpatient admission following index ED attendance and death or epilepsy-related readmission within the following 12 months.

Results

Demographics

- Median age at index was 46 (IQR 33-58).
- 57.8% of patients were male.
- 74.2% of patients resided in areas of higher deprivation (SIMD quintiles 1 & 2).

Clinical Characteristics at index event

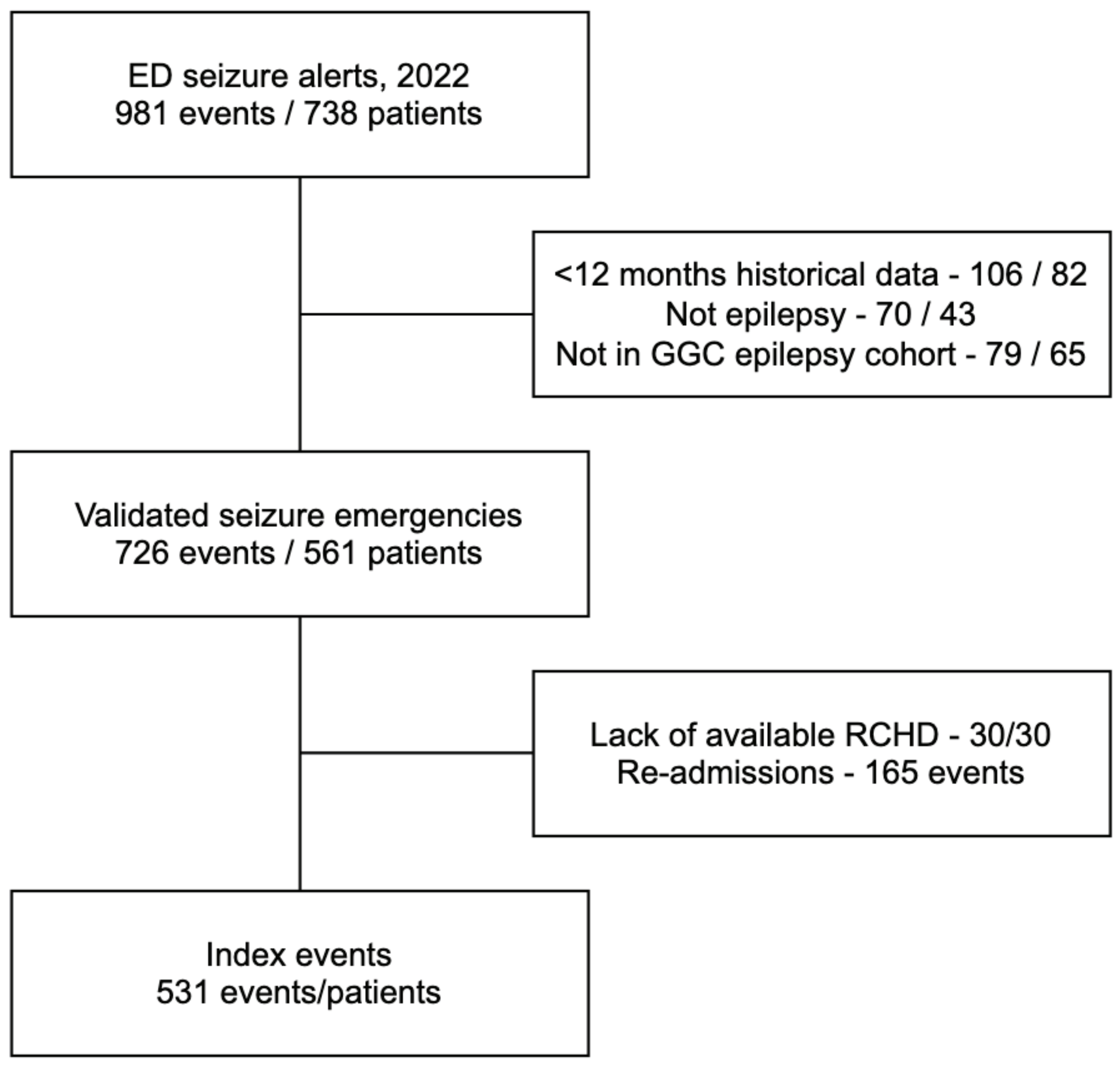
- Focal onset epilepsy = 54.2%, Genetic Generalised Epilepsy = 23.2%, unclassified epilepsy = 22.6%.
- Drug-resistant epilepsy = 30.5%, Intellectual disability = 17.5%.
- At least one recorded mental health comorbidity = 32.6%. Recorded substance misuse = 28.6%.
- Charlson Comorbidity index of 2 or more = 46.7%
- At least 1 ED seizure visit in the prior 12 months = 29.8%
- Only 11.9% patients had a recorded rescue medication plan before index.
- Only 3.4% of patients had an MPR of >= 80% during the 3 months prior to ED attendance. 10.2% of patients had no ASM supply during these 3 months.

Index Attendance

- Seizure duration was noted in 70.6% of cases.
- 9.8% of patients had seizures of less than 2 minutes, 13.9% had PS (12.4.% convulsive), a SC was noted in 16.2%, and SE in 30.7%.
- Rescue medication was administered during 23.5% of index events.
- 37.3% of attendances resulted in an inpatient admission, with 1.5% of patients spending 1 or more day in ICU or high-dependency.

Post event care

- 33.1% of patients had their ASM adjusted within 8 weeks of discharge.
- Despite proportion of PWE presenting with PS or SE, only 2.1% additional patients had a rescue medication plan initiated following the index event.
- 39.0% of patients did not attend an outpatient neurology clinic in the following 12 months.
- 41.1% of patients had at least 1 epilepsy-related readmission over the following 12 months and 6.8% of patients died.



ED seizure alerts, 2022
981 events / 738 patients

<12 months historical data - 106 / 82
Not epilepsy - 70 / 43
Not in GGC epilepsy cohort - 79 / 65

Validated seizure emergencies
726 events / 561 patients

Lack of available RCHD - 30/30
Re-admissions - 165 events

Index events
531 events/patients

Figure 2 – Summary of the number of events identified, included and excluded

Conclusions

- The infrastructure provides an efficient solution to support high risk patients in a timely manner and affords an opportunity to collect key clinical variables as part of routine clinical practice.
- Combining granular data with routinely collected health data has the potential to provide a rich source of real-world evidence.
- Further prospective studies are ongoing to consider the key clinical factors associated with poor outcomes and allow patients at highest risk to be identified and prioritised for rapid access to care.
- As part of the Scottish Epilepsy Register Project, we aim to offer this infra-structure to all health boards in Scotland in the near future.

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Author Contributions:
• Taha M: Data collection and poster review. Marshall A: Data analysis and interpretation, poster review. Mackay D: Data analysis and interpretation.
Heath CA: Study design, data interpretation, and poster review. Hasset R, Todd J, and MacBride-Stewart S: Data collection and poster review.
Laloyaux C, Radunz O, Roberts J, and Wilson JC: Study design, data interpretation and poster review.

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