

## Journal Pre-proof

National audit of pathways in epileptic seizure referrals (NAPIER): a national, multicentre audit of first seizure clinics throughout the UK and Ireland

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### Highlights

- First seizure patients face delays to assessment with epilepsy specialists
- A sizeable proportion awaiting first appointment experience seizure recurrence
- There is variability in the documented care of suspected first seizure patients
- National variability suggests underlying systematic and organisational barriers

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# National audit of pathways in epileptic seizure referrals (NAPIER): a national, multicentre audit of first seizure clinics throughout the UK and Ireland

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## Abstract

**Background:**

Current guidelines set clinical standards for the management of suspected first seizures and epilepsy. We aimed to assess if these standards are being met across first seizure clinics nationally, to describe variations in care and identify opportunities for service delivery improvement.

**Methods:**

Multicentre audit assessing the care of adults ( $\geq 16$  years) referred to first seizure clinics from 31st December 2019 going backwards (30 consecutive patients per centre). Patients with pre-existing diagnosis of epilepsy were excluded. Anonymised referral, clinic, and follow-up data are reported with descriptive statistics.

**Results:**

Data provided for 727 patients from 25 hospitals in the UK and Ireland (median age 41 years [IQR 26–59], 52% males). Median time to review was 48 days (IQR 26–86), with 13.8% (IQR 3.3%–24.0%) of patients assessed within 2 weeks. Seizure recurrence was seen in 12.7% (IQR 6.6%–17.4%) of patients awaiting first appointment. Documentation for witness accounts and driving advice was evident in 85.0% (IQR 74.0%–100%) and 79.7% (IQR 71.2%–96.4%) of first seizure/epilepsy patients, respectively. At first appointment, discussion of sudden unexpected death in epilepsy was documented in 30.1% (IQR 0%–42.5%) of patients diagnosed with epilepsy. Among epilepsy patients, median time to MRI neuroimaging was 37 days [IQR 22–56] and EEG was 30 days [IQR 19–47]. 30.4% ([IQR 0%–59.5%]) of epilepsy patients were referred to epilepsy nurse specialists.

**Conclusions:**

There is variability nationally in the documented care of patients referred to first seizure clinics. Many patients are facing delays to assessment with epilepsy specialists with likely subsequent impact on further management.

**Keywords:** Epilepsy, seizure, first seizure, first seizure clinic, seizure mimic

## INTRODUCTION

The diagnosis and management of suspected first seizures poses an important clinical challenge. A first seizure may signal the onset of new epilepsy, previously undiagnosed epilepsy, or a focal brain lesion. They may also represent important differentials such as psychogenic seizures. Following a single unprovoked seizure, the risk of recurrence is greatest in the first 3-6 months, prompting the development of national guidelines setting standards of care (1–3). The National Institute of Health and Care Excellence (NICE) have set recommendations for suspected first seizures and new epilepsy to be assessed within two weeks by an epilepsy specialist (4). This has led to the emergence of first seizure clinics and rapid referral pathways within secondary and tertiary centres throughout the United Kingdom (UK), with influence beyond in countries such as the Republic of Ireland.

Epilepsy carries significant socioeconomic implications, affecting more than 600,000 individuals, with annual costs of over £1.5 billion in the UK alone (5). The need for accessible and organised epilepsy care has been reinforced by the National Audit of Seizure management in Hospitals (NASH). This study focused on those attending emergency departments with suspected seizures and demonstrated considerable variations in standards of care across the UK (6). NASH informed the NICE quality standards, as well as the NHS Getting It Right First Time (GIRFT) and RightCare programmes for epileptic seizures (4,7,8). However, no national assessment has been made to assess patient care following referral to a first seizure clinic, limiting plans for relevant service development.

Furthermore, a considerable proportion of referrals to first seizure clinics involve seizure mimics – conditions that are mistaken for epileptic seizures (e.g. syncope, migraine, functional/dissociative seizure) (9–11). Improved understanding of first seizure and seizure mimic referrals may provide useful data for the development of clinical biomarkers and appropriate referral pathways. National guidelines (NICE – Epilepsies: diagnosis and management) set clinical standards for the management of first seizures and new epilepsy (4). NAPIER aims to assess if such standards are being met across specialist clinics throughout the UK and Ireland, and describe variations in care delivered to identify

opportunities for service delivery improvement. This paper reports on the clinical data for 727 patients from 25 hospitals in 2019.

## **METHODS**

NAPIER is a retrospective, national multicentre clinical audit coordinated by the Neurology and Neurosurgery Interest Group (NANSIG), an international medical student and junior doctor led collaborative interest group (12). This audit was overseen by a multidisciplinary steering committee of clinicians, academics, and patient representatives. Epilepsy Action, a dedicated epilepsy charity, was consulted for the development of the protocol, who also recruited and trained a patient expert by experience who formed part of the project steering group.

### **Study population and inclusion criteria**

NAPIER collected data on adults ( $\geq 16$  years of age on the day of the seizure event) referred to first seizure clinics for suspected first seizures or new epilepsy. Patients referred on and including 31<sup>st</sup> December 2019 going backwards to reach 30 consecutive patients were included. Previous experience with the NASH audit has shown that 30 cases provides sufficient data for comparison between an individual hospital with the national average. Moreover, this encouraged participation from centres, minimising administrative burden and workload for healthcare professionals.

### **Exclusion criteria**

- <16 years of age at time of seizure
- Known diagnosis of epilepsy prior to seizure clinic referral
- Patients referred and seen outside of the study period
- Unavailability of medical/clinic records

### **Study definitions used**

First seizures were defined as individuals suspected of having a first seizure as deemed by the clinician making the referral. The International League Against Epilepsy (ILAE) definition

of epilepsy was used in this audit (13,14). Epilepsy was defined by the following conditions (1) two or more unprovoked seizures occurring more than 24 hours apart; (2) one unprovoked (or reflex) seizure with a probability of further seizures similar to the general recurrence risk ( $\geq 60\%$ ) after two unprovoked seizures, occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome.

Epilepsy specialists were defined as medical practitioners (consultant neurologist or consultant with epilepsy expertise), who have epilepsy as a significant part of their workload (at least the equivalent of 1 session a week) with training and continuing education in epilepsy, usually working as part of a specialist epilepsy team. Tertiary hospitals were defined as hospitals providing specialist, multidisciplinary, and regionalised care after receiving referrals from primary or secondary care (including emergency department or acute medical units).

#### **Data collection**

Cases were identified by local data collaborators using existing electronic and seizure clinic records. Due to heterogeneity in the coding of first seizures and their referral to specialists throughout the UK and Ireland, local database administrators ascertained cases by identifying any outpatient clinics that assessed patients with first seizures (this could be a dedicated first seizure clinic or a general neurology/rapid access neurology clinic depending on the hospital) and then manually identifying first seizures from the list of clinic attenders. In some centres, referral pathways between primary or secondary care to first seizure clinics differed – in such cases, local study coordinators were given discretion to identify 30 consecutive patients in a representative manner.

Baseline patient demographics, referral pathway, clinic assessment, and further referral outcomes were collected and uploaded anonymously to an end-to-end encrypted online database (Research Electronic Data Capture [REDCap]), based at the University of Liverpool and Walton Centre NHS Foundation Trust. The clinical proforma was modified and refined by a multi-centre pilot study undertaken at the University of Aberdeen and the Walton Centre NHS Foundation Trust to assess compliance with national standards from evidence

based guidelines for suspected first seizures and new epilepsy (NICE – Epilepsies: diagnosis and management) (4).

Domains included in the audit included data on service organisation: presence of dedicated first seizure referral pathways and specialist clinics; referred patients being seen by an epilepsy specialist within 2 weeks of referral. Data on clinical care were also included: investigations (ECG, CT/MRI neuroimaging, EEG); documented care plan (anti-seizure medications, driving, occupational, lifestyle, SUDEP advice), epilepsy specialist nurse (ESN) referral, follow-up appointments and referral to tertiary specialists.

### **Data analysis**

NAPIER is a descriptive clinical audit providing summary statistics and to investigate potential reasons for variability between participating centres. Subgroup analysis was performed for documented seizure advice (first seizure/new epilepsy patients), for MRI neuroimaging/EEG (new epilepsy patients where indicated), and SUDEP advice (new epilepsy patients). Results are shown as the percentage for all patients, and where appropriate, the median and IQR for site performance. Statistical analysis was performed on RStudio (R Core Team [2022]. R Foundation for Statistical Computing, Vienna, Austria).

### **Ethical approval**

This study was considered within the remit of a clinical audit/service evaluation without affecting routine patient care. Therefore, individual patient consent and ethical approval were not needed in accordance with guidelines set by the NHS Research Ethics Committee. Local clinical governance approval was obtained at each participating centre.



## RESULTS

The study population included data on 727 patients (median age 41 years [IQR 26 – 59], 52% males, 48% females) referred to specialist outpatient clinics for suspected first seizures in 25 hospitals in the UK and Ireland. The median number of patients included per site was 30 [IQR 29 – 30]. There were 16 participating hospitals from England, 5 from Scotland, 2 from Northern Ireland, 1 from Wales, and 1 from the Republic of Ireland.

44% (11/25) of hospitals provided information on how they assessed first seizure patients (i.e. first seizure clinics/epilepsy clinics/general neurology/rapid access clinics) and overall patients seen over a one year period. The average number of suspected first seizure patients assessed per site in 2019 (period of 12 months) was 277 (range 58 – 551). The average number of suspected first seizure patients that did not attend (DNA) their clinic appointment at each site in 2019 was 57 (range 18 – 119), accounting for 17.2% of referred patients. 63.6% (7/11) of hospitals assessed first seizure patients in dedicated first seizure clinics, 18.2% (2/11) in epilepsy clinics, and a further 18.2% (2/11) in general neurology/rapid access neurology clinics. 72.7% (8/11) of clinics provided pre-printed leaflets (advice on driving, lifestyle, and seizure recurrence) to patients.

### Referral and seizure clinic characteristics

44.2% (321/727) of patients were referred from the ED, 41.7% (303/727) from general practice, and 12.8% (93/727) from secondary/tertiary care. Among patients referred from the ED or from secondary/tertiary care, 68.2% (282/414) were referred from university teaching hospitals and 27.3% (113/414) from district general hospitals (Table 1).

Standardised first seizure clinic referral proformas were available for 50.6% (368/727) of patients. Where referral proformas were available, they were used by the referring clinician in 79.6% ([IQR 63.9% – 100%], 293/368) of cases.

55.4% (403/727) of patients were seen by a consultant neurologist with a subspecialist interest in epilepsy and 25.4% (185/727) patients were seen by a general neurology consultant. The remainder of patients were assessed by neurology specialty trainees/registrar, ESNs, or general practitioners with specialist interest under the

supervision of consultant neurologists. 96.8% (704/727) of patients were assessed in-person at the clinic. 3.2% (23/727) were assessed over the phone or virtually, and 34.8% (8/23) of these patients were subsequently seen in-person for further assessment (Table 1).

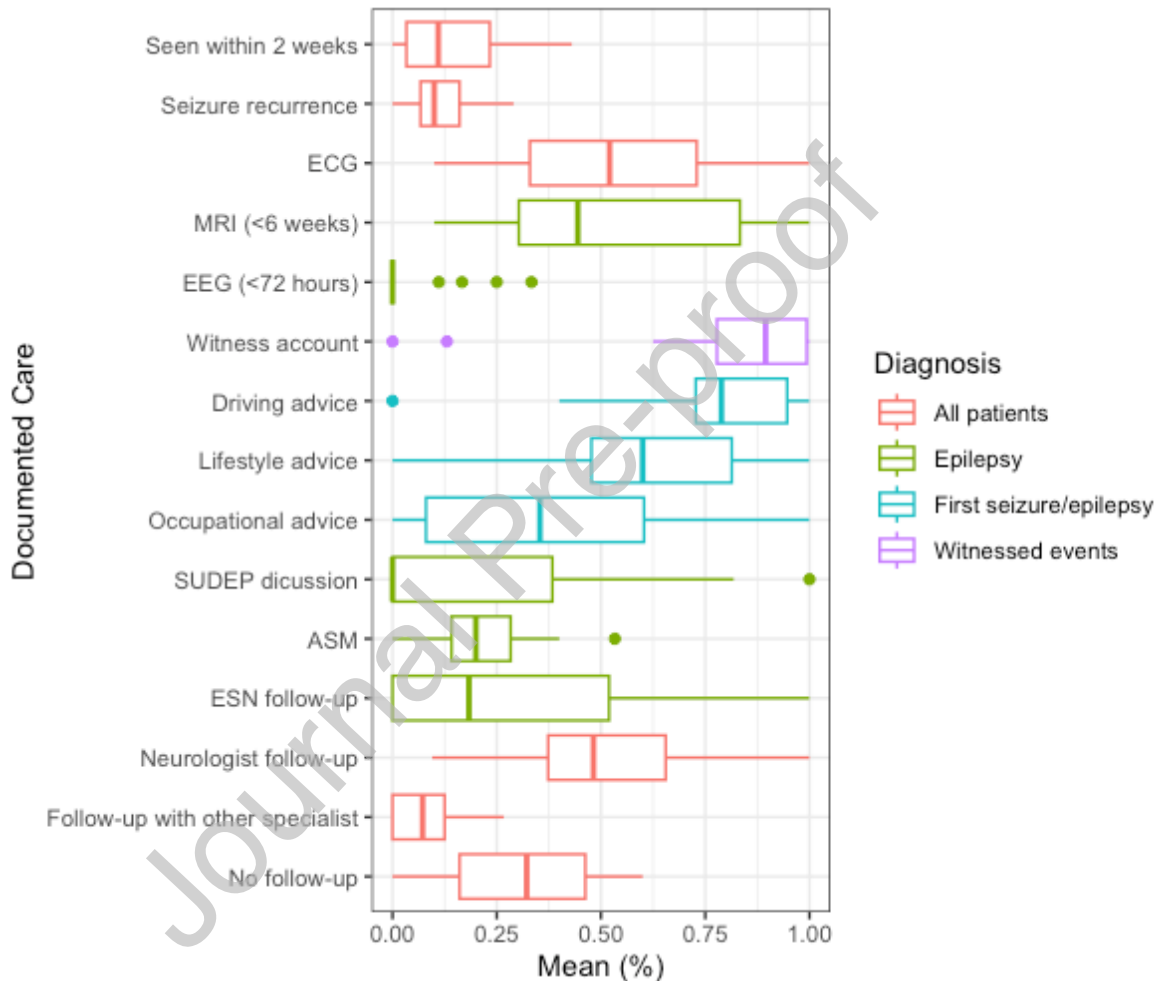
Following the suspected first seizure event, 85.6% (622/727) of patients were not commenced on an anti-seizure medications(ASM) by the referring clinician. If patients were commenced on an ASM, levetiracetam (46.7%) and lamotrigine (21.0%) were the commonest prescribed.

<b>Table 1: Referral and seizure clinic characteristics</b>	
	<b>% (n)</b>
<b>Referral source:</b>	
Emergency department (ED)	44.2% (n = 321)
General practice	41.7% (n = 303)
Secondary/tertiary care	12.8% (n = 93)
Other/not clear	1.4% (n = 10)
<b>Type of hospital if referred from ED or hospital ward:</b>	
District general hospital	27.3% (n = 113)
University teaching hospital	68.2% (n = 282)
<b>Standardised referral proforma:</b>	
Availability of standardised referral proforma	49.2% (n = 368)
No availability of standardised referral proforma	49.4% (n = 359)
<b>Grade of assessing clinician at seizure clinic:</b>	
Neurology consultant with subspecialist interest in epilepsy	55.4% (n = 403)
General neurology consultant	25.4% (n = 185)
Neurology specialty trainee/registrar	13.2% (n = 96)
Epilepsy specialist nurse	3.6% (n = 26)
GP with specialist interest in epilepsy	2.1% (n = 15)
Information not available	0.3% (n = 2)
<b>Method of patient review:</b>	
In-person consultation	96.8% (n = 704)
Telephone/virtual consultation	3.2% (n = 23)

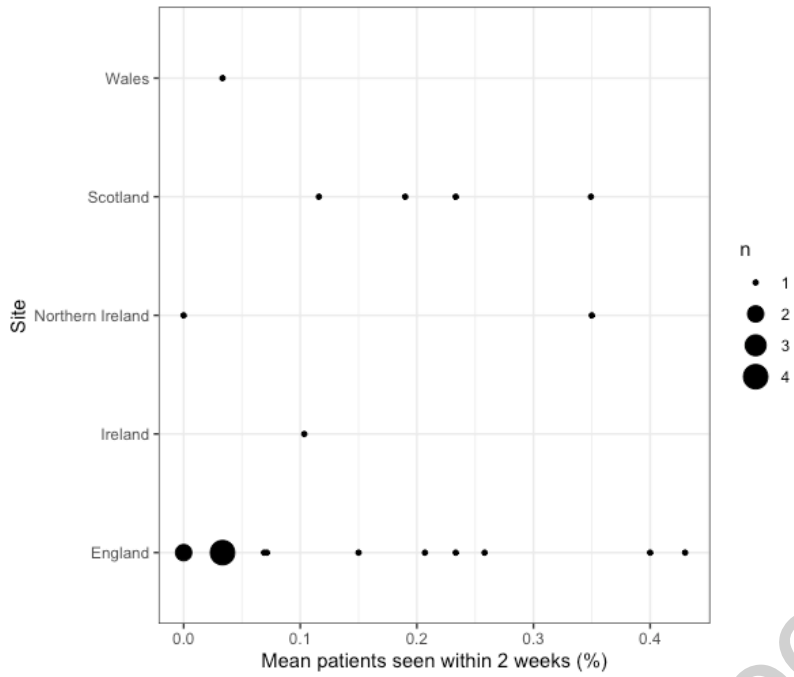
### **Documented care and management**

There was a median wait of 48 days [IQR 26 – 86] between the date of referral and date seen by a specialist at the first seizure clinic. From the date of referral, 13.8% ([IQR 3.3% – 24.0%], 100/727) of patients were seen within 2 weeks and 83.4% (606/727) were seen after 2 weeks. 2.9% (21/727) of patients did not attend their initial clinic review but rescheduled for a later date beyond 2 weeks. 12.7% ([IQR 6.7% –17.4%], 92/727) of patients

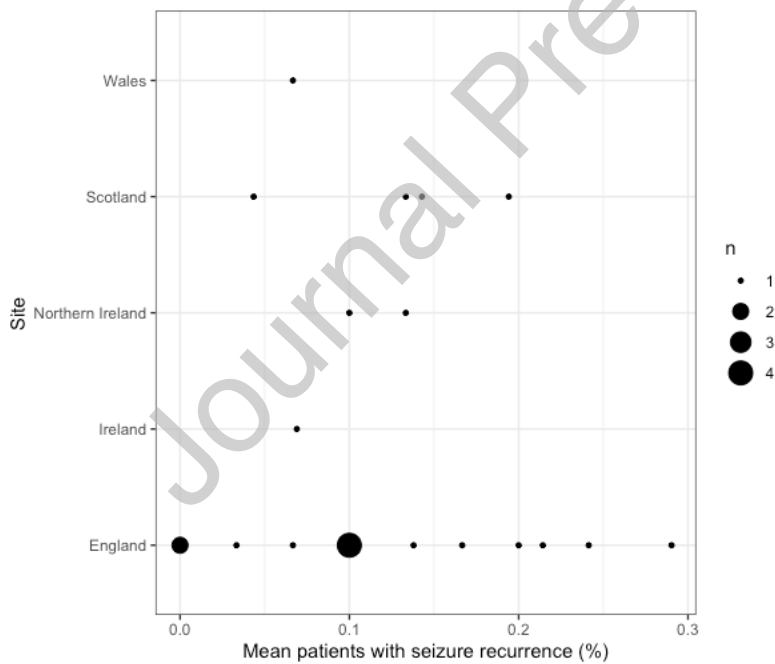
experienced seizure recurrence whilst awaiting their first appointment (Figure 1). 88.0% (81/92) of patients experiencing seizure recurrence were seen by a specialist after 2 weeks of referral and 23.9% (22/92) were commenced on an ASM by the referring doctor before their first seizure clinic appointment. Variability between sites were apparent for patients being seen within the recommended 2 weeks (figure 2) and for seizure recurrence whilst awaiting first appointment (figure 3).



**Figure 1:** Variation between sites in investigations and documented care. Box and whisker plots showing median of site means, 25th and 75th centiles, and range. ASM: anti-seizure medication; ESN: epilepsy specialist nurse.



**Figure 2:** Variation in patients seen within 2 weeks by a specialist across sites



**Figure 3:** Variation in patients experiencing seizure recurrence across sites (whilst awaiting first clinic appointment)

There were wide variations for both the investigations and documented care of patients. Documentation of electrocardiograms (ECG) being performed was evident for 53.5% ([IQR 31.7% – 76.6%], 389/727) of patients (Figure 1). Among patients diagnosed with first

seizures or new epilepsy, computerised tomography (CT) neuroimaging was performed in 30.6% (107/350) of patients. Among patients with new epilepsy, magnetic resonance imaging (MRI) was performed in 58.8% (80/136). Electroencephalograms (EEG) were performed in 52.9% (72/136). 88.2% (328/372) of EEGs were performed as routine, 7.0% (26/372) as ambulatory, and 4.8% (18/372) as sleep deprived (Supplementary Table 1). Among patients with new epilepsy, 46.3% (37/80) of MRIs were performed within 6 weeks of request (median 37 days [IQR 22 – 56]). Among patients with new epilepsy, 6.9% (5/72) of EEGs were performed within 72 hours of request (median 30 days [IQR 19 – 47]).

85.0% (618/727) of patients experienced loss of consciousness during the seizure event and 80.6% (498/618) of these events were witnessed. If a seizure was witnessed by a bystander or if this was not clear, there was documentation of a witness account being sought (or attempt to be sought) in 85.0% ([IQR 74.1% – 100%], 446/525) of cases (Figure 1). Among patients diagnosed with first seizure or new epilepsy, documentation on driving advice was evident for 79.7% ([IQR 71.2% – 96.4%], 279/350) of patients. Documentation for lifestyle (59.4% [IQR 44.9% – 84.1%], 208/350) and occupational (37.4% [7.0% – 65.2%], 131/350) advice was lower. Documentation on advice being provided for relatives/carers to video future seizure events was evident for 11.8% ([IQR 1.6% – 20.0%], 86/727) of patients. Documentation for sudden unexpected death in epilepsy (SUDEP) discussion at the initial first seizure clinic appointment was evident for 30.1% ([IQR 0% – 42.5%], 41/136) of patients diagnosed with new epilepsy (Figure 1).

A sizeable proportion of patients (21.3% [IQR 12.7% – 29.3%], 155/727) were commenced on an ASM at first appointment at the first seizure clinic (Figure 1). If ASMs were commenced, lamotrigine (54.2%), levetiracetam (25.2%), and valproate (6.5%) were the commonest prescribed by specialists. Following the first seizure clinic appointment, 47.3% ([IQR 35.8% – 67.7%], 344/727) of all patients had a follow-up clinic appointment booked with a neurologist and 30.4% ([IQR 0% – 59.5%], 42/138) of new epilepsy patients were referred to ESNs. The median time to review by an ESN was 133 days [IQR 37 – 205]. 34.1% ([IQR 14.7% – 46.7%], 248/727) of patients had no further follow-up arranged. 7.9% ([IQR 0% – 13.3%], 58/727) patients were referred to other specialists such as cardiologists, psychiatrists, or neurosurgeons (Figure 1).

## Diagnoses

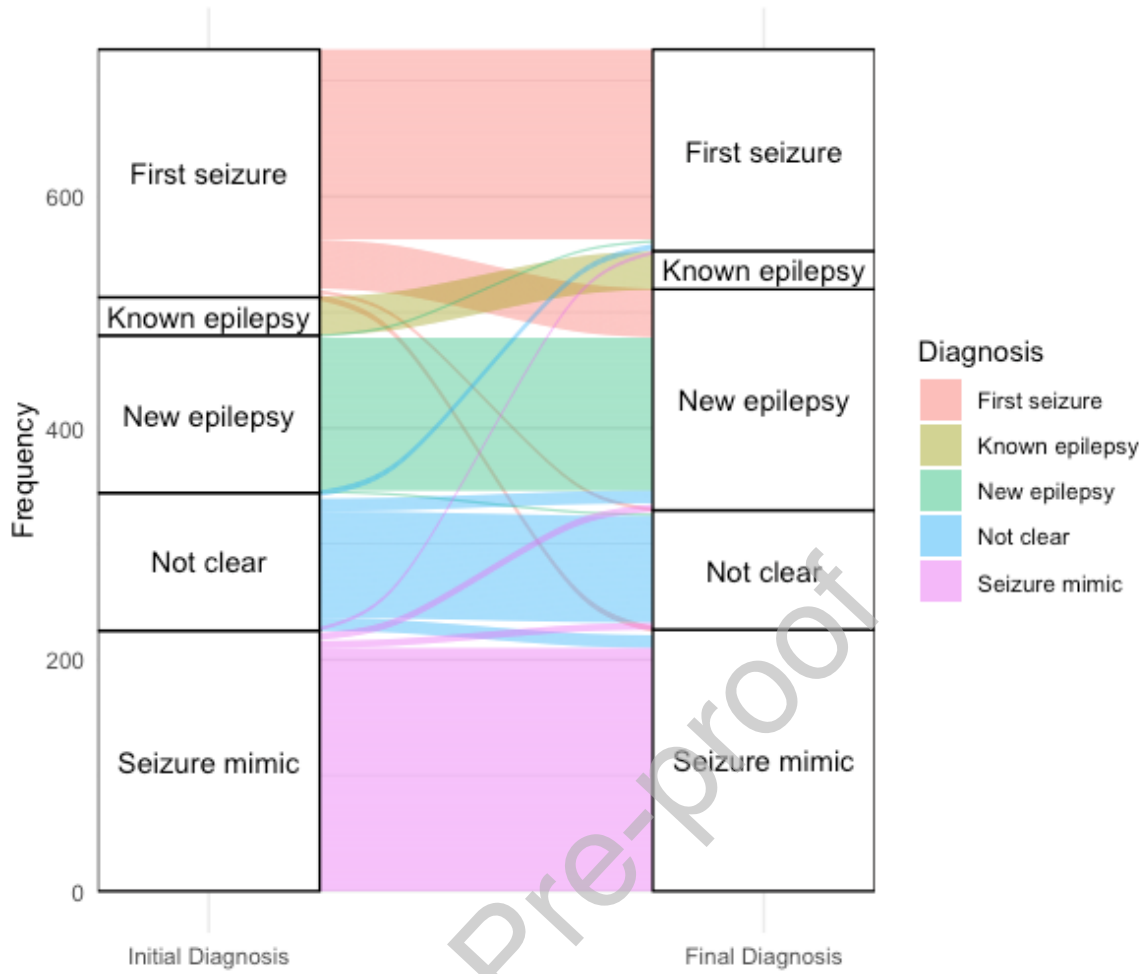
The commonest diagnosis made at first appointment by an epilepsy specialist were seizure mimics in 30.3% (220/727). This is followed by first seizures in 29.4% (214/727), new epilepsy in 18.7% (136/727), and unexplained events with unclear diagnoses in 16.9% (123/727). 4.5% (33/727) of patients had a seizure in previously diagnosed epilepsy. Syncopal events (53.6%) constituted the largest proportion of seizure mimics. Non-epileptic attacks (22.3%) were the second commonest, followed by migraines (3.6%) (Table 2).

22.4% (163/727) of seizure events were provoked. Common provoking factors for seizures included excess alcohol intake (28.2%), recreational drugs (16.6%), sleep deprivation (9.8%), and stroke (7.4%) (Table 2). Mood and anxiety disorders were the commonest co-morbidities present (14.6% and 12.4%, respectively). Other common co-morbidities included intellectual disability (5.9%), traumatic head injury (5.4%), and stroke (5.1%).

<b>Table 2: Specialist diagnoses and seizure characteristics</b>	
	<b>% (n)</b>
<b>Specialist diagnosis:</b>	
Seizure mimic	30.3% (n = 220)
First seizure	29.5% (n = 214)
Not clear (unexplained event)	16.9% (n = 123)
New diagnosis epilepsy	18.7% (n = 136)
Seizure in previous epilepsy	4.5% (n = 33)
<b>Seizure mimics:</b>	
Syncope	53.6% (n = 118)
Non-epileptic attack	22.3% (n = 49)
Migraine	3.6% (n = 8)
Other	20.0% (n = 44)
Not clear	15.5% (n = 113)
<b>Was the seizure event provoked:</b>	
Provoked	22.5% (n = 163)
Not provoked	54.5% (n = 396)
Not clear	23.0% (n = 167)
<b>Provoking factors for seizure event:</b>	
Alcohol	28.2% (n = 46)
Drug-induced	16.6% (n = 27)
Emotional stress/stimuli	9.8% (n = 16)
Sleep deprivation	9.8% (n = 16)
Stroke	7.4% (n = 12)
Metabolic	7.4% (n = 12)
Head injury	5.5% (n = 9)
Infection	4.9% (n = 8)

Other	10.4% (n = 17)
<b>Co-morbidities/past medical history:</b>	
Depression	14.6% (n = 106)
Anxiety	12.4% (n = 90)
Intellectual disability	5.9% (n = 43)
Traumatic head injury	5.4% (n = 39)
Stroke	5.1% (n = 37)
Cancer	2.8% (n = 20)
Dementia	19.3% (n = 14)
Brain tumour	1.2% (n = 9)
Cerebral palsy	0.3% (n = 2)
None of the above	38.1% (n = 277)

The diagnosis made by the specialist at the initial first seizure clinic appointment remained unchanged for 79.6% of patients (579/727) with a minimum follow-up period of two years (Figure 4). 10.5% (76/727) patients developed epilepsy during this follow-up period. 3.7% (27/727) of patients had their initial diagnosis changed to an unexplained event, retrospectively. 4.5% (33/727) of patients were previously diagnosed with epilepsy and were inappropriately referred to a first seizure clinic (although they are represented in figure 4, they were excluded from the analysis).



**Figure 4:** Change in diagnoses made at the initial seizure clinic (minimum follow-up period of 24 months).



## DISCUSSION

This is the first national audit of adult first seizure clinics in the UK and Ireland. Participating hospitals were asked to record consecutive first seizure cases, thereby mitigating selection bias. A degree of clerical and documentation errors are inevitable within audit studies, and whilst this confounds data interpretation from small sample sizes at the local level, it does not invalidate aggregated multi-centre national data.

The audit proforma was developed with expert medical and patient input, and the questionnaires piloted to assess the robustness of data collection repeatability.

Retrospective audits can only record what is documented in the medical records, and whilst documentation plays an important role medicolegally, recorded variations will arise from differences in documentation practice, accessibility of clinical records, and hospital type/geographical location (i.e. university teaching hospital vs district general hospital).

NICE have set out quality standards and guidelines for the management of patients presenting with suspected first seizures and new epilepsy, setting recommendations that patients should be seen by an epilepsy specialist within 2 weeks of referral. The findings in this audit suggests that delays in referral to specialist clinics may be contributing to subsequent delays in management.

### **Referral to first seizure clinics**

Previous studies from the UK and New Zealand report median first seizure clinic wait times of 5 to 6 weeks (15,16). Some Canadian and Australian centres report median wait times of 2 to 3 weeks, with half of referred patients being seen within 2 weeks, demonstrating what can be achieved (11,17,18). A sizeable proportion of patients in our audit experienced seizure recurrence whilst awaiting specialist review. An Australian and Scottish study of first seizure clinics report similar seizure recurrence rates of 8.9% and 9.0%, respectively (between the index seizure and time of clinic appointment) (17,19). They also find that patients experiencing seizure recurrence experienced delays in specialist assessment.

Despite the availability of dedicated first seizure referral proformas and pathways, they were not always utilised by referring clinicians, which may play a factor in delayed referrals. Reasons for this may include unfamiliarity with referral pathways and variations between intrahospital and primary care referrals to first seizure clinics. In the post-pandemic era, hospitals are increasingly utilising hybrid systems where patients are triaged virtually or over the telephone. Published literature suggests these can help reduce DNAs and clinic wait times (20). Future studies should assess whether face-to-face DNAs among first seizure patients should be called and how this will impact on other referrals.

### **Specialist care at first seizure clinics**

There were considerable variations in documented care. Investigations are important for excluding important differentials such as cardiac arrhythmias. However, documentation of an ECG being performed was evident in half of patients, indicating inappropriate gaps in routine care. 63.2% of ECGs were performed by the referring clinician and 37.5% by specialists at the seizure clinic – routine care can be improved across the whole patient pathway. Moreover, neuroimaging and EEGs were not being performed within recommended timeframes. It is likely that delays with the initial first seizure clinic appointment impacted on the timing of subsequent management.

55.4% of patients were assessed by neurologists with subspecialist interest in epilepsy (epileptologist), and 25.4% by general neurology consultants. Published data from a London study suggests that dedicated first seizure rapid referral pathways adversely affect the quality of referrals from the ED and that epileptologist led-clinics lead to an increase in diagnoses being revised from 'seizure' to 'syncope' (21). This has significant implications if patients are misdiagnosed or inappropriately commenced on ASMs.

Seizure mimics were the commonest diagnosis made at a first seizure clinic, findings corroborated by other first seizure clinics nationally and internationally (15,16,18). This indicates that clinicians who are proficient in working through the differential diagnoses and management of both epileptic seizures and seizure mimics may be best placed to run these clinics. This also highlights the diagnostic challenges that referring clinicians face, as both seizures and many seizure mimics largely remain a clinical diagnosis. Tackling this challenge

may involve a multifaceted approach, ranging from improving national seizure education, to standardisation and better awareness of first seizure referral pathways and for alternative diagnoses such as non-epileptic attacks. Moreover, the proportion of referred patients with a background of intellectual disability in this audit was quite low (5.9%) and may indicate that these individuals were reaching epilepsy specialist services via different pathways (22).

ASMs were commenced in 21.3% (155/727) of overall patients by specialists at the clinic, and in 14.7% (105/727) by referring clinicians. National data suggest that few patients are commenced on ASMs at initial assessment (6). Diagnosing epilepsy and commencement of ASMs requires expertise; challenging for non-specialists who most commonly assess these patients at initial presentation. A Royal College of Physicians report suggests that an 'acute neurology' service be present in every hospital. There may be merit to this recommendation to allow appropriate early management with the sizeable proportion of patients experiencing seizure recurrence (23).

Guidelines emphasise the importance of a collateral witness history, yet this was variably documented even by specialists. Variations in documented care were also evident for driving, lifestyle, and occupational advice, although this may have been confounded by patients being given pre-printed leaflets. These are gaps in routine care with important medico-legal implications. Moreover, there is limited national data and consensus is lacking in how clinicians should discuss SUDEP with patients. Numerous organisations including the American Epilepsy Society, NICE, and Scottish Intercollegiate Guidelines Network advocate for early SUDEP discussion (24).

### **Care after first seizure clinics**

Following the first appointment, half of patients had a follow-up clinic appointment booked with a neurologist. This is an interesting finding given that not all first seizure patients need a follow-up. Moreover, only a third of new epilepsy patients were referred to ESNs, indicating that access to these services was still variable nationally. However, this may represent an underestimate considering that most patients were seen in university teaching hospitals where ESNs are available, and may be the fact that not all referrals are documented in clinic letters. Over a minimum follow-up period of two years, initial specialist

diagnoses remained unchanged for 79.6% (579/727) of patients, suggesting stability of the original diagnosis over time (Figure 4).

### **Implications of this audit**

NAPIER demonstrates that the documented care of first seizure and new epilepsy patients in first seizure clinics remains variable nationally. Variations were seen throughout the whole patient pathway, ranging from primary/secondary care referrals to specialist clinics. Similar variability has also been reported by national adult and paediatric epilepsy audits in the UK (6,25). Therefore, service delivery improvement of first seizure clinics must be commissioned alongside improvements in the community and hospitals.

Among patients with a specialist diagnosis of a first seizure or new epilepsy, 16.2% (57/350) were seen by specialists within 2 weeks of referral, suggesting that even patients who may have been triaged as high risk for an epileptic seizure were not being seen within the recommended timeframes. However, delays in outpatient referrals are not unique to first seizure clinics; key waiting time standards are being missed across all specialities and sectors ranging from primary care to urgent and emergency services (26,27). Outpatient clinics are continuing to face ongoing pressures and backlogs from the COVID-19 pandemic. Epilepsy care can lose out to cardiovascular diseases, cancer care, and other chronic conditions if there are no clinicians or data to advocate for it. The National Service Framework for coronary heart disease has led to the widespread establishment and funding for rapid access chest pain clinics, where average clinic wait times are as fast as 9 days from referral (28). This funding has led to significant improvements in clinic wait times and patient outcomes (29,30).

Epilepsy poses a significant socioeconomic burden. Seizures greatly impact on quality of life, having implications on driving, employment, and psychosocial wellbeing. Improved access to epilepsy specialists and commencement of appropriate treatment regimens would lead to fewer ED attendances and inpatient admissions. NICE have released new seizure and epilepsy guidelines, providing updated standards of care (31). This represents a pragmatic step in benchmarking ideal first seizure and epilepsy management, with aims to minimising national variations in patient care.

## CONCLUSION

There has been considerable variation nationally in the documented care of patients referred to first seizure clinics in the pre-COVID-19 era. Many patients are facing delays to assessment with epilepsy specialists, impacting on subsequent management. Tackling this will mandate an organisational approach involving the whole patient pathway, with scope to improve documented care at patient referral to specialist assessment. We aim to repeat the second cycle of NAPIER to assess where current practice lies in the post-COVID-19 era.

Journal Pre-proof

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