

# **National Audit of Seizure Management in Hospitals – Round 3**

Data Analysis and methodology report

St Elsewhere Hospital

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## Executive Summary

*The purpose of the audit (or why we audited the emergency care or people having seizures or possible seizures)*

Seizures are unpredictable and worrying events, and people that have them will commonly be taken to an emergency department (ED) for assessment and treatment. In fact, seizures are a common reason for attending an emergency department (ED) and they are the cause for around 1% of hospital admissions.

Almost two thirds of people attending an ED with a seizure have a known diagnosis of epilepsy. Whilst epileptic seizures can be controlled for 70% people with epilepsy, previous studies have shown that only 50% of people in the UK achieve that control, indicating problems with the delivery of care. When someone with epilepsy attends an ED with a seizure, there is an opportunity to put a plan in place to ensure specialist intervention and follow-up, which will most commonly require out-patient appointments in neurology services. It is neurologists and epilepsy specialists that have the expertise to ensure that treatments and strategies are put in place to maximise seizure control, and to reduce the need for ED attendance should a seizure occur.

For almost a fifth of those attending the ED with a seizure it is their first episode. They need timely assessment to identify a possible cause and to get advice about any treatment that might be required as well as the risk of future seizures, driving and employment.

If the needs of people attending an ED with seizure are to be met, care must be coordinated across differing disciplines including emergency care and neurology, and neurology services must be accessible and have sufficient capacity to meet the need. Previous rounds of NASH (2011 and 2013) found that care is often poorly coordinated, identifying that:

- many aspects of routine care were not being done
- many bed-days were probably being used unnecessarily
- some investigations were being overused
- onward referral to a neurologist or epilepsy expert for future management and advice was often not done.

The purpose of the 2018 audit was to assess whether there had been improvement since the 2011 and 2013 audits, and to provide data that can inform decisions about improving care. It was designed by a team of researchers consisting of neurologists, emergency department consultants, specialist nurses, and representatives from patient charities.

These reports are being shared with all 137 participating sites. The intention is that healthcare professionals, NHS managers, chief executives, board members, as well as service

commissioners, policymakers, and voluntary organisations work together to actively plan to improve care delivery.

### Characteristics of patients included in the 2018 audit.

The study population includes 4,132 patients presenting to 137 Type 1 Emergency Departments (EDs) across the UK (95.6% of these were from England). The median number of ED attendances per site was 30. Their median age was 43 with nearly 20% over 65. The majority (61%) had an existing diagnosis of epilepsy, 16.6% of whom had a learning disability. 16% had a previous history of blackouts or seizure type events, and 23% had experienced a likely first seizure, 9.5% of whom were recorded as having dementia, which can present added diagnostic, treatment and care challenges.

### Summary of key points and messages from NASH3

## **An overall message from the 2018 audit is that very little has changed over 8 years.**

For ease in demonstrating the audit findings we have summarised a few variables selected by our advisory group for two different sub-groups of patients.

- a) Group 1: with an established epilepsy diagnosis (n = 2,529 (61% of all cases)); and
- b) Group 3: with a likely first seizure (n= 956 (23% of all cases))

### A) Group 1: Patients with an Established Epilepsy Diagnosis

For this group, the key points relate to sections 3, 6, and 9 of the main report (below). In each section mean values are presented but the range across sites is very wide (see figure below).

#### Past History

Half had had a seizure attendance in the prior year (55% vs 45% in 2013;  $p < 0.001$ ). Half had been seen in a specialist clinic in the prior year (45% vs 37% in 2013)

A quarter (25.1%) had had an attendance but not seen a specialist in the year before indicating missed opportunities to access specialist care.

### Prior Anti-Epileptic Drug (AED) Therapy

23% were on no antiepileptic drugs therapy and 44% were taking only one antiepileptic drug indicating opportunities modify treatment to improve seizure control

### Assessments

Making a diagnosis of seizure and identifying the likely cause, in the first instance require the collection of some basic information on arrival. Just as in the earlier audits this process remains very variable (see figure 1 below) – some trusts did all/most while others did not. As an example, only 34.1% of established epilepsy patients medical notes had documented if the patient was asked about alcohol or illicit drug usage; information that is useful in determining if a seizure was provoked, and can be used to aid treatment and management decisions.

Fever and infection can be an important provoking factor for seizure, and it is surprising therefore that recording of temperature, a routine observation for most patients attending an ED whatever the reason was missing in a number of cases in a significant number of hospitals (see figure 1 below).

### Investigations

CT Brain scans were undertaken in 30% during their ED attendance or admission - which has increased from 21.6% in NASH2 and 16.5% in NASH1. The audit did not collect information on the specific reason for the scan, which will be important to consider in future audits. However, most epilepsy patients will have had brain imaging (usually MRI) previously as part of their diagnostic work up. Many of the urgent CT Brain scans are unlikely to inform acute management and likely represent an unnecessary use of resources and radiation exposure. Patients would be better served by urgent specialist assessment and subsequent outpatient imaging investigations if indicated.

### Referral to Epilepsy / Neurology Service

Specialist referral was made directly from the ED, or via a request to the GP to organise a referral, for 39.1% of patients (vs 35.4% in 2011 and 43.6% in 2013).

Worryingly, the referral rate was lower for the 35% of patients that had not seen a specialist in the prior 12 months (35% vs 44%).

These results are paradoxical and highlight the challenge for those outside of specialist care to get access to it.

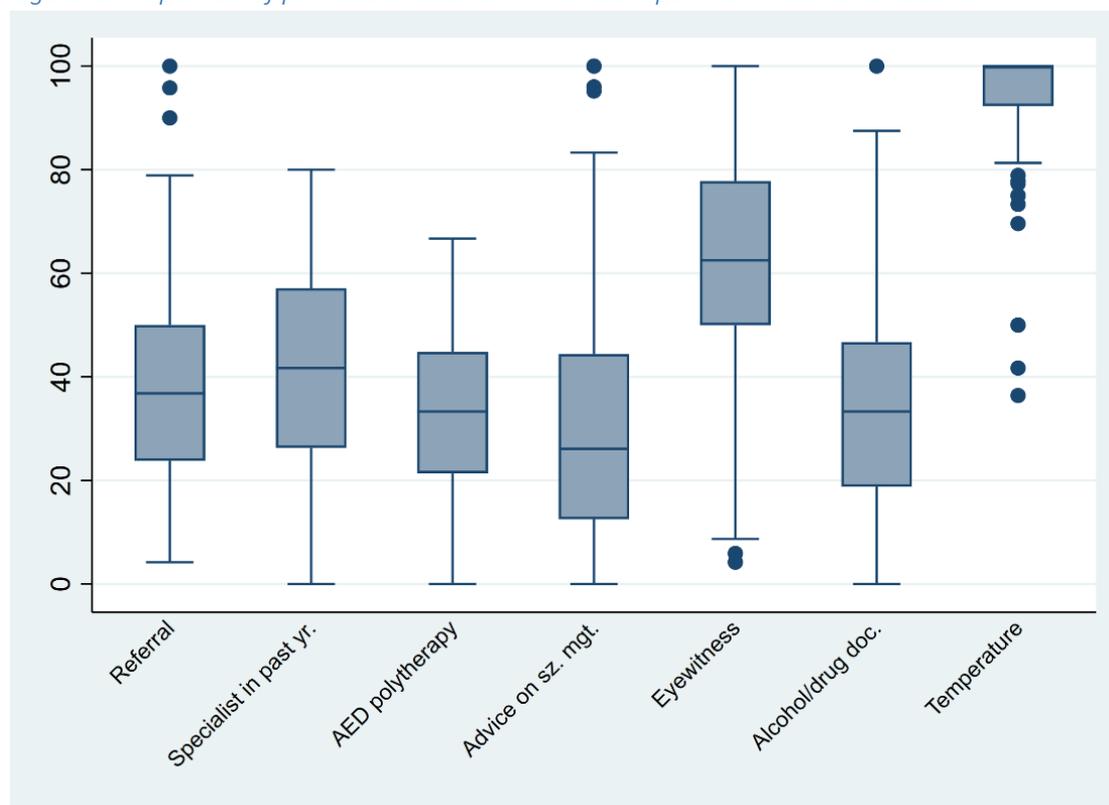
### Patient Advice

30.4% of patients (ranging from 0 to 100% at different sites) did not have specific advice about what do to with future episodes. NHS England recommends that patients should have a 'First Point of Contact', usually a specialist nurse, and an individualised 'care plan'. How else will a future episode be averted?

### Variability Among Sites

Our advisory group nominated a short list of 7 variables to summarise key aspects of care, which are illustrated as a box and whisker plot in Figure 1. This demonstrates **wide variability among sites that is way beyond chance**. These are aspects of care that should be attended to and for each some hospitals show that it's possible to do so.

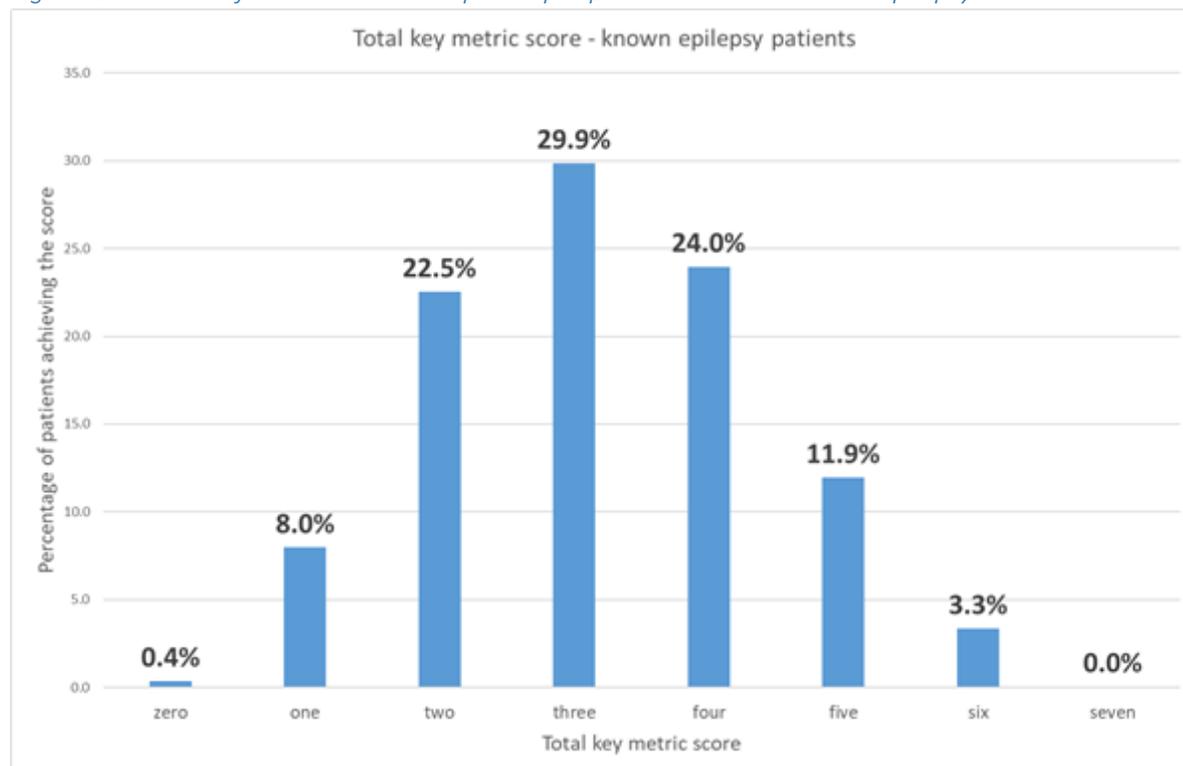
Figure 1: Proportion of patients at each site that had a particular item attended to



If we examine the same 7 items highlighted in figure 1 at a patient level and record a score out of 7 then we get figure 2. If we consider best care to be 6 or 7 of the variables attended to, then figure 2 shows that only 3.4% or 1 in 30 had “best care” – i.e. most patients were missing more than two items that should be routine for every case. A challenge for the future.

Put another way, if this were your relative attending, then is current care satisfactory?

Figure 2: Number of interventions completed per patient with established epilepsy across all sites



### B) Group 3: Likely First Seizure Patients

The key points relate to sections 6, 8, and 9 of this report.

#### Prior History

A diagnosis of seizure relies on a good description of the event. Given that most people lose awareness during a seizure event, this requires access to an eye witness account. For the purpose of the audit, an attempt to gain an eye witness was accepted to have occurred if a history was obtained, that an attempt was made, or that the attack was noted to be unwitnessed. Even with this latitude – a history or attempt to get it was only documented for 70.3% of likely first seizure patients. This varies from never at some sites to always at others (see figure 3).

Similar issues apply to assessments of alcohol use (38.8%) and illicit drug use (14.3%) of patients – both of which are recognised potential seizure provoking factors, with different and specific investigation and treatment.

#### Assessments

Routine assessments were undertaken in most patients, for example:

95.2% had their temperature measured and 96.9% had their pulse measured – but there were sites that fell well short of this (Figure 3).

Only 86.7% had an ECG, even though an ECG should be mandatory to help the clinician differentiate between seizure and arrhythmia.

These are gaps in routine care that should not be there.

### Investigations

Intracranial imaging is an important component of the patient assessment following a first suspected seizure. The best investigation is an MRI brain scan, usually as an out-patient. CT imaging should be undertaken in the acute setting if serious pathology is suspected, e.g. haemorrhage or tumour, but this is a small minority of patients.

CT Brain was requested in the ED in 65% of first seizure presentations ranging from 0% to 100% across sites. The high and increasing use of CT (up from 55% in NASH 2 and 45% in NASH 1, and the wide variability suggests that much of this unnecessary. Guidelines are needed to help define the role of CT head imaging (and other modalities) following a first presentation.

### On Going Care - Referral

NICE guidance states that people with a first seizure should be referred to and seen by a specialist (usually neurology) within 2 weeks of their seizure.

Referral patterns were again very variable among trusts. Onward referral was made either directly from the ED, or via a request to the GP to arrange it for 63.6% of patients presenting with a first suspected seizure. Although NICE states referral should be within 2 weeks, the median time to an appointment was 39 days.

Disappointingly, over one third of patients were not put on a pathway to see a seizure specialist with a range across trusts from 0% to 100%. Who else is likely to make a definitive diagnosis, provide advice on driving, advise on the risk of seizure recurrence and whether treatment might be required.

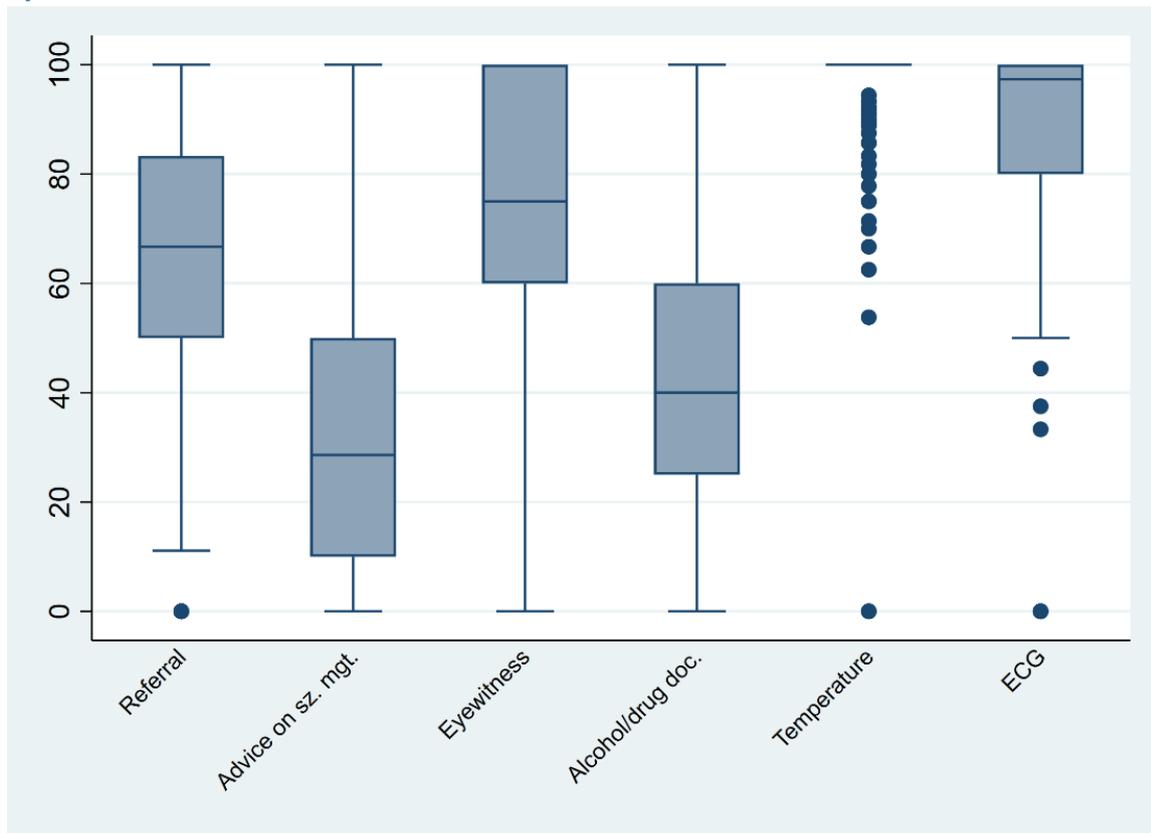
### Advice to Patients

The provision of advice about the management of future seizures was documented in only 32.9% of first seizure patients.

### Variability Among Sites

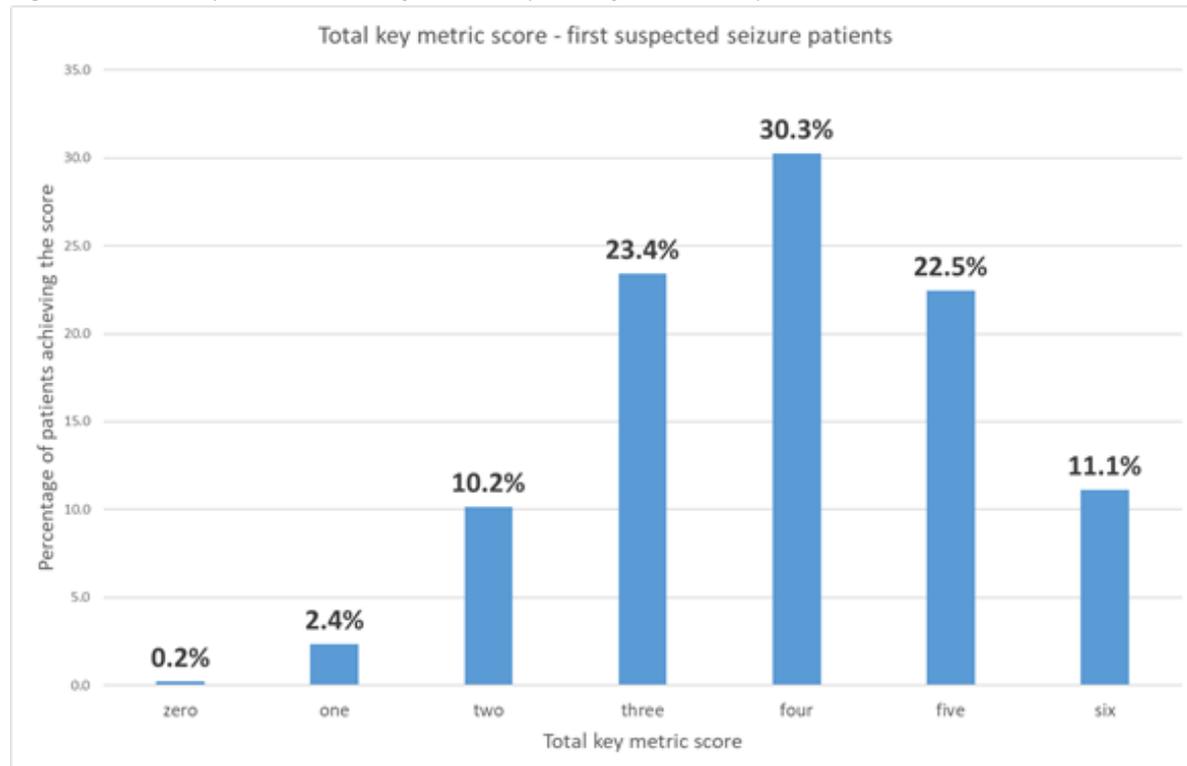
The wide variation among sites is clearly seen in the 6 items selected by the advisory group as illustrated in Fig 3. We do not know why so many “gaps” should exist in so many trusts.

Figure 3: Variability in mean values at each site for key metrics for the care of a person presenting with a first seizure



If we consider the 6 items highlighted in Fig 3 and record a score out of 6 then we get the following figure (figure 4) showing that two-thirds of people presenting with a first fit are “missing” 4 or more of the 6 indicators.

Figure 4: Total key metric score – for the suspected first seizure patients.



## Conclusion

Much remains to be done to bring epilepsy care up to a standard that the UK can be happy with. Some sites score well showing that good care is possible despite the constraints of busy units.

It is clear that for too many patients, simple assessments are not being done, investigations are being used inappropriately, care is inadequately coordinated, and opportunities to improve care are patient outcomes are being missed. This is likely associated with harm to patients and represents an inefficient use of NHS resources.

One last thought for service providers. 45% of all seizure patients were admitted and stayed a mean of 3-5 days in hospital. But in 80% of cases this reason given for the admission was 'seizure' and there was no other medical or social reason. Since most seizures settle over a few hours and need no specific medical care – perhaps there is a target to instead arrange that these patients should have an EARLY out-patient referral.

How the NHS links specialist tertiary care to ED units in secondary care and to GPs for local care is not easy but it is essential if people with epilepsy are to get "joined-up care" in a timely manner.

## How to use this report

### Scope and data collection

This report presents results of an analysis of data derived from the third round of the National Audit of Seizure management in Hospitals (NASH). This report presents data describing the cohort of patients that arrived in Type 1 EDs across the UK from 01 June 2018.

Previous rounds took place in 2011 and 2013. The audit captures the care given to patients attending EDs as a result of a seizure, as well as information about their care pre and post attendance at the ED.

Details of data collection and statistical analysis can be found in appendix 1.

### Report Structure

Data are presented largely in a tabular form with explanatory notes where appropriate. **The values for your hospital** are presented alongside the national values. Some fields have figures in **red**; these represent the equivalent national result in NASH and NASH2. Further details and a discussion of the results can be found in the associated clinical report (copies were sent to all trusts at the time – further copies available from [info@nash.org.uk](mailto:info@nash.org.uk)).

### Report Coverage

All UK trusts with a Type 1 ED were invited and this report covers the 137 hospitals that provided data (most (95.6%) came from England).

### Audience and links to relevant guidelines and standards

This report is intended to be read by healthcare professionals, NHS managers, chief executives, board members, as well as service commissioners, policymakers, and voluntary organisations.

The report references throughout the appropriated National Institute for Health and Care Excellence (NICE), which can be found at <https://www.nice.org.uk/guidance/cg137> and the previous NASH reports that can be found at <http://www.nashstudy.org.uk>.

## Interpretation of data in this report

Rather than focus on individual variables, we suggest it is more useful to look at the patterns across groups of variables and, in particular, to examine issues where there is an opportunity to make a local change. This will vary between hospitals, but in most hospitals, there is an opportunity to make improvements.

We would also highlight that it's likely that concentrating on one aspect of care alone e.g. the emergency department, or the referral to tertiary care is unlikely to solve the overall problem of quality of care and it's likely that a more co-ordinated approach involving primary secondary and tertiary care will be needed to really make a difference.

A second reason for examining the overall pattern rather than concentrating on single items is that your hospital data is based on a small sample of 30 cases so that, for example, a figure of 60% achievement for a given variable has a 95% confidence interval of approx. 18% i.e. it could be between 42 and 78%.

## Audit Data

### Overview

Patient data was received from 137 hospital sites within 113 NHS Trusts/Health Boards.

4,132 attendances at EDs from 1<sup>st</sup> June 2018 were available for analysis. The median number of attendances per site was 30, range 6 – 50.

St Elsewhere Hospital contributed **34** to the analysis.

### Section 1 - Auditor details

	National audit	Your Site
	n=4,132	n=34
Doctor (%)	80.6	100
Nurse (%)	14.4	0
Other (%)	5.0	0

### Section 2 - Patient Demographics

#### 2.1 Age

	National Audit	Your Site
	n=4,132	n=34
Median age	<b>43</b>	44
Aged under 45 years (%)	<b>51.3</b> <i>(51.6/49.0)</i>	50
Aged between 45 and 65 years (%)	<b>28.9</b> <i>(29.8/29.5)</i>	32.4
Aged over 65 years (%)	<b>19.6</b> <i>(18.6/21.4)</i>	17.7

The national age median was 43 (IQR 28 - 60). In NASH2 the median age of patients was 45 (IQR 30-62)

The median age at your site was 44 (IQR of 30 –60).

## 2.2 Gender

	National Audit	Your Site
	n=4,132	n=30
Male (%)	<b>53.3</b> <i>(57.0/57.4)</i>	50
Female (%)	<b>46.7</b> <i>(43.0/42.6)</i>	50

**COMMENT:** The characteristics of seizure patients presenting to ED have changed little over time.

### Section 3 - Care pre-seizure

- **3.1 Classification of patients**
- **3.2 Previous Seizures**
- **3.3 Provoking factors for Group 2 patients**
- **3.4 Previous Emergency Department attendance**
- **3.5 AEDs prior to arrival**
- **3.6 Patients that have seen medical specialists in previous 12 months**
- **3.7 Relevant Co-morbidities**

#### 3.1 Classification of patients by type of presentation

The questions asked in this section make it possible to split the patients into 3 distinct groups:

- **GROUP 1 – Those who are known to have epilepsy (n=2529 or 61%)**
- **GROUP 2 – Those who are known to have previous seizures or blackouts, but no current epilepsy diagnosis (n=639 or 16%)**
- **GROUP 3 – Those who are not known to have either epilepsy or previous seizures or blackouts – likely first seizures (n=956 or 23%)**

**NB 8 patients cannot be assigned to these categories due to missing data.**

**These 3 groups will be used throughout the rest of this report**

#### 3.2. – Comparison of patient classifications with previous audit rounds

	<b>Group 1 – patients with an existing epilepsy diagnosis</b>	<b>Group 2 – patients with known blackouts or seizures, but no epilepsy</b>	<b>Group 3 – Likely first seizure patients</b>
<b>NASH1</b>	66%	15%	18%
<b>NASH2</b>	61%	17%	22%
<b>NASH3</b>	61%	16%	23%

**COMMENT:** A broadly similar pattern of presentation over the years.

3.3 Provoking factors for **Group 2** patients (those with history of seizures and/or blackouts but no current epilepsy diagnosis)

For Group 2 (previous history of seizure/blackout, but no epilepsy diagnosis) patients, the audit asked if their previous seizures/blackouts were provoked by alcohol, head injury or other.

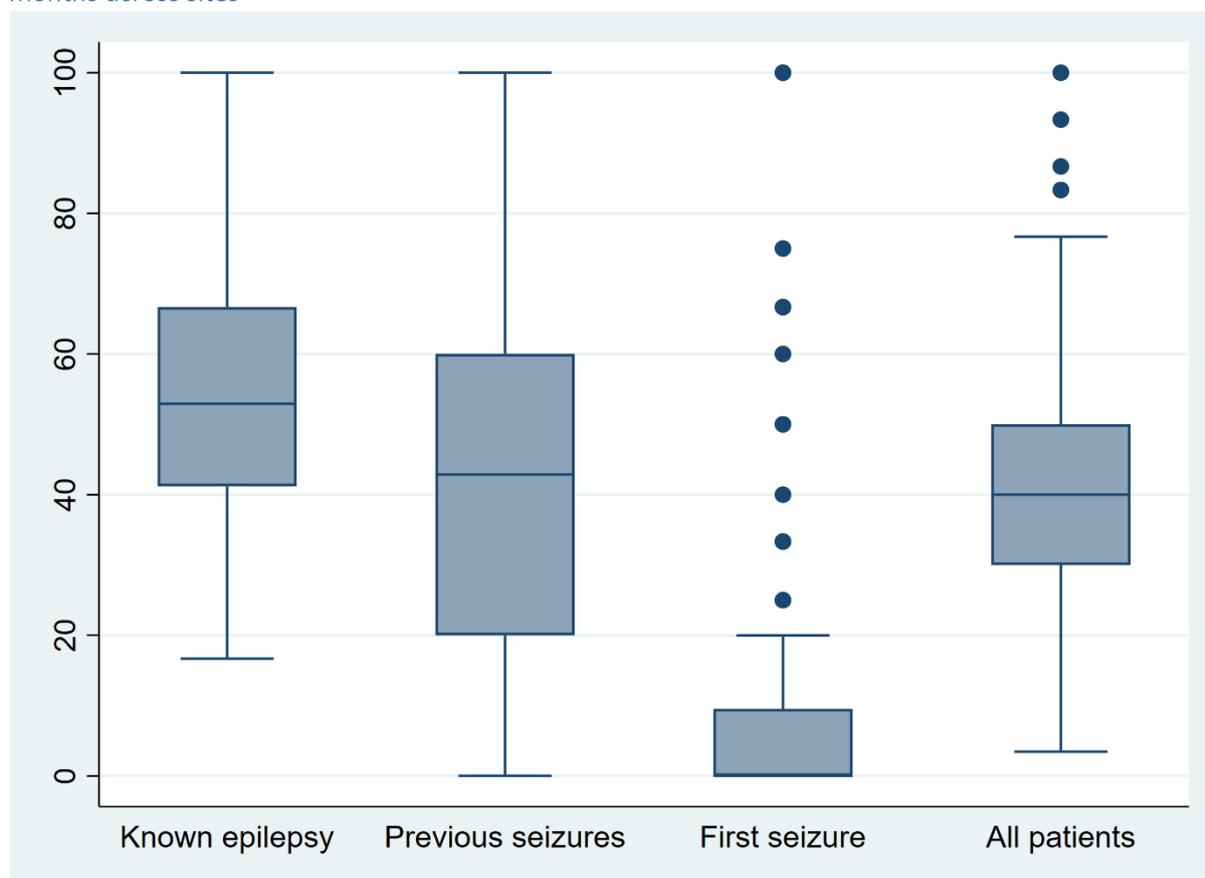
	National Audit n=639			Your site n=0		
	Provoked by alcohol	Provoked by head injury	Provoked by other	Provoked by alcohol	Provoked by head injury	Provoked by other
Yes (%)	11.6 <i>(13.7/14.0)</i>	2.8 <i>(4.4/5.1)</i>	17.2 <i>(20.7/20.4)</i>	0	0	0

3.4 Emergency Department attendance in previous 12 months

	National audit/Your site							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Yes (%)	54.8 <i>(45.1)</i>	65.6	43.7 <i>(40.8)</i>	0	6.8 <i>(3.9)</i>	0	41.9 <i>(35.1)</i>	61.8

NB previous audit figures only available from NASH2

Figure 5 Distribution of percentage of patients who had attended ED with a seizure in the previous 12 months across sites



Over half of those with epilepsy had attended the ED with a seizure in the previous year, which has increased by 10% since NASH2. This likely represents failed opportunities to access treatment and advice from epilepsy services to better control seizures and to better manage acute seizures when they occur.

Almost half of Group 2 patients (blackouts but no current epilepsy diagnosis) are also repeat visitors indicating similar problems. This has huge cost implications for the NHS and society and wider society, quite part from the impact on patients' health and quality of life.

### 3.5 Antiepileptic drug treatment taken prior to ED attendance

#### 3.5.1 – Breakdown of what type of therapy patients were receiving prior to ED attendance

National audit/ <i>Your site</i>						
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2
No therapy (%)	22.5	25	81.7	0	88.6	100
Monotherapy (%)	44.4	34.4	14.1	0	7.8	0
Polytherapy (%)	32.1	40.6	2.5	0	0.7	0
Unclear (%)	1.0	0	1.7	0	2.8	0

#### 3.5.2 Number of AEDs taken

Number of AEDs being taken	Percentage of polytherapy patients
2	60.1(%)
3	28.0(%)
4	8.7(%)
5	2.5(%)
6	0.1(%)
7	0.1(%)

Most frequent duo therapy combinations (those in over 5% of cases)	Percentage of duo therapy cases
Lamotrigine/Levetiracetam	17.8%
Levetiracetam /Valproate	13.1%
Lamotrigine /Valproate	6.9%
Carbamazepine /Levetiracetam	6.7
Clobazam/Levetiracetam	5.1

**COMMENT:** Around one fifth of patients with known epilepsy are recorded as not being on an AED on their attendance. This is similar to findings in the previous two audits. In fact, those on 'no therapy' were less likely to have visited the ED in the previous year (18.5% vs 27%) or a specialist in the prior year (18.5% vs 25.9%). In other words, these may have been a better controlled cohort prior to this event – thus it is even more important they are re-referred and re-established on appropriate therapy.

Some patients can be seizure-free by taking only one antiepileptic drug (monotherapy), others need additional drugs and finding an effective combination is a treatment goal. The audit found 44.4% of patients attending with an existing epilepsy diagnosis were only taking one drug. This indicates there may be opportunities to improve treatment.

### 3.6 Patients that have seen one of the listed epilepsy specialists in previous 12 months

National Audit/your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Neurologist (%)	37.1 (29.9/31.5)	37.5	21.6 (16.7/26.0)	0	4.7 (3.5/4.4)	0	27.2 (23.0/24.5)	35.3
Epilepsy Specialist Nurse (%)	15.0 (5.5/9.6)	9.4	3.3 (0.7/1.4)	0	0.4 (0.0/0.1)	0	9.8 (3.8/6.1)	8.8
Neurosurgeon (%)	2.3 (2.3/2.0)	0	1.9 (2.1/3.1)	0	2.3 (0/0)	0	2.3 (2.1/2.3)	0
Alcohol Liaison Service (%)	2.4	0	2.3	0	1.7	0	2.2	0
Intellectual disability specialist (%)	1.5 (1.1/1.4)	0	0.8 (0.5/0.8)	0	0.3 (0.6/0.2)	0	1.1 (0.9/1.0)	0
Paediatrician (%)	0.8 (8.8/14.1)	0	0.9 (N/A/0)	0	0.4 (N/A/0)	0	0.8 (6.3/9.8)	0
Paediatric neurologist (%)	0.6	0	0.6	0	0.1	0	0.5	0
None of the above (%)	54.6 (66.2/62.9)	59.4	72.1 (80.9/70.0)	No patients	90.6 (94.4/93.1)	100	65.6 (73.6/70.9)	61.8

NB in NASH1 and NASH2 Neurologist and paediatric neurologist were combined.

As some patients may have seen more than one specialist, in the 12 months prior to the audit, your individual site figures may add up to more than 100%.

**COMMENT:** Over half (55%) of epilepsy patients had not seen an epilepsy specialist in the previous 12 months indicating missed opportunities to improve management. Whilst this has improved over the course of the 3 audits, there is still clearly still room for improvement.

### 3.7 Relevant Co-Morbidities

The audit also asked about several comorbidities (**NEW for NASH3**):

	National Audit/your site							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Brain Tumour (%)	4.2	0	3.6	N/A	3.5	0	3.9	0
Cerebral Palsy (%)	4.1	6.3	1.3	N/A	0.8	0	2.9	5.9
Dementia (%)	6.3	0	6.9	N/A	9.5	0	7.1	0
History of significant head injury (%)	6.0	3.1	4.7	N/A	3.2	0	5.2	2.9
Intellectual disability (%)	16.6	6.3	4.5	N/A	4.4	0	11.9	5.9
Stroke (%)	8.5	28.1	7.0	N/A	8.9	0	8.3	26.5
None recorded (%)	62.5	56.3	75.4	N/A	73.4	100	67.0	58.8

NB some patients have been recorded as having more than one co-morbidity. Therefore, figures may add up to more than 100%.

**COMMENT:** Seventeen percent of attendees with a diagnosis of epilepsy had a learning disability and 9.5% of those with suspected first seizures were recorded as having dementia. These patients present added diagnostic, treatment and care challenges.

Section 4 – Attendance at Emergency Department

- 4.1 Was patient seen within 4 hours of arrival at emergency department?
- 4.2 What grade of doctor was the patient seen by?

The section 4 questions in NASH3 differ from NASH1 and NASH2 which queried if the patient had been seen by a consultant / ST4, and if this was within 4 hours. As these questions are subtly different, we have not drawn any direct comparisons at this time.

4.1 Was the patient seen within 4 hours of arrival in ED?

National Audit/your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n= 956	n=2	n= 4132	n=34
Patients seen within 4 hours (%)	92.9	90.6	90.8	0	90.8	100	92.0	91.2

4.2 What was the most senior grade of clinician that the patient was seen by?

Nation Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Advance Nurse Practitioner (%)	3.7	9.4	2.5	0	3.7	50	3.5	11.8
Foundation Doctor level 2 (%)	14.4	25	16.3	0	13.4	50	14.4	26.5
Core Medical Trainee (%)	13.0	0	14.4	0	11.9	0	13.0	0
House Officer (%)	0.3	0	0.3	0	0.2	0	0.3	0
Speciality Trainee 3 (%)	31.7	50	32.6	0	34	0	32.4	47.1
Consultant (%)	22.6	15.6	20.0	0	22.7	0	22.2	14.7
Missing response (%)	0.3	0	0	0	0.3	0	0.3	0
Doctor Grade not documented (%)	14.1	0	13.9	0	13.8	0	14.0	0

Section 5 - Acute Seizure Management

- **5.1 Rescue Medication**
- **5.2 Treatment in Emergency Department**

5.1 Rescue Medication administered prior to arrival in ED (either by patient’s care person/family member or paramedic)

For people with treatment refractory epilepsy, the use of buccal midazolam or other rescue treatments can be effective at terminating seizure and help avoid the need for ED care.

National Audit/your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Diazepam (%)	<b>12.3</b> <i>(14.1/13.3)</i>	6.3	<b>7.0</b> <i>(6.4/7.0)</i>	0	<b>5.8</b> <i>(7.6/6.5)</i>	0	<b>9.9</b> <i>(11.7/10.7)</i>	5.9
Midazolam (%)	<b>7.8</b> <i>(4.3/4.2)</i>	15.6	<b>0.9</b> <i>(0.9/0.5)</i>	0	<b>0.7</b> <i>(0.6/0.1)</i>	0	<b>5.1</b> <i>(3.1/2.7)</i>	14.7
Other (clobazam, lorazepam or paraldehyde) (%)	<b>2.2</b> <i>(1.2/1.1)</i>	18.8	<b>1.6</b> <i>(0.2/0.3)</i>	0	<b>1.5</b> <i>(0.3/0.5)</i>	0	<b>1.9</b> <i>(1.0/0.8)</i>	17.7

NB this question refers to rescue medication given either by the patient’s carer or by paramedics attending the patient prior to attending the ED.

**COMMENT:** Little has changed between audits.

## 5.2 Treatment given in Emergency Department

### 5.2.1 Patients that were Unconscious patients upon arrival in ED

	National Audit/ <i>your site</i>							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=565*	n=9	n=74	n=0	n=175	n=1	n=815	n=10
IV Lorazepam (%)	28.8	44.4	21.6	N/A	29.1	0	28.2	40
IV Phenytoin (%)	13.8	11.1	13.5	N/A	12	0	13.4	10
IV Levetiracetam (%)	5	0	4.1	N/A	6.9	0	5.3	0
IV Diazepam (%)	3.5	0	2.7	N/A	4.6	0	3.7	0
IV Thiamine / pabrinex (%)	2.1	0	6.8	N/A	2.3	0	2.6	0
IV Valproate (%)	1.2	0	0	N/A	1.7	0	1.2	0
Buccal Midazolam (%)	1.1	0	1.4	N/A	0	N/A	0.9	0
IV Phenobarbital (%)	0.4	0	0	N/A	0.6	0	0.4	0
Rectal Diazepam (%)	0.9	11.1	0	N/A	0	0	0.6	10
IV Clonazepam (%)	0.2	0	0	N/A	0	0	0.1	0
Lamotrigine (%)	0.2	0	0	N/A	0	0	0.1	0
IV Glucose (%)	0	0	0	N/A	0	0	0.1	0
Patients given more than one treatment in ED (%)	11.7	11.1	12.2	N/A	12.6	0	11.9	10

\* refers to number of unconscious patients that were given treatment

**COMMENT:** There is a lack of consistency in treating on-going seizures and the need for nationally agreed guidance.

## Section 6 - Initial Emergency Department Assessment

- 6.1 Consciousness on arrival in Emergency Department
- 6.2 Vital signs collated in Emergency department
- 6.3 Measures of consciousness used in Emergency department
- 6.4 Patients discharged home from Emergency Department
- 6.5 Hospital admissions from Emergency department
- 6.6 Care during hospital admission
- 6.7 Main reason for hospital admission
- 6.8 Length of stay
- 6.9 Eyewitness account of seizure
- 6.10 Alcohol and Illicit drug use

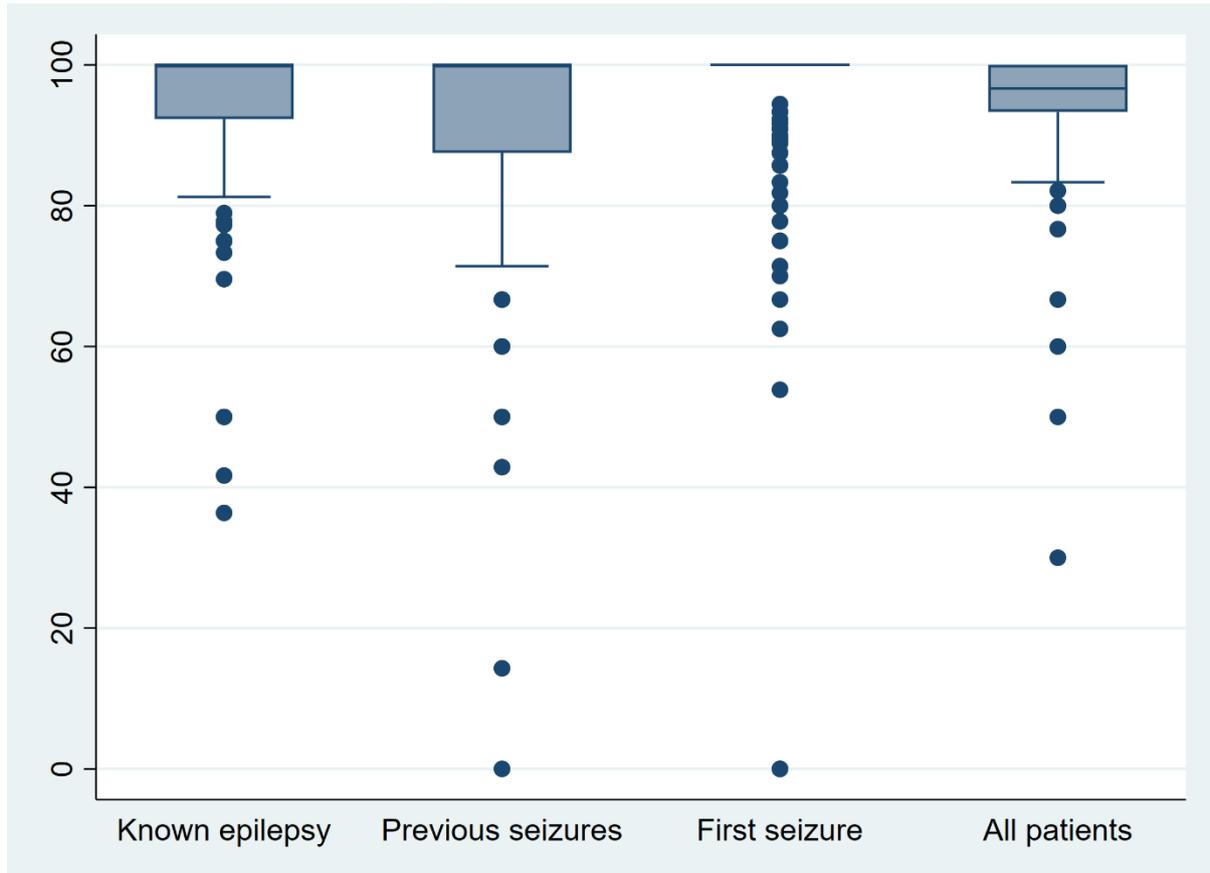
### 6.1 Consciousness on arrival in Emergency Department

National Audit/ <i>your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Conscious (%)	74.5	71.9	86.2	0	78.9	50	77.3	70.6
Not Conscious (%)	22.3	28.1	11.6	0	18.3	50	19.7	29.4
Not Documented (%)	3.0	0	2.2	0	2.8	0	2.8	0

6.2 Vital signs collated in Emergency Department

National Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Pulse was measured (%)	97.0	96.9	96.6	N/A	96.9	100	96.9	97.1
Temperature was measured (%)	94.4	96.9	92.2	0	95.2	100	94.2	97.1
<i>Further responses relate to those patients whose temperature was measured</i>								
	n=2,387	n=31	n=589	n=0	n=910	n=2	n=3,894	n=33
Temperature was measured within 20 minutes (%)	76.4	100	70.8	N/A	74.5	100	75.1	100
Temperature was lower than 35C (%)	0.5	0	0.3	N/A	0.7	0	0.5	0
Temperature between 35C – 37C (%)	93.6	96.8	95.9	N/A	95.9	100	94.4	97.0
Temperature above 37C (%)	5.9	3.2	3.7	N/A	3.4	0	5.0	3.0

Figure 6: Distribution of percentage of patients who had their temperature measured across sites



**COMMENT:** In NASH 2 92.3 % patients had temperature taken (75.2% of these within 20 minutes of arrival), and 97.5% had their pulse measured. It is surprising that any measures of temperature or pulse should be missing – note the figure shown above indicates this is a particular issue for a few sites.

6.3 Measures of consciousness and neurological examination

National Audit/ <i>Your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Glasgow Coma Scale scored? (%)	89.4	71.9	87.0	0	88.2	50	88.7	70.6
AVPU scored? (%)	67.0 (n=267)	77.8 (n=9)	73.5 (n=83)	N/A (n=0)	76.8 (n=112)	100 (n=1)	70.3 (n=465)	80 (n=10)
* Only asked if response to GSC was no								
Any neurological exam including power of the limbs (%)	64.1	46.9	71.5	0	72.9	100	67.3	50

**COMMENT:** A neurological examination is an important part of the patient assessment and can help determine whether the patients has likely serious intracranial pathology and the need for acute brain imaging and admission, yet a neurological examination was only documented for 72.9% of first seizure patients.

#### 6.4 Patients discharged home from Emergency Department

National Audit/ <i>Your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Discharged (%)	<b>46.8</b> <i>(42.7/43.8)</i>	28.1	<b>55.4</b> <i>(49.1/48.4)</i>	0	<b>46.2</b> <i>(37.1/34.6)</i>	50	<b>47.9</b> <i>(42.6/42.5)</i>	29.4
Self-discharged (%)	2.5	3.1	2.0	0	2.4	0	2.4	2.9

**COMMENT:** The decision on whether to admit a patient has significant resource implications. The variability among sites suggests that there is little agreement as to when admission is or is not required – a topic for a future guideline.

#### 6.5 Hospital Admissions from Emergency Department

National Audit/ <i>your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=1,283	n=22	n=272	n=0	n=490	n=1	n=2,052	n=23
Medical Ward (%)	<b>60.2</b>	59.1	62.9	N/A	<b>60.4</b>	100	<b>60.7</b>	60.9
Medical Decision Unit (MDU) (%)	<b>17.1</b>	40.9	16.9	N/A	<b>18</b>	0	<b>17.3</b>	39.1
Emergency Department Observation Ward (EDOW) (%)	<b>6.4</b>	0	5.1	N/A	<b>4.9</b>	0	<b>5.8</b>	0
CDU (%)	<b>5.7</b>	0	4.4	N/A	<b>6.5</b>	0	<b>5.8</b>	0

Intensive Care Unit (ICU) (%)	3.4	0	1.1	N/A	4.7	0	3.4	0
Neurological ward (%)	1.5	0	3.3	N/A	1.2	0	1.7	0
Emergency Medical Unit (EMU) (%)	0.2	0	0	N/A	0	0	0.1	0
AMU (%)	0.1	0	0	N/A	0	0	0	0
'Other' ward (%)	5.5	0	6.3	N/A	4.3	0	5.3	0

NB – in a number of cases the audit responders did not answer this question.

### 6.6 Care during hospital admission

National audit/your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=1,283	n=22	n=272	n=0	n=490	n=1	n=2,052	n=23
General Physician (%)	73.7	77.3	75.0	N/A	70.0	0	73.0	73.9
Remained under care of ED (%)	7.1	0	6.3	N/A	8.2	0	7.2	0
Neurologist (%)	4.1	18.2	4.4	N/A	4.1	100	4.1	21.7
Other Medical Practitioner (%)	15.2	4.5	14.3	N/A	17.6	0	15.6	4.3

\* Excludes patients who were discharged (and self-discharged) directly from the emergency department

COMMENT: In NASH and NASH2 the majority of patients (77.4% and 78.8%) came under the care of a general physician during their admission.

6.7 Primary reasons for admission to hospital

	National audit/your site							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=1,283	n=22	n=272	n=0	n=490	n=1	n=2,052	n=23
Seizure (%)	81.8	100	75	N/A	71	100	78.2	100
Significant medical problem other than seizure (%)	11.2	0	12.5	N/A	16.1	0	12.7	0
Not clear (%)	2.7	0	1.1	N/A	3.7	0	2.7	0
Alcohol consumption (%)	1.0	0	5.9	N/A	4.9	0	2.6	0
Patient Safety (%)	1.6	0	1.8	N/A	1.0	0	1.5	0
Social reasons (%)	0.9	0	2.2	N/A	1.8	0	1.3	0
Mental Health (%)	0.3	0	1.1	N/A	0.6	0	0.5	0
Infection (%)	0.1	0	0	N/A	0	0	0	0

**COMMENT:** The prime reason for admission was suggested to be seizure alone without added problems which makes one wonder why rates of admission should vary so widely.

## 6.8 Length of stay (days)

### 6.8.1 National Audit

	Group 1 - Patients with existing epilepsy diagnosis	Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis	Group 3 - Likely first seizure Patients	All Patients
	n=1,283	n=272	n=490	n=2,052
Mean	3.9	3.2	4.2	3.9
Median	2	2	2	2
Lower Quartile	1	1	1	1
Upper Quartile	3	3	5	4
Maximum	186	48	53	186 <i>NASH2 = 100</i>

### 6.8.2 Your site

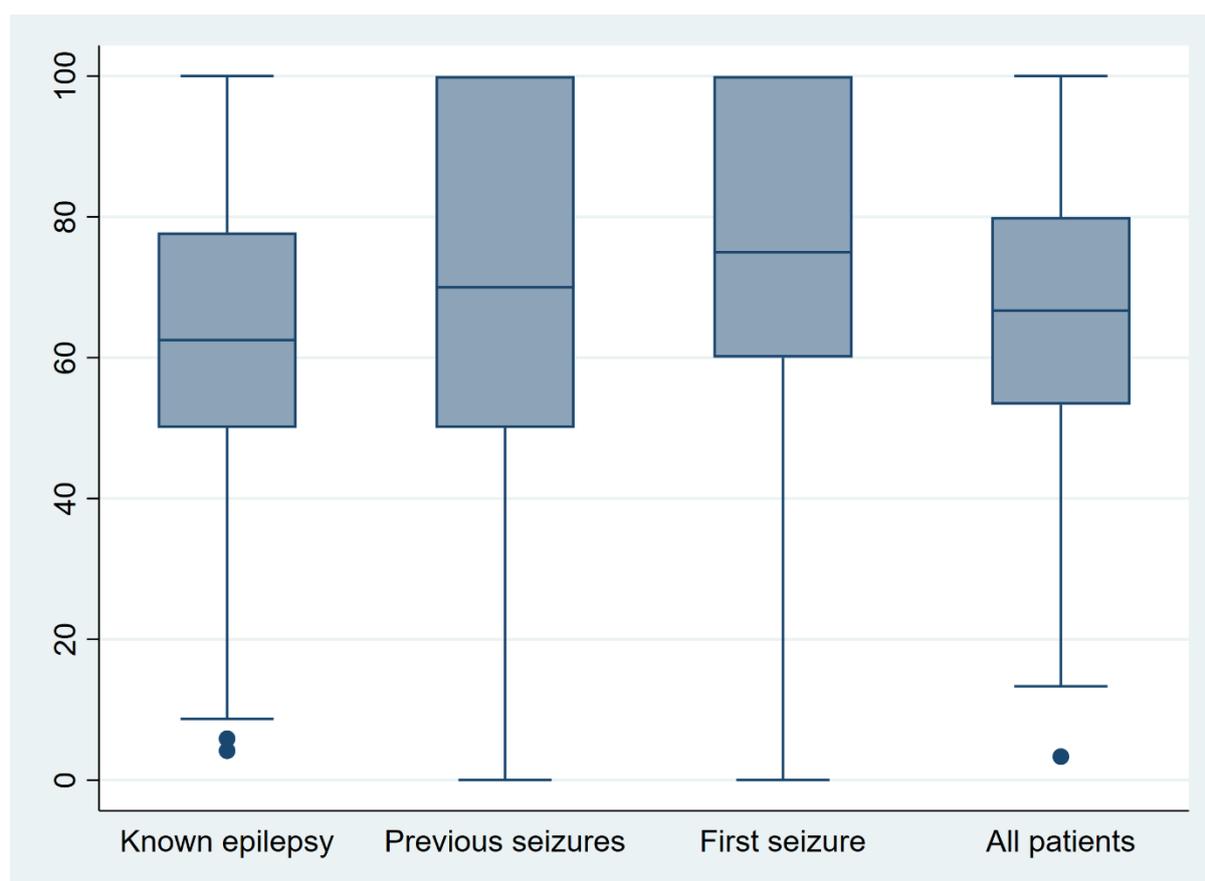
	Group 1 - Patients with existing epilepsy diagnosis	Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis	Group 3 - Likely first seizure patients	All Patients
	n=22	n=0	n=1	n=23
Mean	3.4	N/A	2	3.3
Median	1	N/A	2	1
Lower Quartile	1	N/A	2	1
Upper Quartile	3	N/A	2	3
Maximum	15	N/A	2	15

6.9 Eyewitness accounts of seizure

National Audit/your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 -Likely first seizure patients		All Patients	
	n=2529	n=32	n=639	n=0	n=956	n=2	n=4132	n=34
Good Practice Figure (%)	62.7	90.6	65.0	N/A	70.3	100	64.8	91.2

*\*Good Practice Figure is where eyewitness contacted, sought, or documented as unwitnessed*

Figure 7: Distribution of percentage of patients for whom an eyewitness was contacted, sought or the event was documented as unwitnessed across sites



**COMMENT:** Gaining an eye-witness description is essential to help differentiate seizure from other causes of blackout and should be sought in the majority of cases, and especially for first seizures. An attempt to gain an eye witness or statement that the seizure was not witnessed should be documented

## 6.10 Alcohol and illicit drug use

### 6.10.1 Documentation of alcohol intake

National Audit/ <i>your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Documentation present (%)	31.9	3.1	45.5	0	38.8	0	35.7 <i>42.1/42.4</i>	2.9

### 6.10.2 Classification of alcohol intake

National Audit/ <i>Your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=808	n=1	n=291	n=0	n=371	n=0	n=1,475	n=1
Excessive (> 21 units per week) (%)	17.2	0	23.4	N/A	21.6	N/A	19.5	0
Moderate (14 – 21 units per week) (%)	10.5	0	12.7	N/A	12.4	N/A	11.5	0
Low (< 14 units per week) (%)	31.1	0	33.3	N/A	35.6	N/A	32.7	0
Non-drinker (%)	41.0	100	29.6	0	30.2	0	35.9	100

6.10.3 Change in alcohol consumption in week prior to seizure

National Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
There was a change (%)	3.6	0	7.2	0	6.1	0	4.7	0
<i>For those who recorded a change in consumption:</i>								
	n=91	n=0	n=46	n=0	n=58	n=0	n=195	n=0
Change was an increase in consumption (%)	76.9	N/A	47.8	N/A	55.2	N/A	63.6	N/A

6.10.4 Documentation of illicit drug use

National Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Documentation is present (%)	7.9	3.1	13.0	0	14.3	0	10.1	2.9
<i>For those who documentation is present, Is patient documented as a user of illicit drugs?</i>								
	n=199	n=1	n=83	n=0	n=137	n=0	n=419	n=1
User of illicit drugs (%)	48.7	100	43.4	N/A	51.8	0	48.7	100

**COMMENT:** It is very important to ask about drugs and alcohol. It may be that we are missing Alcohol Withdrawal Seizures. There are patients who may benefit from onward referral to community alcohol services. Even brief intervention advice may help reduce the chance / frequency of further seizures by reducing alcohol intake.

## Section 7 – Investigations

- 7.1 Investigations in Emergency department or during subsequent admission
- 7.2 Deaths during Emergency Department attendance or resulting hospital admission
- 7.3 Post Discharge Investigations

### 7.1 Investigations in Emergency Department or during subsequent admission

National Audit/Your Site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 – Likely first seizure patients		All Patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
Anti-Epilepsy Drug Levels (%)	14.0 <i>22.1/24.3</i>	0	9.1	N/A	0.0 <i>6.1/16.0</i>	N/A	13.7	0
CT scan (%)	30.0 <i>16.5/21.6</i>	18.8	40.1	0	65.5 <i>44.6/54.3</i>	50	39.8	20.6
ECG (%)	74.9	75	82.6	0	86.7	100	78.8	76.5
Blood Glucose (%)	83.0 <i>70.8/81.5</i>	90.6	85.1	0	85.9 <i>74.1/86.5</i>	100	84.0	91.2
MRI (%)	3.6	40.6	6.1	0	7.1	100	4.8	44.1

NB - Percentages for AED levels are expressed for those patients who on attendance were recorded as being on an AED for which it is easy to test the levels, i.e. carbamazepine, phenytoin, phenobarbital, primidone or sodium valproate.

**Comment:** where investigations are undertaken in the emergency department it is important to ensure that systems are in place to follow-up and take action on results. Antiepileptic drug levels are likely to become available after the patient has left the ED and it is usually the neurologist that is best able to interpret and take action on the result.

Figure 8 Variation across sites of investigations performed in ED on Established Epilepsy patients

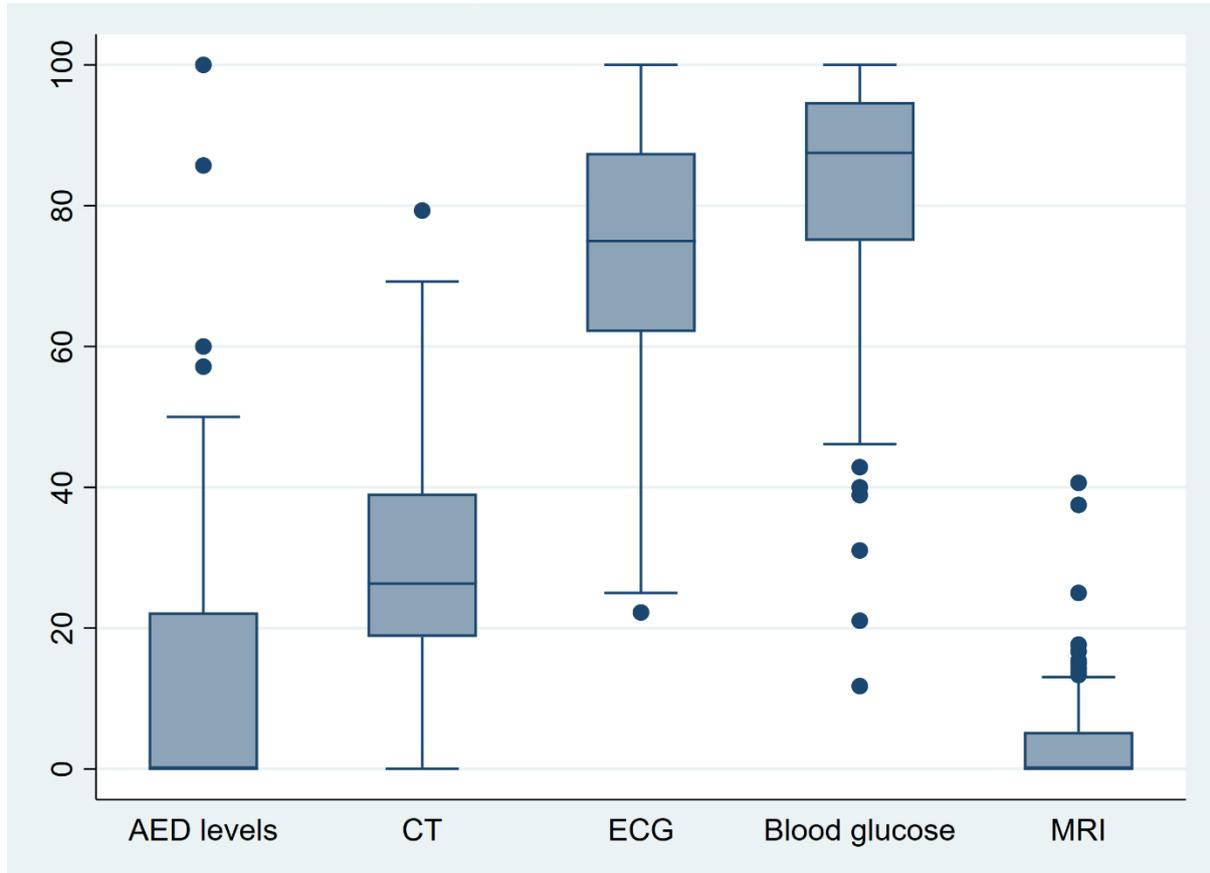
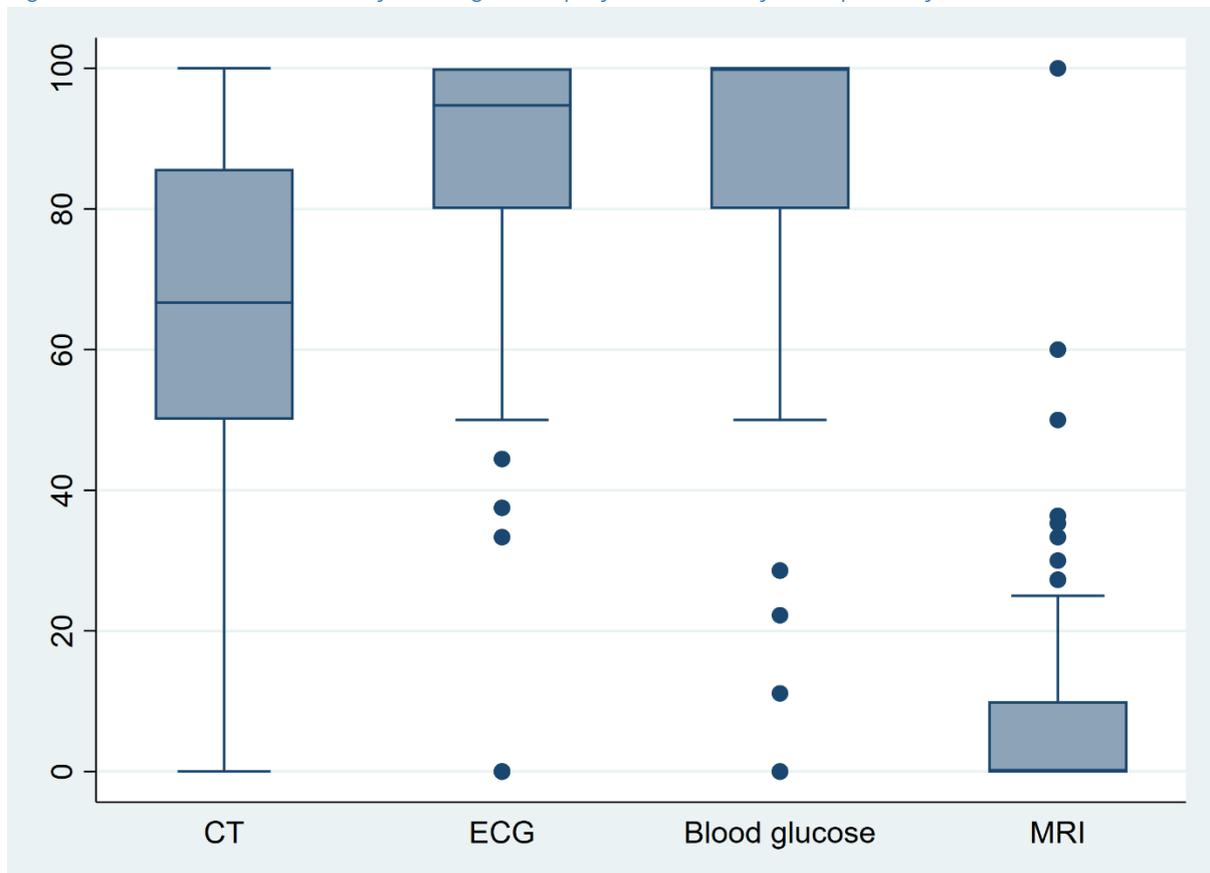


Figure 9 Variation across sites of investigations performed in ED for suspected first seizure cases.



**COMMENT:** Brain CT scans were performed on 30% of patients with known epilepsy, 40.1% of patients with a history of blackouts and 65.5% of those presenting with a first suspected seizure. There has been an increased use of CT scans across the audits (in 2013 only 16.5% of people with known epilepsy were scanned).

This indicates increasing and likely unnecessary CT head imaging. Guidelines should help to get a consensus about the use of neuroimaging in the ED following a first seizure

In 2013 AED levels in those with known epilepsy were measured in 22.1% of cases. In NASH3 this had dropped to 14.0%. In some patients, understanding if they are adhering to their prescription is key to ongoing care.

## 7.2 Deaths during Emergency Department attendance or resulting hospital admission

National Audit n=4,132	
Yes (%)	0.9
No (%)	99.0

National Audit			
	Group 1 - Patients with existing epilepsy diagnosis	Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis	Group 3 - Likely first seizure patients
	n=2,529	n=639	n=956
Died %	0.6 15 deaths	0.5 3 deaths <i>NASH2: 0.4</i>	<b>2.1</b> 20 deaths <i>NASH2: 1.8</i>

**COMMENT:** The median age of the patients who died was 75 (IQR 61-88), 50% of them had at least one of the comorbidities listed in section 3.7.

7.3 Post discharge Investigations (numbers only include those discharged alive)

National Audit/ <i>Your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,512	n=32	n=635	n=0	n=935	n=2	n=4,090	n=34
CT requested as outpatient (%)	1.9	15.6	2.5	0	2.6	50	2.2	17.7
MRI requested as outpatient (%)	2.8	0	13.9	0	16.9	0	7.7	0

Section 8 – Primary Diagnosis on discharge/death

- 8.1 Diagnosis on discharge/death
- 8.2 Patients starting Anti-epileptic drug (AED) treatment upon discharge from Emergency department/hospital
- 8.3 Driving post seizure
- 8.4 future seizure management

8.1 diagnosis on discharge/death

	National Audit/ <i>Your site</i>					
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2
Seizure in someone with established diagnosis of epilepsy (%)	80.3	50	4.4	0	2.5	0
Other (%)	5.9	3.1	7.5	0	13.9	0
Unprovoked seizure with history of seizures, but no current epilepsy diagnosis (%)	4.2	25	50.1	0	4.5	0
Psychogenic non-epileptic attack (%)	2.7	0	7.7	0	2.5	0
Provoked seizure – alcohol induced (%)	2.3	0	7.0	0	6.5	0
First unprovoked Seizure (%)	0.9	3.1	10.3	0	53.5	100
Provoked Seizure - drug use (%)	0.7	0	0.9	0	2.6	0
Blackout with seizure markers (%)	0.6	0	7.4	0	6.0	0
Self-discharged (prior to diagnosis being made) (%)	0.6	0	0.9	0	0.8	0
Provoked Seizure – acute stroke (%)	0.3	0	0.5	0	1.8	0
Provoked seizure – head injury (%)	0.2	0	0.6	0	0.9	0
Syncope/faint (%)	0.1	0	1.1	0	2.5	0
Not recorded (%)	1.0	18.8	1.6	0	2.0	0

NB a number of patients may have had their epilepsy diagnosis altered between their initial attendance at ED and patient discharge/death.

## 8.2 Patients starting Anti-epileptic drug (AED) treatment upon discharge from Emergency Department/hospital

### 8.2.1 AED's on discharge – only for those NOT taking an AED upon arrival

	National Audit/ <i>Your site</i>							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=510	n=5	n=508	n=5	n=815	n=2	n=1,835	n=7
No AED on discharge (%)	85.7	80	76.6	N/A	82.8	50	81.9	71.4
Monotherapy on discharge (%)	12.8	20	23.0	N/A	16.3	50	17.2	28.6
Polytherapy on discharge (%)	1.6	0	0.4	N/A	0.9	0	0.9	0

**COMMENT:** The majority of patients are not started on treatment during their ED attendance or admission, which is as expected as care should continue in out-patient services, which again highlights the importance of ensuring that a specialist referral is made.

### 8.3 Driving advice post seizure

	National Audit/ <i>Your site</i>							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,251	n=32	n=653	n=0	n=935	n=2	n=4,090	n=34
Percent of patients asked if they are a driver	11.5 <i>12.0/11.6</i>	9.4	26	0	29.2 <i>26.2/34.8</i>	100	17.8 <i>16.2/19.6</i>	14.7
% of patients given advice about driving	10.9	10.5	35.3	N/A	42.8	100	22.9	19.0

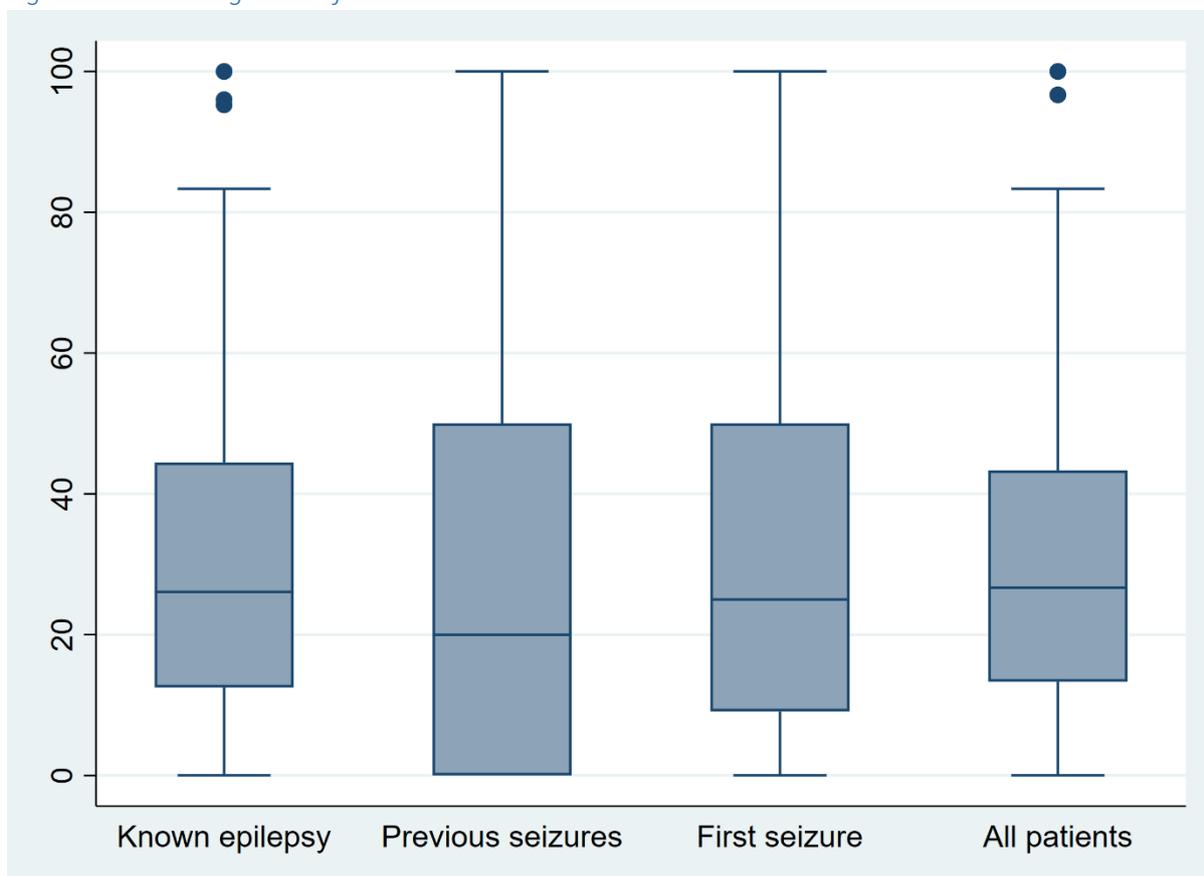
NB percent of patients given advice about driving excludes patients aged 16 years old and those were marked as 'N/A patient does not drive'.

**COMMENT:** It is important that patients are given advice about driving according to DVLA guidance, yet less than a third of first seizure patients were asked if they were drivers and less than half were given advice about driving.

#### 8.4 Management of future seizures

National Audit/ <i>Your site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,512	n=32	n=635	n=0	n=935	n=2	n=4,090	n=34
Patients given advice about future seizures (%)	<b>30.7</b> <i>29.4/28.0</i>	34.4	<b>31.3</b> <i>26.7/26.8</i>	0	<b>32.9</b> <i>26.8/26.7</i>	100	<b>31.3</b> <i>28.5/27.5</i>	38.2

Figure 10 – Advice given on future seizures



**COMMENT:** Advice about future seizures was given in only 31.3% of cases. Giving a leaflet about what to do if there is a subsequent seizure is best practice as this can be shared with family members and potentially lead to more appropriate actions and reduced risk of harm.

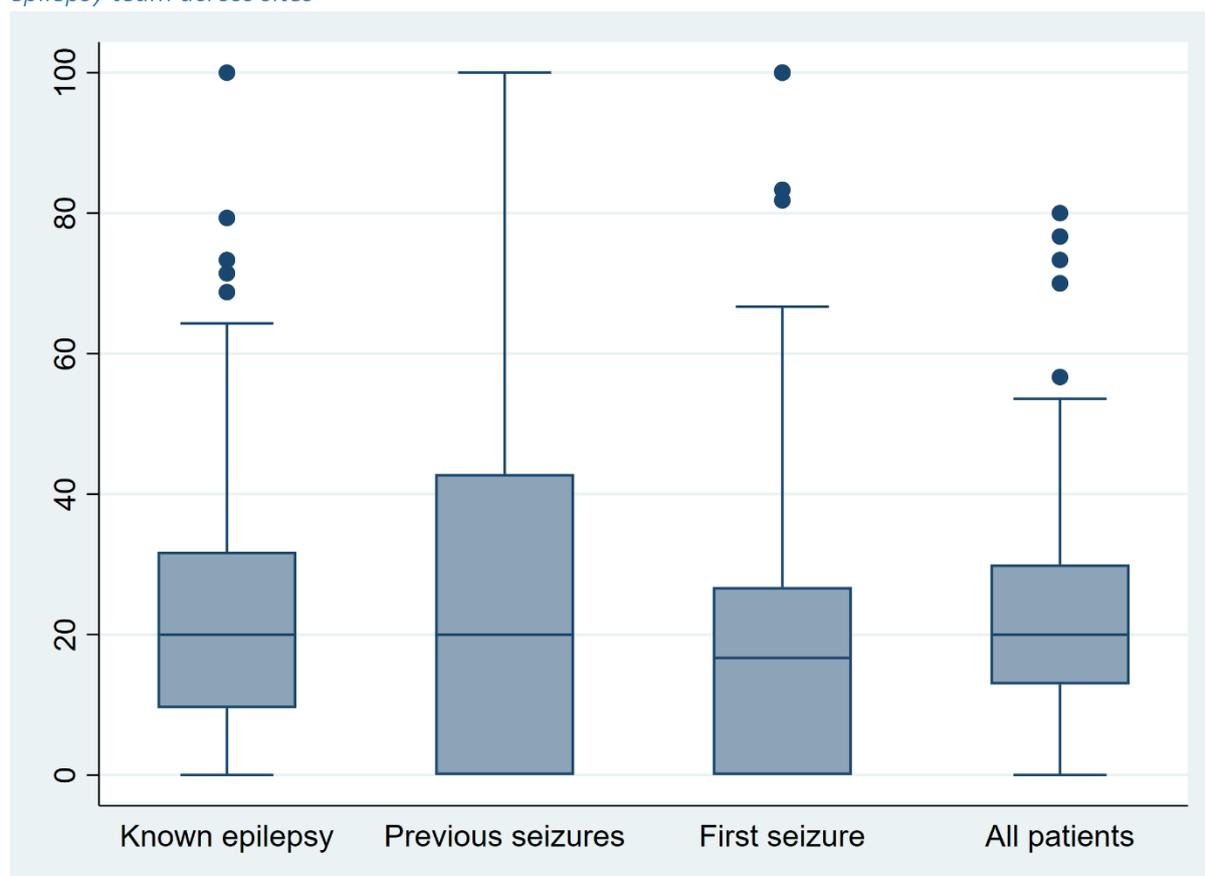
Section 9 – Neurology/epilepsy team assessment

- 9.1 Advice was sought from, or an assessment was made by, the neurology/epilepsy team during attendance or subsequent admission
- 9.2 Onward referral made as part of ED attendance/admission
- 9.3 Who was onward referral due to take place with?
- 9.4 Where was onward referral due to take place?
- 9.5 Length of time (days) between ED presentation and appointment date
- 9.6 Referrals requested by hospital or by GP
- 9.7 Was a GP letter sent?
- 9.8 Referral combined with neurology team input

9.1 Advice was sought from, or an assessment was made by, the neurology/epilepsy team during attendance or subsequent admission

National Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,529	n=25	n=639	n=3	n=956	n=2	n=4,132	n=30
Advice sought or assessment made (%)	23.4	20	25.2	0	20.1	50	22.9 <i>17.2/20.0</i>	20

Figure 11: Distribution of percentage of patients for whom advice was sought from neurologist or epilepsy team across sites



**COMMENT:** Access to advice from neurology or epilepsy services can be vital to inform future management, yet we identified significant variability in access to that advice, which likely represents variability in service provision and coordination.

### 9.2 Onward referral made as part of ED attendance/admission

	National Audit/Your site							
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,512	n=32	n=635	n=0	n=935	n=2	n=4,090	n=34
An onward referral was made as part of the ED attendance / admission event(%)	26.3 35.4/36.2	28.1	49.6 40.5/51.2	0	55.8 42.0/48.4	50	36.7 37.3/41.4	29.4

**COMMENT:** Referral rates from ED for those with known epilepsy has dropped from the first two audits, whilst there has been a steady increase for those with suspected first seizures to the extent that over half of this patient group are being directly referred as a result of this index admission. Whilst this is encouraging, it is still some way off the ideal scenario as recommended by the NICE guidelines which is for all suspected first seizure patients to be referred on for a specialist appointment.

The long standing low referral rate is likely due to a lack of understanding of benefits of alerting neurology services that patients under neurology care have attended the ED

### 9.3 Who was onward referral due to take place with?

National Audit/Your Site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=657	n=9	n=315	n=0	n=522	n=1	n=1,496	n=10
Neurologist (%)	64.2	88.9	42.5	0	24.7	0	45.9	80
Epilepsy Service or First Fit Clinic (%)	17.2	0	50.2	0	68.8	100	42.2	10
Epilepsy Specialist Nurse (%)	15.5	11.1	3.2	0	0.8	0	7.7	10
Neurosurgeon (%)	1.5	0	1.9	0	4.2	0	2.5	0
Alcohol/Drug Liaison service (%)	0.9	0	1.0	0	1.5	0	1.1	0
Intellectual Disability Psychiatrist (%)	0.5	0	0.3	0	0.0	0	0.3	0
Paediatrician (%)	0.2	0	0.3	0	0.0	0	0.1	0
Paediatric Neurologist (%)	0.0	0	0.6	0	0.0	0	0.1	0



9.4 Where was onward referral due to take place?

National Audit/Your site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=657	n=9	n=315	n=0	n=522	n=1	n=1,496	n=10
This hospital (%)	68.7	22.2	72.7	N/A	76.8	0	72.3	20
Other Hospital(%)	26.8	77.8	23.8	N/A	18.8	100	23.4	80
Not documented (%)	4.6	0	3.5	N/A	4.4	0	4.3	0

9.5 Length of time (days) between ED presentation and appointment date

National Audit/Your Site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=657	n=9	n=315	n=0	n=522	n=1	n=1,496	n=10
Mean	83.9	160.7	87.2	N/A	75.8	N/A	81.7	160.7
Median	48.5	95	46.0	N/A	39.0	N/A	45.0	95
Min.	0	15	0	N/A	0	N/A	0	15
Max.	458	372	569	N/A	486	N/A	569	372
IQ1	20	15	20	N/A	18	N/A	19	15
IQ3	102	372	115	N/A	91.5	N/A	100	372

NB if none of the appointments recorded for your site had a valid appointments date then the values in the table above will be represented by a N/A entry

**COMMENT:** Of the 1,496 onward referrals, 1,056 (70.6%) had a valid appointment date recorded. 40 (2.7%) had an appointment date that was invalid (i.e. prior to their attendance at ED), and 400 (26.7%) had a missing or unknown date, highlighting that when ED and

neurology services are on different sites or in different Trusts, it can be a challenge for ED departments to know whether an appointment has been made and attended.

NICE guidance recommends that all patients presenting with their first suspected seizure should be referred on to a specialist appointment which should take place within 2 weeks. The median wait time for this group is around 5 ½ weeks, and no doubt reflects issues with capacity.

The attendance rate at the appointments were 52.7% for those with known epilepsy, 60% for those with previous seizure or blackouts, and 59.8% for those with suspected first seizure.

### 9.6 Referrals requested by hospital or by GP

Feedback from NASH1 indicated that some hospitals were unable to make consultant-consultant referrals, but needed to go via their local GPs. Therefore, as we did for NASH2, we added a question asking if a letter was sent to the GP (87.0% of all cases - see below) and if that letter advised the GP to refer on (18.9% of letters). We have no data to know if the GP responded but even if that is considered an alternative to direct referral, and allowing for double counting, then the total referral rates are as in the table below.

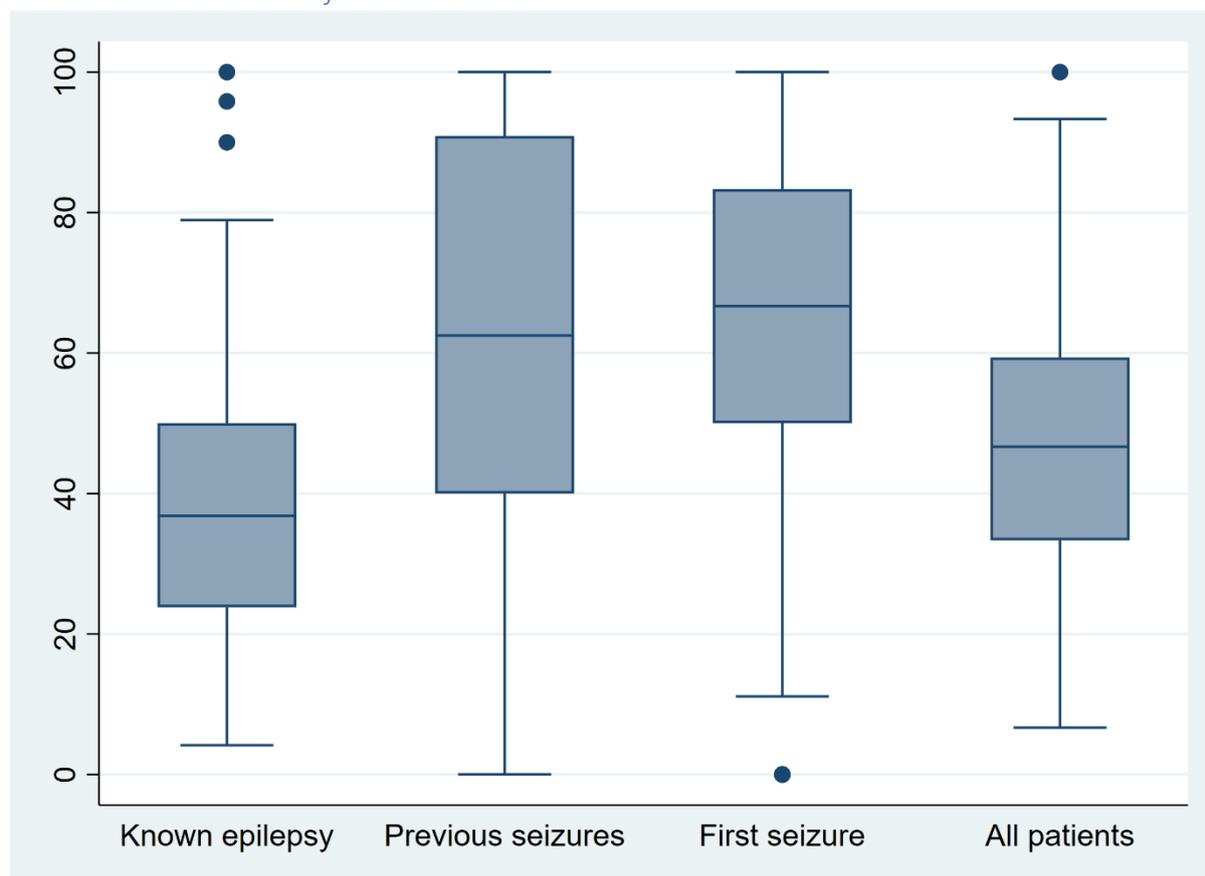
National Audit/ <i>Your Site</i>								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure patients		All Patients	
	n=2,512	n=25	n=635	n=3	n=935	n=2	n=4,090	n=30
Referred (%)	39.1 NA/43.6	48	60.2 NA/59.0	100	63.6 NA/54.9	100	47.9 NA/48.7	56.7

**COMMENT:** Using this more generous interpretation of whether a referral was made, does increase the referral rate across all three groups. For both the known epilepsy patients and the patient with previous seizures/blackouts, this “combined” referral rate is roughly in line with that found in NASH2. For the first seizure patients it is encouraging that the referral rate has risen. However, it is important to note that there are still around one third of patients who have presented with their first suspected seizure who are not being referred for a specialist opinion.

Neurology and epilepsy specialists are not commonly part of the emergency or acute medical team in the UK and access to their expertise will require a referral to their service. NASH3, as with our previous audits, has identified significant variability in referral rates (see figure 12 below). This is of particular concern for patients with first seizures who need

urgent assessment, and for patients with known epilepsy for whom there may be treatment options to improve seizure control and strategies to better manage acute seizures to avoid ED attendance.

Figure 12: Distribution of percentage of patients for whom a referral was made by the hospital or the GP was asked to make a referral across sites



### 9.7 Was a GP letter sent?

National Audit/Your Site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis Group 3 – likely first seizure Patients		Group 3 - Likely first seizure patients		All patients	
	n=2,529	n=32	n=639	n=0	n=956	n=2	n=4,132	n=34
GP letter was sent (%)	86.8	84.4	88.4	0	86.6	100	87.0	85.3

### 9.8 Referral combined with neurology team input

It is also of interest to look at how many patients had at least an assessment sought or made by the neurology/epilepsy team during attendance or subsequent admission, or a referral (made either directly by the hospital or there was a request to the GP to arrange the referral). This gives the following figures.

National Audit/Your Site								
	Group 1 - Patients with existing epilepsy diagnosis		Group 2 - Patients with history of seizures and/or blackouts. No current epilepsy diagnosis		Group 3 - Likely first seizure Patients		All Patients	
	n=2,512	n=32	n=635	n=0	n=935	n=2	n=4,090	n=34
Combined (%)	47.9	56.3	65.2	N/A	69.5	100	55.6	58.8

**COMMENT:** This provides a further small increase to the number of patients receiving specialist epilepsy advice. In fact, patients who were assessed by the neurology team, were more likely to be referred for an appointment than those who did not. There is no material difference to the variability between sites as evidenced in figure 12 above.

There are three key messages to take from the findings of this section:

- Around one third of patients presenting with their first suspected seizure are not receiving a referral, or having any input from a neurologist, during their emergency episode.
- Just under one quarter of sites are not referring, or involving a neurologist in the care of, half of first seizure emergency episodes.
- Where referrals do take place for this group of patients, the median time to the appointment is over 5 weeks, despite NICE guidance stating it should take place within 2 weeks.



## Section 10 – Social Deprivation and Health Inequalities

It is well known that different social groups can have different experiences of health services; this is termed ‘health inequalities’. Indeed, in the previous NASH audits we found that older people were, in general, less likely to be referred to a neurologist than people in younger age groups.

This section is different to preceding section of the report, as instead of simply presenting descriptive statistics, multi-level mixed effects logistic regression models have been run to look at the effects of the characteristics of each presentation on previous ED attendance and onward referral.

We have used the patient’s postcode of residence to derive the level of deprivation experienced by people living in an area. As the devolved nations of the UK use different, non-comparable, measures of deprivation we have restricted the analysis to presentations at English hospitals. Deprivation is measured using the latest Index of Multiple Deprivation (IMD 2019) which is the official measure of relative deprivation in England (<https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>). English sites represent 3,899 attendances/admissions, or 94.3% of the total NASH3 data. Of these, there are 3,595 (92.2%) with a valid postcode that allows a deprivation score to be given.

We have classified the presentations as coming from one of five deprivation quintiles. A summary of the characteristics of those quintiles is shown below:

IMD quintile	Number of entries	Mean age	% male
<b>1 – most deprived</b>	1,057	42.4	53.8%
<b>2</b>	827	44.9	50.1%
<b>3</b>	639	46.8	54.4%
<b>4</b>	617	49.5	54.2%
<b>5 – least deprived</b>	455	49.9	51.9%

The tables report odds ratios, where a number above 1 shows an increase in odds, and a number below one shows a decrease in odds. For IMD, the reference category is the most deprived quintile, i.e. the odds reported are relative to that group. For age, the reference group is the youngest age group. For gender, odds above 1 indicate an increase for female patients.

Figures in red indicate where there are statistically significant findings. Narrative text is provided after each table to give context.

10.1 Patients who had attended this Emergency Department as a result of a seizure in the previous 12 months

Variable	Group 1 - Existing epilepsy diagnosis n=2,212		Group 2 - History of seizures and/or blackouts n=557		Group 3 - Likely first seizure n=802		All patients n=3,556	
	OR	p-value	OR	p-value	OR	p-value	OR	p-value
<b>IMD quintile</b>								
<b>1 – most deprived</b>	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
<b>2</b>	0.78	0.054	0.74	0.241	0.62	0.341	0.78	0.014
<b>3</b>	1.02	0.868	0.76	0.314	1.03	0.958	0.91	0.395
<b>4</b>	0.74	0.038	0.38	0.001	0.86	0.773	0.67	<0.001
<b>5 – least deprived</b>	0.68	0.022	0.48	0.016	0.78	0.647	0.61	<0.001
<b>Sex</b>	1.01	0.873	1.22	0.264	1.35	0.363	1.10	0.169
<b>Age category</b>								
<b>1 (&lt;30)</b>	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
<b>2(31-44)</b>	1.13	0.324	0.91	0.711	1.30	0.607	1.23	0.041
<b>3(45-60)</b>	1.16	0.233	0.64	0.083	1.50	0.376	1.12	0.256
<b>4(61+)</b>	0.85	0.227	0.96	0.875	0.60	0.282	0.75	0.004

**COMMENT:** For each of the groups, gender was not related to prior ED visits, and there is not a consistent picture regarding age. However, the patients who come from deprived areas are more likely to have visited the ED in the previous 12 months. This is consistent with a lot of research which indicates that high levels of ED use are associated with deprivation.

10.2 A referral for an appointment was requested by the hospital

Variable	Group 1 - Existing epilepsy diagnosis n=2,195		Group 2 - History of seizures and/or blackouts n=553		Group 3 - Likely first seizure n=802		All patients n=3,556	
	OR	p-value	OR	p-value	OR	p-value	OR	p-value
<b>IMD quintile</b>								
<b>1 – most deprived</b>	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
<b>2</b>	0.93	0.640	0.79	0.412	0.63	0.075	0.84	0.133
<b>3</b>	1.02	0.894	0.72	0.295	0.97	0.896	1.04	0.760
<b>4</b>	1.12	0.539	1.30	0.400	0.64	0.106	1.08	0.544
<b>5 – least deprived</b>	1.48	0.058	0.96	0.907	<b>1.80</b>	<b>0.044</b>	<b>1.58</b>	<b>0.001</b>
<b>Sex</b>	0.95	0.665	0.86	0.470	1.01	0.943	0.97	0.678
<b>Age category</b>								
<b>1 (&lt;30)</b>	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
<b>2(31-44)</b>	1.06	0.727	0.58	0.052	1.04	0.891	0.83	0.091
<b>3(45-60)</b>	0.83	0.247	<b>0.42</b>	<b>0.003</b>	<b>0.54</b>	<b>0.015</b>	<b>0.60</b>	<b>&lt;0.001</b>
<b>4(61+)</b>	<b>0.61</b>	<b>0.005</b>	<b>0.36</b>	<b>&lt;0.001</b>	<b>0.29</b>	<b>&lt;0.001</b>	<b>0.46</b>	<b>&lt;0.001</b>
<b>ED past year</b>	0.84	0.143	<b>0.61</b>	<b>0.023</b>	<b>0.46</b>	<b>0.042</b>	<b>0.54</b>	<b>&lt;0.001</b>
<b>Specialist past yr.</b>	<b>1.43</b>	<b>0.004</b>	0.78	0.306	0.63	0.132	<b>0.78</b>	<b>0.007</b>
<b>Admitted</b>	<b>1.56</b>	<b>0.001</b>	1.02	0.928	<b>0.34</b>	<b>&lt;0.001</b>	0.91	0.287
<b>Neuro advice</b>	<b>5.54</b>	<b>&lt;0.001</b>	<b>6.25</b>	<b>&lt;0.001</b>	<b>2.76</b>	<b>&lt;0.001</b>	<b>4.92</b>	<b>&lt;0.001</b>

There is no consistent picture of patients living in the more deprived areas being less likely to be referred on to a specialist.

There is no evidence of any gender differences.

Patients who have had a seizure-related ED attendance in the previous year are, in general, less likely to have a referral made.

For known epilepsy patients if they have seen a specialist in the preceding 12 months the likelihood of them having a referral made is increased. This has also been seen in analysis of Hospital Episode Statistics (HES) data (Grainger R, Pearson M, Dixon P, et al. Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data. *BMJOpen* 2016; 6:e010100.doi:10.1136 / bmjopen-2015-010100), and is suggesting that the patients who are already known to the system are more likely to be referred. This relationship is reversed for the suspected new seizure patients, although most of those would not have been expected to have seen a specialist previously, so this could be explained by a misclassification of the patients.

Known epilepsy who were admitted are more likely to be referred than those who were not – which is to be expected. However, this direction is reversed for the suspected first seizure patients – what could be the explanation for this?

The biggest changes are seen for patients where some sort of neurology advice had been received during their admission. Such patients are much more likely to have a referral made.

Age effects are apparent across the patient groups. This reinforces the message seen in previous NASH audits, i.e. older patients are much less likely to be referred on to neurology specialists than younger patients. It may be the case that they are being referred to other services, e.g. care of the elderly. However, case note review (unpublished) from one region of the country suggests this is not the case, and it remains the case that the neurology service is best place to provide advice and management on seizures.

## Appendices

### Appendix 1 – data collection and statistical analyses

#### Organisation and monitoring

The audit was coordinated from the University of Liverpool, with data collected by members of the team at each site. The study was overseen by a Study Steering Committee consisting of neurologists, Emergency Consultants, Epilepsy Nurses, representatives from patient charities and Statisticians.

#### Recruitment of sites

The audit was registered with HQIP and entered on the 2019/2020 quality accounts list. Hospitals with Type 1 Emergency Departments were identified by the Study Coordinator. Letters were written to the Chief Executive and Medical Director of each of these hospitals inviting them to participate in the audit round. Previous participants in NASH1 and NASH2 (who had requested they be contacted in the event of further audits) were notified of NASH3. Additionally, the Study Coordinator was also able to identify some audit departments via the hospital website and made contact directly.

The ABN and the RCEP very kindly advertised the study in their newsletters, allowing interested parties in both neurology departments and Emergency departments to contact the Study Coordinator and request to participate.

#### Development of the audit tool questions

The questions used in the audit were mostly the same as those in NASH and NASH2. Feedback from the steering group led to the refinement of some questions and some additional questions.

#### Development of the software

Data were collected using a bespoke web audit system written in C#.Net, and JQuery by a developer at the Clinical Trials Research Centre at the University of Liverpool, with the data being stored in a mysql database.

The web system provided access to audit form (one per subject) to capture the clinical care pathway for individual patients.

All sites entered their data over the internet using a web browser of their choice. The system was hosted on servers run by the Clinical Trials Research Centre at the University of Liverpool. Each site and patient were allocated unique identifiers within the system. No identifiable information were recorded in the system. In order to ensure confidentiality a 2-factor verification was developed for logging in to the system. Online help was available for the majority of questions.

### Data collection

Sites were able to choose the most appropriate personnel to complete the audit locally. A variety of different grades of staff completed the audit including consultants, clinical trainees, nurses and medical students.

The clinical data entry took place between March 2019 and December 2019. Anonymised data were requested for the first 30 consecutive patients that:

- a) presented on or over their 18th birthday; and
- b) presented at the Emergency Department with an episode thought to have been a seizure and seizure was the primary reason for their admission / attendance

It was requested that only presentations that were admitted between 1st June 2018 and 30<sup>th</sup> June 2019 were entered to the database. This allowed enough time for these patients to have progressed through the onward care pathway (e.g. referral and attendance at outpatient neurology clinics) for which we wished to collect data and allowed for time period consistency between the sites who opened to data entry at different times.

### Data collation and analysis

A number of consistency checks built into the electronic software helped to reduce typographical errors in data inputting and improve the quality of the data. Frequent data checks were made at the study office and an email highlighting missing data and/or data queries were sent to the participating staff at each centre. Once all data was collected from each site and all queries were resolved, each site was sent a copy of their own data files.

## Appendix 2 – participating sites

	Trust	Hospital
1	NHS Grampian	Aberdeen Royal Infirmary
2	Aintree University Hospital NHS Trust	Aintree University Hospital
3	Worcester Acute Hospitals NHS Trust	Alexandra Hospital
4	Northern Health and Social Care Trust	Antrim Area Hospital
5	Wirral University teaching hospital NHS Foundation Trust	Arrowe Park Hospital
6	Barnsley Hospital NHS Foundation Trust	Barnsley Hospital
7	Basildon and Thurrock NHS Trust	Basildon University Hospital
8	Sandwell and West Birmingham Hospitals NHS Foundation Trust	Birmingham City Hospital
9	University Hospitals Birmingham NHS Foundation Trust	Heartlands Hospital
10	Blackpool Teaching Hospitals NHS Foundation Trust	Blackpool Victoria Hospital
11	Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal Infirmary
12	University Hospitals Bristol NHS Foundation Trust	Bristol Royal Infirmary
13	Calderdale and Huddersfield NHS Foundation Trust	Calderdale Royal Hospital
14	North Cumbria Integrated Care NHS Foundation Trust	West Cumberland Hospital

15	Chelsea and Westminster Hospitals NHS Foundation Trust	Chelsea and Westminster Hospital
16	Gloucestershire Hospitals NHS Foundation Trust	Cheltenham General Hospital
17	Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital
18	Lancashire Teaching Hospitals NHS Foundation Trust	Chorley and South Ribble Hospital
19	East Suffolk and North Essex NHS Foundation Trust	Colchester Hospital
20	East Sussex Healthcare NHS Trust	Conquest Hospital
21	Countess of Chester Hospital NHS Foundation Trust	Countess of Chester Hospital
22	University hospitals Coventry and Warwickshire NHS Trust	University Hospital, Coventry
23	Croydon Health Services NHS Trust	Croydon University Hospital
24	North Cumbria Integrated Care NHS Foundation Trust	Cumberland Infirmary
25	Dartford and Gravesham NHS Trust	Darent Valley Hospital
26	County Durham and Darlington NHS Foundation Trust	Darlington Memorial Hospital
27	University Hospitals Plymouth NHS Trust	Derriford Hospital
28	Northern Lincolnshire and Goole NHS Foundation Trust	Diana Princess of Wales Hospital
29	Doncaster and Bassetlaw NHS Trust	Doncaster Royal Infirmary

30	London North West University Healthcare NHS Trust	Ealing Hospital
31	East Sussex Healthcare NHS Trust	Eastbourne Hospital
32	Pennine Acute Hospital NHS Trust	Fairfield General Hospital
33	south tees hospitals NHS Foundation Trust	Friarage Hospital
34	Frimley Health NHS Foundation Trust	Frimley Park Hospital
35	University Hospitals of Morecambe Bay NHS Foundation Trust	Furness General Hospital
36	George Eliot Hospital NHS Trust	George Eliot Hospital
37	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital
38	University Hospitals Birmingham NHS Foundation Trust	Good Hope Hospital
39	Great Western Hospitals NHS Foundation Trust	Great Western Hospital
40	The Hillingdon Hospitals NHS Foundation Trust	Hillingdon Hospital
41	North west Anglia Foundation Trust	Hinchingbrooke Hospital
42	Homerton University Hospitals NHS Foundation Trust	Homerton University Hospital
43	Calderdale and Huddersfield NHS Foundation Trust	Huddersfield Royal Infirmary
44	Hull University Teaching Hospitals NHS Trust	Hull Royal Infirmary
45	East Suffolk and North Essex NHS Foundation Trust	Ipswich Hospital

46	South Tees Hospitals NHS Foundation Trust	James Cook University Hospital
47	James Paget University Hospitals NHS Foundation Trust	James Paget Hospital
48	KGH Foundation Trust	Kettering General Hospital
49	Sherwood Forest Hospitals Trust	King's Mill Hospital
50	Kingston Hospital NHS Foundation Trust	Kingston General Hospital
51	University hospitals of leicester NHS Trust	Leicester Royal Infirmary
52	East and North Hertfordshire NHS Trust	Lister Hospital
53	Luton and Dunstable University Hospital	Luton and Dunstable Hospital
54	East Cheshire NHS Trust	Macclesfield District General Hospital
55	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
56	Manchester University NHS Foundation Trust	Manchester Royal Infirmary
57	Walsall Healthcare NHS Trust	Walsall Manor Hospital
58	Milton Keynes University Hospital NHS Foundation Trust	Milton Keynes University Hospital

59	Abertawe Bro Morgannwg University Health Board	Morrison Hospital
60	Taunton and Somerset NHS Foundation Trust	Musgrove Park Hospital
61	Barts Health NHS Trust	Newham University Hospital
62	Norfolk and Norwich University Hospitals NHS Trust	Norfolk and Norwich University Hospital
63	Northern Devon Healthcare NHS Trust	North Devon District Hospital
64	Pennine acute hospitals NHS Trust	North Manchester General Hospital
65	Northampton General Hospital NHS Trust	Northampton General Hospital
66	London North West University Healthcare NHS Trust	Northwick Park Hospital
67	North West Anglia Foundation Trust	Peterborough City Hospital
68	United Lincolnshire Hospitals NHS Trust	Pilgrim Hospital
69	Mid Yorkshire Hospitals NHS Trust	Pinderfields Hospital
70	Poole Hospital NHS Foundation Trust	Poole General Hospital
71	Princess Alexandra Hospital NHS Trust	Princess Alexandra Hospital
72	Shrewsbury and telfrd Hospitals NHS Trust	Princess Royal Hospital
73	Kings college Hospital NHS Foundation Trust	Princess Royal Hospital (KCH)
74	Portsmouth Hospitals NHS Foundation Trust	Queen Alexandra Hospital

75	The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Queen Elizabeth Hospital Kings Lynn
76	Lewisham and Greenwich NHS Trust	Queen Elizabeth Hospital L&G
77	East Kent Hospitals University NHS Foundation Trust	Queen Elizabeth the Queen Mother Hospital
78	Burton Hospitals NHS Foundation Trusts	Queen's Hospital Burton
79	Barking, Havering and Redbridge University hospitals	Queen's Hospital Romford
80	Wrightington Wigan and Leigh NHS Foundation Trust	Royal Albert Edward Infirmary
81	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
82	East Lancashire Hospitals NHS Trust	Royal Blackburn Teaching Hospital
83	Bolton NHS Foundation Trust	Royal Bolton Hospital
84	University Hospitals of Derby and Burton NHS Foundation Trust	Royal Derby Hospital
85	Royal Devon and Exeter NHS Foundation Trust	Royal Devon and Exeter (Wonford) Hospital
86	Royal Free Hospital NHS Foundation Trust	Royal Free London
87	Anerin Bevan University Health board	Royal Gwent Hospital
88	University Hospitals of Morecambe Bay	Royal Lancaster Infirmary
89	Barts Health NHS Trust	Royal London Hospital

90	Pennine acute hospitals NHS Trust	Royal Oldham Hospital
91	Lancashire Teaching Hospitals NHS Foundation Trust	Royal Preston Hospital
92	Shrewsbury and Telford Hospitals NHS Trust	Royal Shrewsbury Hospital
93	Royal Surrey County Hospital NHS FT	Royal Surrey County Hospital
94	Brighton and Sussex NHS Trust	Royal Sussex County Hospital
95	Royal United Hospitals Bath NHS Foundation Trust	Royal United Hospital Bath
96	Belfast Health and Social Care Trust	Royal Victoria Hospital
97	Newcastle upon Tyne Hospitals NHS Foundation Trust	Royal Victoria Infirmary
98	Royal Wolverhampton NHS Trust	Royal Wolverhampton Hospital
99	Dudley group NHS Foundation Trust	Russells Hall Hospital
100	Salford Royal NHS Foundation Trust	Salford Royal Hospital
101	Salisbury NHS Foundation Trust	Salisbury district Hospital
102	Sandwell and West Birmingham Hospitals NHS Foundation Trust	Sandwell Hospital
103	York Teaching Hospital NHS Foundation Trust	Scarborough General Hospital
104	Northern Lincolnshire and Goole NHS Foundation Trust	Scunthorpe General Hospital
105	University Hospitals Birmingham NHS Foundation Trust	Solihull Hospital

106	South Tyneside and Sunderland NHS Foundation Trust	South Tyneside Hospital
107	University Hospital Southampton NHS Foundation Trust	Southampton General Hospital
108	Southend University NHS Foundation Trust	Southend University Hospital
109	North Bristol NHS Trust	Southmead Hospital
110	Southport and Ormskirk hospital NHS Trust	Southport Hospital
111	St George's University Hospital NHS Foundation Trust	St George's Hospital
112	Imperial College Healthcare NHS Trust	St Mary's Hospital
113	Ashford and St Peter's Hospitals NHS Foundation Trust	St Peter's Hospital
114	Western Sussex Hospitals NHS Foundation Trust	St Richard's Hospital
115	Stockport NHS Foundation Trust	Stepping Hill Hospital
116	City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital
117	Tameside and Glossop Integrated Care NHS Foundation Trust	Tameside General Hospital
118	Wye Valley NHS Trust	The County Hospital

119	Sheffield Teaching Hospitals NHS Foundation Trust	The Royal Hallamshire
120	Royal Liverpool and Broadgreen NHS Trust	The Royal Liverpool University Hospital
121	Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
122	South eastern Health and social care Trust	Ulster Hospital
123	County Durham and Darlington NHS Foundation Trust	University Hospital of North Durham
124	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North tees
125	Cardiff and Vale University Health board	University Hospital of Wales
126	South Warwickshire NHS Foundation Trust	Warwick Hospital
127	Chelsea and Westminster Hospitals NHS Foundation Trust	West Middlesex University Hospital
128	West Suffolk Hospital NHS Foundation Trust	West Suffolk Hospital
129	Frimley Health NHS Foundation Trust	Wexham Park Hospital
130	St Helens and Knowsley Teaching Hospitals NHS Trust	Whiston Hospital
131	Whittington Health NHS Trust	Whittington Hospital
132	East Kent Hospitals University NHS Foundation Trust	William Harvey Hospital

133	Worcester Acute Hospitals NHS Trust	Worcester Royal Hospital
134	Western Sussex Hospitals NHS Foundation Trust	Worthing Hospital
135	Betsi Cadwaladr University Health Board	Wrexham Maelor Hospital
136	Manchester University NHS Foundation Trust	Wythenshawe Hospital
137	York Teaching Hospital NHS Foundation Trust	York District Hospital

**NB Trust and Hospital names reflect what they were during the course of the data collection period. Some trusts have merged/change name since the end of this period.**

## Appendix 3 – audit questions

Section	Question number	Question	Response
1	1.1	Auditor discipline	<ul style="list-style-type: none"> <li>• Doctor</li> <li>• Nurse</li> <li>• Other health professional</li> </ul>
2	2.1	patient audit number	<i>derived by system</i>
	2.2	age	<ul style="list-style-type: none"> <li>• 16 years or older</li> </ul>
	2.3	gender	<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Not specified/Prefer not to say</li> <li>• Not known</li> </ul>
	2.4	What is the patients Postcode?  <i>(audit researchers will only be able to see Lower layer Super Output Area)</i>	Free Text
3	3.1	Is there a statement that the patient is known to have epilepsy?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No/Not documented</li> </ul>
	3.1a)	<i>If no to 3.1, is there documentation that the patient has had previous seizures or blackouts?</i>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No/Not documented</li> </ul>
	3.1ai)	<i>If yes to 3.1ai, was the patient's previous seizure or blackout provoked by alcohol?</i>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No/Not documented</li> </ul>
	3.1aii)	<i>If yes to 3.1a, was the patient's previous seizure or blackout provoked by head injury?</i>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No/Not documented</li> </ul>
	3.1aiii)	<i>If yes to 3.1a, was the patient's previous seizure or blackout provoked by something else?</i>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No/Not documented</li> </ul>
	3.1aiv)	<i>If yes to 31.iiiii, please specify</i>	Free text

	3.2	Has the patient attended this Emergency Department as a result of a seizure in the previous 12 months?	<ul style="list-style-type: none"> <li>• yes</li> <li>• No/Not documented</li> </ul>
	3.3	On attendance which anti-epileptic drug(s) was the patient being prescribed?	<ul style="list-style-type: none"> <li>• Carbamazepine/Tegretol/ Tegretol Retard</li> <li>• Lamotrigine/Lamictal</li> <li>• Levetiracetam/Keppra</li> <li>• Phenytoin/Epanutin</li> <li>• Valproic acid/Epilim/Epilim Chrono/Orlept</li> <li>• Acetazolamide/Diamox</li> <li>• Clobazam/Frisium</li> <li>• Clonazepam/Rivotril / Rivatril</li> <li>• Diazepam/Valium</li> <li>• Eslicarbazepine Acetate/ Zebinix</li> <li>• Ethosuximide/Emeside/ Zarontin</li> <li>• Gabapentin/Neurontin</li> <li>• Lacosamide/Vimpat</li> <li>• Oxcarbazepine/Trileptal</li> <li>• Oxazepam/Serax</li> <li>• Perampanel/Fycompa</li> <li>• Pregabalin/Lyrica</li> <li>• Phenobarbital</li> <li>• Primidone/Mysoline</li> <li>• Retigabine/Trobalt</li> <li>• Rufinamide/Inovelon</li> <li>• Stiripentol/Diacomit</li> <li>• Sulthiame/Ospolot</li> <li>• Tiagabine/Gabatril</li> <li>• Topirimate/Topamax</li> <li>• Vigabatrin/Sabril</li> <li>• Zonisamide/Zonegran</li> <li>• •</li> <li>• Brivaracetam/Briviact</li> <li>• No Drugs</li> </ul>

	3.4	Is it documented that the patient has seen any of the following in the previous 12 months: Epilepsy Specialist Nurse Neurologist Intellectual Disability Psychiatrist Neurosurgeon Paediatrician Paediatric Neurologist Drug/alcohol Liaison Service	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• Not Known</li> </ul>
	6	Is it documented that the patient has any co-morbidities? Brain Tumour Cerebral Palsy Dementia History of Significant head injury Intellectual disability Stroke	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
4	4.1	When did the patient arrive in the Emergency Department?	<ul style="list-style-type: none"> <li>• Date</li> <li>• hour</li> </ul>
	4.2	Was the patient seen within 4 hours of arrival in the Emergency Department?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• not documented</li> </ul>
	4.3	What was the highest grade of doctor the patient was seen by while in the ED?	<ul style="list-style-type: none"> <li>• Foundation doctor (F2)</li> <li>• Core Medical Trainee</li> <li>• Advance Nurse Specialist (ANP)</li> <li>• Specialist Trainee (ST3 and above)</li> <li>• Consultant/Associate Specialist</li> </ul>
5	5.1	Is it documented that diazepam (rectal or IV) was administered prior to arrival at hospital?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> </ul>
	5.2	Is it documented that midazolam (buccal, nasal, iv, im) was administered prior to arrival at hospital?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> </ul>

	5.3	Is it documented that another drug (oral clobazam, iv lorazepam or paraldehyde) was administered prior to arrival at hospital?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> </ul>
	5.3a	<i>If yes to 5.3, specify which drug was administered</i>	<ul style="list-style-type: none"> <li>• free text</li> </ul>
	5.4	What treatment was given in the emergency room	<ul style="list-style-type: none"> <li>• IV diazepam</li> <li>• IV clonazepam</li> <li>• IV lorazepam</li> <li>• Rectal diazepam</li> <li>• Buccal midazolam</li> <li>• IV glucose</li> <li>• IV levetiracetam</li> <li>• IV phenobarbitol</li> <li>• IV phenytoin</li> <li>• IV thiamine / pabrinex</li> <li>• IV valproate</li> <li>• Rectal or intramuscular paraldehyde</li> <li>• NONE</li> </ul>
6	6.1	Was the patient fully conscious upon arrival at the Emergency Department?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• not documented</li> </ul>
	6.2	Were the following assessments performed in the ED?	<ul style="list-style-type: none"> <li>•</li> </ul>
	6.2a	Temperature	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• not documented</li> </ul>
	6.2ai)	<i>If yes to 6.2a, what was the patients' temperature?</i>	<ul style="list-style-type: none"> <li>• Below 35</li> <li>• 35-37.5</li> <li>• Above 37.5</li> </ul>
	6.2aii)	<i>If yes to 6.2a, was their temperature taken within 20 minutes of arrival</i>	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• not documented</li> </ul>
	6.2b)	Was the patient's pulse measured in the Emergency Department?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• not documented</li> </ul>

	6.2c)	Was the patient's Glasgow Coma Scale (GCS) recorded in the Emergency Department?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>•</li> </ul>
	6.2ci)	<i>If no to 6.2c, was AVPU recorded</i>	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>•</li> </ul>
	6.3	Where was the patient transferred to directly from the Emergency Department?	<ul style="list-style-type: none"> <li>• Medical ward</li> <li>• Neurology ward</li> <li>• Epilepsy monitoring unit (EMU) or equivalent</li> <li>• Clinical decision unit</li> <li>• Emergency Department observational ward</li> <li>• Intensive Care Unit</li> <li>• Medical decision unit</li> <li>• Discharged</li> <li>• Self-Discharged</li> <li>• Died</li> <li>• Other - please specify</li> <li>•</li> </ul>
	6.4	Once admitted/transferred who took over the patients care?	<ul style="list-style-type: none"> <li>• Neurologist</li> <li>• General physician or other medical specialist</li> <li>• Other</li> <li>• Remained under care of Emergency Department</li> </ul>
	6.5	What was the main reason for admitting/transferring the patient?	<ul style="list-style-type: none"> <li>• Seizure</li> <li>• Significant medical problem other than seizure</li> <li>• Safety</li> <li>• Social</li> <li>• Mental Health</li> <li>• Alcohol</li> <li>• Not clear</li> </ul>

6.6	How long was the patient admitted for (days)?	<ul style="list-style-type: none"> <li>Free text</li> </ul>
6.7	Was an eyewitness to the seizure contacted?	<ul style="list-style-type: none"> <li>Yes</li> <li>no</li> <li>not documented</li> <li>Event unwitnessed</li> </ul>
6.7a	<i>If no to the 6.7, is there a statement that an attempt was made to contact an eyewitness?</i>	<ul style="list-style-type: none"> <li>yes</li> <li>no</li> <li>Witness was uncontactable</li> </ul>
6.7b	<i>If no to 6.7a, is it documented that the event was unwitnessed?</i>	<ul style="list-style-type: none"> <li>Yes</li> <li>No</li> </ul>
6.8	Is it documented that the patient was asked whether they are a driver?	<ul style="list-style-type: none"> <li>yes</li> <li>no</li> </ul>
6.9	Is there documentation of the patient's general alcohol intake?	<ul style="list-style-type: none"> <li>yes</li> <li>no</li> </ul>
6.9a	<i>If yes to 6.9, how is their drink intake best classified?</i>	<ul style="list-style-type: none"> <li>Excessive (&gt;21 units/week)</li> <li>Moderate (14-21/week)</li> <li>Low (&lt;14)</li> </ul>
6.9b	<i>If yes to 6.9, is it documented that in the week prior to arrival at the Emergency Department there was a significant change to the patients alcohol consumption?</i>	<ul style="list-style-type: none"> <li>Yes</li> <li>no</li> </ul>
6.9bi	<i>If yes to 6.9b, did this increase or decrease?</i>	<ul style="list-style-type: none"> <li>Increase</li> <li>Decrease</li> </ul>
6.10	Is there documentation of illicit drug use?	<ul style="list-style-type: none"> <li>yes</li> <li>no</li> </ul>
6.10a	<i>If yes to 6.10, are they documented as a user or a non-user of illicit drugs?</i>	<ul style="list-style-type: none"> <li>user</li> <li>non - user</li> </ul>

	6.11	Is there evidence that a neurological exam, including power of the limbs, was performed in the ED?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> </ul>
7	7.1	Was advice sought from a neurology/epilepsy team or an assessment made by a neurologist or epilepsy specialist?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> </ul>
	7.1a	<i>If yes to 7.1, from whom was advice sought?</i>	<ul style="list-style-type: none"> <li>• Epilepsy Specialist Nurse</li> <li>• Neurologist</li> <li>• Neuropsychiatrist</li> <li>• Neurosurgeon</li> <li>• Paediatrician</li> <li>• Paediatric neurologist</li> </ul>
8	8.1	Were any of the following investigations performed during the emergency department admission and/or during the subsequent admission?	
	8.1a	Were AED levels tested?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't Know/Not Documented</li> </ul>
	8.1b	Was a CT (head) performed?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know/Not Documented</li> </ul>

	8.1c	Was an ECG undertaken during the emergency department attendance or admission?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know/Not Documented</li> </ul>
	8.1d	Was the blood glucose level tested?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't Know/Not Documented</li> </ul>
	8.1e	Was an MRI performed?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't Know/Not Documented</li> </ul>
	8.2	Did the patient die while attending the Emergency Department or during their admission?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
	8.2a	<i>If yes to 8.2, what was the cause of death?</i>	<ul style="list-style-type: none"> <li>• Free text</li> </ul>
	8.3	Were either of the following investigations requested as an out-patient following discharge?	
	8.3a	Was a CT head scan ?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know/Not Documented</li> </ul>
	8.3b	Was a MRI head scan?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know/ot documented</li> </ul>

9	9.1	What was the diagnosis at discharge/death?	<ul style="list-style-type: none"> <li>• Blackout with seizure markers, not sure if seizure</li> <li>• Syncope/faint</li> <li>• First unprovoked seizure</li> <li>• Unprovoked seizures with history of previous seizures, but no current epilepsy diagnosis</li> <li>• Seizure in someone with established diagnosis of epilepsy</li> <li>• Provoked seizure – alcohol induced</li> <li>• Provoked seizure – drug induced</li> <li>• Provoked seizure – head injury</li> <li>• Provoked seizure – acute stroke</li> <li>• Psychogenic non-epileptic attack / pseudo-seizure</li> <li>• Self-discharged</li> <li>• Other - please specify</li> <li>• Not recorded</li> </ul>
	9.2	If the patient was not being prescribed one or more AED on attendance at ED, did they start AED during this attendance or admission?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• don't know</li> </ul>

	2a	If yes to 9.2, which drugs were they sent home on?	<ul style="list-style-type: none"> <li>• Carbamazepine/Tegretol/ Tegretol Retard</li> <li>• Lamotrigine/Lamictal</li> <li>• Levetiracetam/Keppra</li> <li>• Phenytoin/Epanutin</li> <li>• Sodium Valproate/Epilim/Epilim Chrono/Orlept</li> <li>• Acetazolamide/Diamox</li> <li>• Clobazam/Frisium</li> <li>• Clonazepam/Rivotril / Rivatril</li> <li>• Diazepam/Valium</li> <li>• Eslicarbazepine Acetate/ Zebinix</li> <li>• Ethosuximide/Emeside/ Zarontin</li> <li>• Gabapentin/Neurontin</li> <li>• Lacosamide/Vimpat</li> <li>• Oxcarbazepine/Trileptal</li> <li>• Oxazepam/Serax</li> <li>• Perampanel/Fycompa</li> <li>• Pregabalin/Lyrica</li> <li>• Phenobarbital</li> <li>• Primidone/Mysoline</li> <li>• Retigabine/Trobalt</li> <li>• Rufinamide/Inovelon</li> <li>• Stiripentol/Diacomit</li> <li>• Sulthiame/Ospolot</li> <li>• Tiagabine/Gabatril</li> <li>• Topirimate/Topamax</li> <li>• Vigabatrin/Sabril</li> <li>• Zonisamide/Zonegran</li> <li>• Brivaracetam/Brivact</li> </ul>
	9.3	Was advice about driving given to the patient?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know</li> <li>• Not applicable (patient does not drive)</li> </ul>

	9.4	Was the management of future seizures discussed with the patient or their carer/next of kin?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• not documented</li> </ul>
10	10.1	Was a referral made for the patient following this attendance/admission?	<ul style="list-style-type: none"> <li>• yes</li> <li>• no</li> <li>• don't know</li> </ul>
	10.1a	<i>If yes to 10.1, where to?</i>	<ul style="list-style-type: none"> <li>• epilepsy service or first fit clinic</li> <li>• Epilepsy Specialist Nurse</li> <li>• Neurologist</li> <li>• Neurosurgeon</li> <li>• Paediatrician</li> <li>• Paediatric Neurologist</li> <li>• Intellectual Disability Psychiatrist</li> <li>• Alcohol/Drug Liaison service</li> </ul>
	10.1b	If yes, was this referral to this hospital or to another?	<ul style="list-style-type: none"> <li>• This hospital</li> <li>• Another hospital</li> <li>• Not documented</li> </ul>
	10.1c	What was the date of the patient's appointment?	<ul style="list-style-type: none"> <li>• Calendar</li> </ul>
	10.1d	Did the patient keep their appointment?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know</li> <li>• Date of apt not yet reached (referral time more than 3 months)</li> </ul>

	10.1e	Following their appointment, what was their diagnosis?	<ul style="list-style-type: none"> <li>• Blackout of uncertain cause</li> <li>• Blackout with other cardiac cause</li> <li>• Epilepsy</li> <li>• First epileptic seizure</li> <li>• Non epileptic attack disorder (NEAD)</li> <li>• Syncope/faint/low blood pressure</li> <li>• Other - please specify</li> </ul>
	10.2	Was a GP letter sent following this Emergency Department attendance?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
	10.2a	If yes to 10.2, did it detail the attendance event?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
	10.2b	If yes to 10.2b, did the letter request GP complete the onward referral process?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>