UNIVERSITY OF LIVERPOOL

National Audit of Seizure Management in Hospitals

St Elsewhere's

Clinical Report, April 2012

2011 NASH Audit Report Prepared by:

Professor Mike Pearson, Professor of Clinical Evaluation

Professor Tony Marson, Professor of Neurology

Pete Dixon, NASH Study Coordinator

Karen Billington, NASH Research Coordinator

Funding

The National Audit of Seizure Management in Hospitals is funded by Eisai Ltd, GlaxoSmithKline and UCB Pharma.

Please forward audit enquiries to:

Dr Pete Dixon
Karen Billington

+44 (0) 151 529 5463
info@nashstudy.org.uk

Contents

FOREWORD

This is the first UK-wide epilepsy audit and includes data from over 3,750 patients across 127 sites (from 108 Trusts/Health Boards) in England, Wales, Scotland and Northern Ireland.

The aims of this audit were to:

a) describe and understand the organisation of care available for people presenting to Emergency Departments with seizures;
b) describe the variations in care actually delivered; and
c) set out options and opportunities for improving care and to share those with the hospitals, with patient organisations and with NHS managers in the hope that together they can act to effect improvement.

We hope that these aims will be achieved in two ways. Firstly by providing comparative data on the process of care and outcomes for individual sites against a benchmark of all other participating UK sites. This should identify areas where care and processes are good, and areas where care and processes are poorer, thus highlighting areas where change, and perhaps investment, are required.

Secondly, it is hoped that a truly national audit will raise the profile of epilepsy providing an opportunity for hospital units to negotiate improved resourcing and organisation of care with health care purchasers. In order to facilitate this process comparative data on both available resources and the organisation of care of patients presenting with a seizure are included in this document.

All possible safeguards to preserve the quality of data collected have been made. Nevertheless it is important to interpret your results in this report using your knowledge of your own service and any difficulties you experienced in collecting your audit data that may have biased your own outcomes. If you are aware of significant biases or inconsistencies in the reported data for your site, please inform the NASH study office as soon as possible (info@nashstudy.org.uk).

To achieve change in epilepsy services requires the support of many different individuals and groups within the health services. We recommend that this report be circulated as widely as possible, and that an action plan be formulated with the agreement of all interested parties to plan improvements that may be needed to your service. We intend to produce regional reports and peer-reviewed papers that will be distributed nationally with the intention of raising the profile of epilepsy at the highest level.

We are grateful to everyone who has helped with the project and appreciate the very considerable amount of time and effort that has gone into obtaining local data. We hope that all participants will feel it has been worthwhile and that the audit represents a significant step in raising the profile of epilepsy. Thanks are also due to Eisai, GlaxoSmithKline and UCB Pharma for their financial support to the audit.



Pete Dixon
Study Coordinator

Prof. Tony Marson
Joint Study Lead

Prof. Mike Pearson
Joint Study Lead

April 2012

EXECUTIVE SUMMARY

The 2011 National Audit of Seizure management in Hospitals (NASH) is remarkable in that it is the first ever comprehensive audit of this condition in the UK. This release contains the patient level data – the trust organisational data is to follow shortly. Sites were asked to provide clinical data on at least 30 consecutive admissions of patients presenting with a seizure (from October 1st 2010) detailing both process of care and clinical outcomes. Data was entered via an online system. This opened on March 14th 2011 and closed on July 14th.

This initial report gives each site's clinical results benchmarked against all 127 UK sites (from 108 Trusts/Heath Boards) that completed the audit. A second report will shortly be produced that examines the available resources and organisation of care. Further reports will be produced aggregating data at SHA level that will allow the variations in care across regions to be assessed.

A seizure presenting to the Emergency Department is a reasonably clear event from which a series of assessments and actions should follow. As well as managing the acute episode, a seizure in someone with known epilepsy represents a failure of therapeutic control, so assessment of past control and revision of therapy should occur to try and prevent a repeat. When it's a new event then clearly full investigation should be mandatory. The audit questionnaire was designed to see if this happened.

The audit creates a national benchmark against which individual sites can assess their own performance compared to others. For many variables reported on it will be quite obvious that the particular item should have been completed. For example, few would argue against the need to examine the neurological system of a patient presenting with a neurological event. This is perhaps so obvious that it is presumed rather than stated in guidelines. From this audit however may come discussion that allows us to set some formal targets/standards along the lines of those put in place by the College of Emergency Medicine.

How to interpret the data

Interhospital variation

The variability across different sites is very wide. We have presented this in two ways:

a) tables giving the mean data for local and national samples side-by-side, and for selected variables have also provided the range and inter-quartile range to describe the variability. If any Trust/Health Board wants the detail for all variables, that can be made available by contacting the study office (info@nashstudy.org.uk).
b) for a few indicators we have presented the data pictorially in a box and whisker plot. The plots show the median and inter-quartile range of sites (as the box) with whiskers extending to show the 95% confidence range and isolated hospitals beyond as dots or stars. Above these are the numerical values for your site, and a visual comparison will show you which quartile you sit within.

Statistical difference

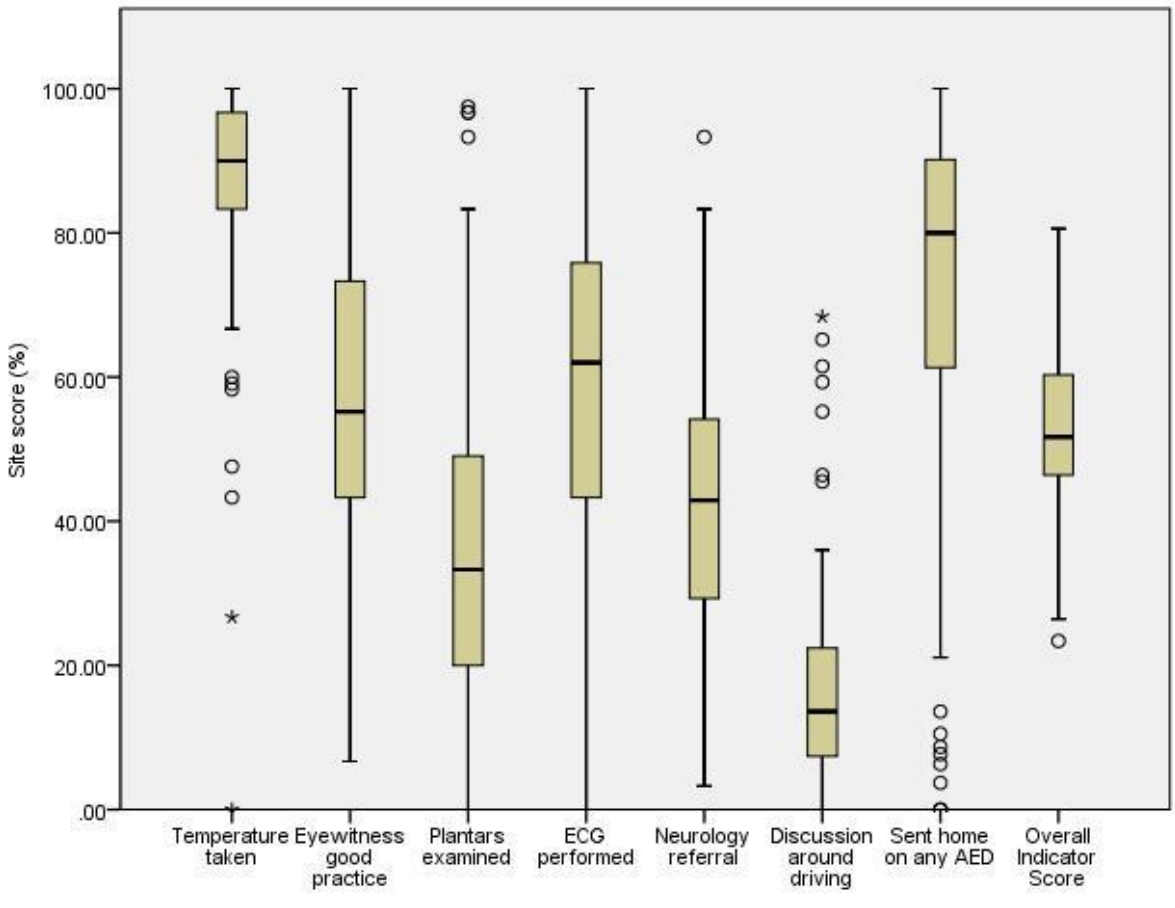
While the confidence interval around the national data is narrow, with only 30 cases per site the local rates have a confidence interval that is typically +/- 20%. In other words, your site may score 40% on an item, but that could be anywhere between 20% and 60% simply by chance. Bear this in mind when interpreting each specific variable. Thus differences of a few percentage points between sites are **not** relevant. However, the wide range of performance means that if your site if in the lowest quartile then sites in the top quartile are significantly better.

Overall Picture

There is a pattern within the data that high performing sites tend to perform well across most variables and *vice versa*. We have created a summary statistic from 7 variables representing independent aspects of the care pathway. These are as follows:

- The patient's temperature was taken in the Emergency Department
- A statement from an eyewitness was taken, or an attempt was made to contact an eyewitness
- The patient's plantar response was examined
- An ECG was performed on the patient
- The patient had some neurology input during their attendance, or was referred to a neurologist as an outpatient
- There was a discussion around driving with the patient
- The patient as sent home on at least one anti-epileptic drug (NB this applies only to patients who are known to have epilepsy)

The graph below shows the variability across all sites, with your site's figures recorded below the x axis. The average of the 7 variables (right hand most box and whisker) has a narrower but still wide range. With more data included, the confidence interval is also less (+/- 8%) so there is less "wriggle room" to argue that the whole is down to "bad luck".



We invite you to comment on this selection and suggest if there is a better selection that reflects overall care. In the stroke audits an 11 point composite became part of the Healthcare Commission's (now Care Quality Commission) standard for hospital assessment – and as a simple, yet relevant, index had substantial beneficial effects.

Interpretation and Actions

The wide range of performance cannot be justified on any medical criteria. Patients deserve a uniform high standard of care and some hospitals are delivering just that, i.e. it is possible. Any physician who has been involved in a medico legal complaint or serious incident is aware that failure to do and record simple things, e.g. measure a temperature, is **not** excusable.

Where local performance falls short, local discussions need to investigate three possible explanations.

- Are there local problems in the data, e.g. an odd case mix, wrong patients included, data fields left blank etc.? In general the quality of data is good, and over 90% of the data was entered by doctors or nurses.
- Are there structural or organisational issues that explain why things could not happen? The results of the organisational audit are to follow, but local staff will know if, for example, there is no scanner, or there are too few nurses available to takes temperatures in the Emergency Department.
- Is there a habit of not doing things? Most of the issues highlighted are issues of omission. That comes down to the medics and nurses and their "attitude" to a seizure.

The headline findings of the clinical audit were as follows:

Clinical Data with Process of Care and Outcomes:

There were a total of 3,755 admissions registered. 57% of admissions were male and the median age was 44.0 years.

- 66% of admissions were of patients who were known to have epilepsy
- 15% were of patients who were known to have had previous seizures or blackouts but did not have a known diagnosis of epilepsy; and
- 19% were of patients with no prior history of epilepsy or blackouts/seizures, i.e. this was their first seizure.

Findings

Anti Epileptic Drugs (AEDs) prior to the event – the 60% of patients presenting to the Emergency Department who are already on AEDs include many on monotherapy and often with older drugs. There is likely to be an opportunity to improve control by switching to more modern alternatives or combinations, i.e. further referral for expert assessment is likely to be worthwhile.
Evidence of Senior Emergency Department Review – many patients are managed without a senior review
Contacting eyewitnesses – patients cannot describe their own seizure yet in many hospitals it is clearly not routine to seek a witness of the event – data essential for an evaluation as to whether the incident was or was not a seizure.
Documentation of whether the patient is a driver – Driving should be documented and advice given – especially where it is a first event. This is not happening at many sites.
Documentation of alcohol intake – DoH guidance recommends alcohol use should be documented in all, and especially where it is a known provoking factor for the event, but it is often not happening.
Recording of data – recording temperature, and recording GCS, should happen for all those who have had a neurological event. In many hospitals it is routine, but there are some sites where it is not.
Neurological examination – after a loss of consciousness a proper neurological examination should be mandatory but neither the plantar reflex nor the fundi are examined in the majority of cases either in the Emergency Department or on the wards.

Obtaining expert epilepsy help – we credited any neurological involvement on this (a consultation in hospital, referral to an epilepsy clinic, referral to a GP with special interest, referral to a specialist nurse etc.) but more than half of patients did not get such an assessment.
Drugs on discharge – it appears that many did not go home on the medication one might have expected.

Food for Thought

This first ever UK national audit has demonstrated:

- Excessive variability in care with some sites performing well, demonstrating that good care can be provided.
- Inadequate assessments (neurological examinations, eyewitness statements, ECGs) with lack of senior oversight.
- Lack of neurological/epilepsy input during attendance/admission – this is a highly charged issue in neurology which needs to be highlighted.
- Wide variability in access to aftercare to epilepsy/neurology services.

Further information:
NICE guidelines on the management of the epilepsies and transient loss of consciousness (TLOC) within the NHS in England and Wales are available from their website:
http://guidance.nice.org.uk/CG20 (epilepsies)
http://guidance.nice.org.uk/CG109 (TLOC)

BACKGROUND

Epilepsy is common and each presentation to an Emergency Department represents a "failure" in control. Anecdotally it is known that care of epilepsy is variable and that there are many patients who are unknown to the specialists and who have not had the opportunity to be optimally controlled.

Whilst there are many research studies in epilepsy that have summarised much of the evidence regarding treatment options for patients, little is known about the organisation and delivery of epilepsy care across the UK.

Regional centres of excellence exist that reach out in variable ways to district hospitals. But epilepsy is rarely a topic of discussion in those local hospitals, taking second (or worse) place to chronic conditions with a higher national profile e.g. myocardial infarction or COPD. The structures linking primary, secondary care and tertiary services are even less well defined and there are many opportunities for patients with epilepsy to be "lost" or "ignored" within the system. There is often no resident clinical "champion" within the district hospitals to argue for epilepsy care within the hospital or with the local PCTs. Thus it is in many ways an orphan condition. But 20 years ago both stroke and COPD were equally ignored.

National audits can change care and practice. Previous experience of the study team in audits of myocardial infarction, stroke, carotid endarterectomy, evidence-based prescribing, COPD, lung cancer, continence, inflammatory bowel disease, blood transfusion, and palliative care have shown them to be successful in improving services as the results have been fed back to sites.

NASH seeks to identify any variation in patient care and identify some of the resource and organisational factors that may account for this. The national audit data provides a first national benchmark against which clinical teams can compare themselves now, and monitor future change. The comparative performance data in this report should therefore provide a means of raising the standards of epilepsy care nationwide.

METHOD

Organisation and monitoring

The audit was coordinated from the University of Liverpool but employed local data collection in each site. It had a multidisciplinary steering committee with representation from professional bodies and patient groups (see Appendix One). The steering group oversaw the preparation, conduct, analysis and reporting of the audit process.

Recruitment

Letters to the Chief Executives and Heads of Clinical Audit were sent in June 2010 to all Trusts/Health Boards in England, Scotland, Wales and Northern Ireland. These contained general information about the audit and had a reply slip (and email address) for the addressee to send back to the study office indicating if they would be interested in learning more about the audit, with no obligation to take part.

In August 2010 reminder letters were sent to both the Chief Executives and Heads of Clinical Audit from the Trusts/Health Boards who did not initially respond. Members of the steering group also identified named individuals from Trusts/Health Boards who had not indicated they would take part for the study coordinator to approach and encourage their participation.

Of the Trusts/Health Boards eligible to take part, 108 participated. Some Trusts had more than one site take part with the result that data was collected from 127 hospital sites. The main reasons for sites declining to participate in, or withdrawing from, the audit were the associated problems of shortage of staff and lack of time in which to complete the data collection. Staff shortages and changes in personnel also affected the data collections and meant that some sites had problems meeting the original targets and deadlines. Participating Trusts/Health Boards and sites are listed in Appendix Two.

Development of the audit tool questions

A one day meeting of the steering committee took place in July 2010 at which items for inclusion were discussed. A number of iterations of the proforma were produced as a result of this and subsequent teleconferences involving the steering committee. Pilot testing took place in January and February 2011, following which minor modifications were made to the questions.

Appendix Three contains the final versions of the clinical and institutional proformas.

Development of the software

These 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 SQL Server database.

The web system consisted of a set of e-forms:

- Organisational – one per site assessing the facilities and staffing available.
- Clinical – one per subject (20-30 subjects per site) 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, or asked for by the e-forms. Online help was available for the majority of questions.

Feedback from the use of the online system were collected following the pilot study and appropriate changes were made for the main data collection period.

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, registrars, nurses and audit department staff. The medical staff involved in data collection were a combination of those from emergency medicine and neurology.

The clinical data entry took place between 14th March and 14th July 2011. Anonymised data were requested for 30 consecutive patients who:

a) presented on or over their 16th birthday; and
b) presented at the Emergency Department with an episode thought to have been a seizure (relevant HES codes for seizures are shown in Appendix Four), and seizure was the primary reason for their admission / attendance

The start date for these presentations was chosen as 1st October 2010. Although this was somewhat before the date that data entry was open, 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.

The data collection was supported by online help notes associated with each question, and a "how to" video was also available on the study website. In addition, a dedicated email address for the study office was available to which any queries could be sent.

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. Weekly 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.

Reliability – pilot study

In order to gain a measure of the reliability of the data, a pilot audit was undertaken in January an February of 2011. Ten sites were asked for two individuals to independently enter data on up to 10 patients. The levels of reliability were generally good. Analysis of the pilot audit resulted in some questions being amended slightly prior to the audit proper commencing in March.

Presentation of results

The presentation of results is primarily comparative, using the national figures as the comparator. For a number of questions, results are split according to the patient's known history of epilepsy and seizures. Variation between sites is summarised for certain questions by use of box plots and/or inter quartile ranges.

PATIENT DATA

Patient Data were received from 127 sites within 108 NHS Trusts/Health Boards.

3,755 attendances at Emergency Departments from October 1st 2011 were available for analysis. The median number of attendances per site was 30, range 20-58.

You contributed **31** attendances to the analysis.

Clinical proforma completed by: %

	National audit n=3,755	**Your site n=31**
Doctor	81.9	**100**
Audit staff	5.5	**0**
Nurse	11	**0**
Other	1.6	**0**

DEMOGRAPHICS

Gender: %

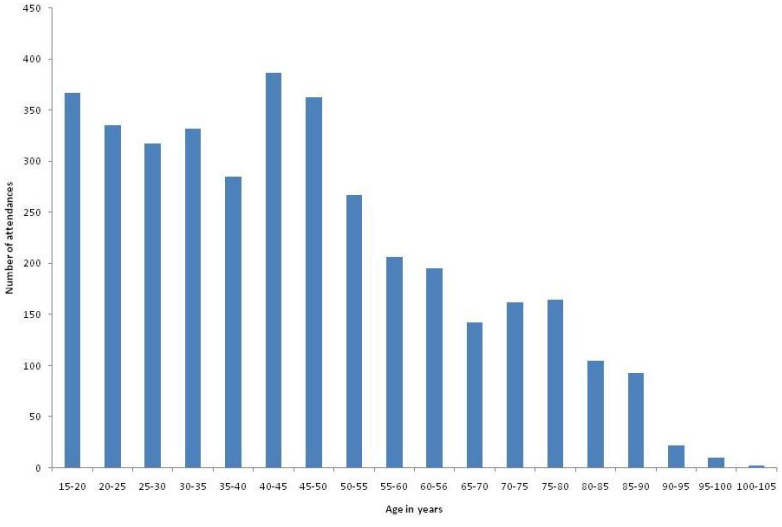
	National audit n=3,755	**Your site n=31**
Males	57	**51.6**
Females	43	**48.4**

Age: %

	National audit n=3,755	**Your site n=31**
<45	51.6	**32.3**
45-65	29.8	**32.3**
>65	18.6	**35.5**

National median = 44 (IQR 29.0 – 60.0)
Your site's median = 58 (IQR 38.5 – 73)

Your site has patients who are significantly older than the national trend.
Figure 1: Age distribution of cases contributing to NASH



PREVIOUS SEIZURE HISTORY AND MANAGEMENT

Is there a statement that the patient is known to have epilepsy?: %

	National audit n=3,755	**Your site n=31**
Yes	66.4	**90.3**
No/Not recorded	33.5	**9.7**

National 'yes' figures

MIN	23.3
LOWER QUARTILE	51.7
UPPER QUARTILE	81.4
MAX	100.0

Is there documentation that the patient has had previous seizures or blackouts?: %

	National audit n=3,755	**Your site n=31**
Yes	76.2	**87.1**
No/Not recorded	23.8	**12.9**

National 'yes' figures

MIN	13.3
LOWER QUARTILE	65.0
UPPER QUARTILE	86.7
MAX	100.0

Nationally, 66% had epilepsy and 76% had previous seizures or blackouts.

Classification of patients

The results above make it possible to split the patients in to 3 distinct groups:

1. Those who are known to have epilepsy (n=2,492)
2. Those who are known to have previous seizures or blackouts, but not epilepsy (n=564)
3. Those who are not known to have either epilepsy or previous seizures or blackouts (n=695)

NB 4 patients cannot be assigned to these categories because of missing data.

These groups will be used throughout the rest of this report – some of the numbers will vary a little in the tables below when data are missing or not recorded – we have not detailed all the reasons to avoid over complicating tables.

Provoking Factors

Of those who are recorded as having previous seizures or blackouts (groups 1 and 2 above):

Was the patient's previous seizure or blackout provoked by alcohol?: %

	National audit n=2,862	**Your site n=27**
Yes	13.7	**0**
No	51.8	**48.1**
Not recorded	33.6	**51.9**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	5.1
UPPER QUARTILE	20.8
MAX	56.3

Was the patient's previous seizure or blackout provoked by head injury?: %

	National audit n=2,862	**Your site n=27**
Yes	4.4	**3.7**
No	58.5	**55.6**
Not recorded	36.1	**40.7**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	0.0
UPPER QUARTILE	6.9
MAX	25.9

Was the patient's previous seizure or blackout provoked by another factor?: %

	National audit n=2,862	**Your site n=27**
Yes	20.7	**55.6**
No	38.7	**7.4**
Not recorded	39.8	**37**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	7.0
UPPER QUARTILE	26.9
MAX	100.0

12.9% had a history of alcohol-related seizure.
Overall 33.7% (IQR 21.6 to 46.3) recorded one or more known provoking factors.

AEDS taken prior to arrival

This table lists the anti-epileptic drugs (AEDs) patients were being prescribed prior to this episode.
N.B. Only drugs taken by at least 5% of patients with established epilepsy are shown

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Valproate/Epilim/Epilim Chrono/Orlept	35.9	**35.7**	6.6	**0**	2.3	**0**	25.3	**32.3**
Lamotrigine/Lamictal	21.4	**7.1**	2.8	**0**	0.9	**0**	14.8	**6.5**
Carbamazepine/Tegretol/ Tegretol Retard	19	**21.4**	4.6	**0**	0.3	**0**	13.4	**19.4**
Levetiracetam/Keppra	19.1	**14.3**	2.8	**0**	0.1	**0**	13.2	**12.9**
Phenytoin/Epanutin	12.1	**7.1**	3.4	**0**	2.3	**0**	9	**6.5**
Clobazam/Frisium	5.5	**0**	0.5	**0**	0	**0**	3.8	**0**
Topiramate/Topamax	5.1	**7.1**	0	**0**	0	**0**	3.4	**6.5**
Other AED	15	**25**	2.8	**0**	2.4	**0**	10.9	**22.6**
No AED	15.7	**14.3**	80.9	**100**	92.4	**100**	39.7	**22.6**
One or More AED								
Mean	84.3	**85.7**	19.1	**0**	7.6	**0**	60.3	**77.4**
Minimum	15.3		0.0		0.0		13.3	
LOWER QUARTILE	78.0		0.0		0.0		47.6	
UPPER QUARTILE	92.6		29.6		12.5		73.3	
Maximum	100.0		100.0		100.0		96.7	

Summary of Polytherapy

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
One drug as monotherapy	49.4	**50**	15.6	**0**	6.9	**0**	36.4	**45.2**
Two or more drugs as polytherapy	34.8	**35.7**	3.5	**0**	0.7	**0**	23.9	**32.3**
Not taking AED prior to attendance	15.7	**14.3**	80.9	**100**	92.4	**100**	39.7	**22.6**

Sodium valproate is the most commonly prescribed AED, taken by 36% of patients with known epilepsy and often as monotherapy – thus 20.4% are on valproate as monotherapy
and 4.4 % are on phenyotin as monotherapy
As the majority of patients are likely to have a focal epilepsy, for which valproate is not a first line treatment, this may suggest sub optimal treatment.

Since 30-40% of patients with epilepsy are refractory, and refractory patients are more likely to attend A&E, the finding that only 41.4% of patients with epilepsy are on polytherapy is also suggestive of undertreatment and possibly that refractory patients are not getting access to appropriate expertise and to newer treatments. The range of drug prescription pre presentation is uncomfortably wide

Summary of polytherapy when used

Number of AEDs being taken	Percentage of polytherapy patients
2	64.9
3	26.0
4	7.0
5	1.8
6	0.2

Most popular duo polytherapy combinations (those in over 5% of cases)	Percentage of polytherapy patients
LEV/VPA	10.0
LTG/VPA	9.5
CBZ/VPA	7.4
LEV/LTG	7.4
CBZ/LEV	6.9
CBZ/LTG	6.0
PHT/VPA	5.5

A few patients who are recorded as not having epilepsy or previous blackouts are recorded as having AEDs prescribed prior to their attendance. This could indicate a recording issue and thus they have been assigned to the wrong group, or it could be that they are taking them for other indications.

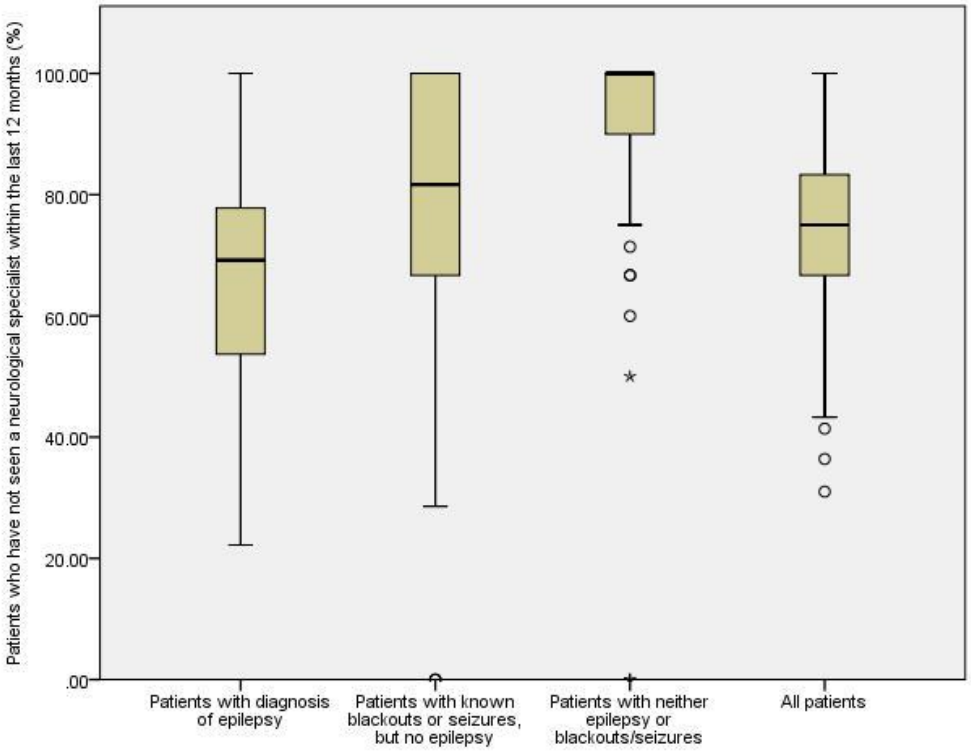
Percentage of patients for whom it is documented that they have seen one of the listed medical specialists within the previous 12 months: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Epilepsy Specialist Nurse	5.5	**3.6**	0.7	**0**	0	**0**	3.8	**3.2**
GPSI (neurology, epilepsy or neuropsychiatry)	1.2	**14.3**	0.7	**50**	0.3	**0**	1	**16.1**
Learning disability psychiatrist	1.1	**0**	0.5	**0**	0.6	**0**	0.9	**0**
Neurologist/paediatric neurologist	29.9	**32.1**	16.7	**0**	3.5	**0**	23	**29**
Paediatrician*	8.8	**0**	3.2	**NA**	0	**NA**	6.3	**0**
Neurosurgeon	2.3	**0**	2.1	**0**	1.7	**0**	2.1	**0**
None of the above	66.2	**53.6**	80.9	**50**	94.4	**100**	73.6	**54.8**

*for paediatrician the denominator used is those patients aged 20 or under

A minority of patients are documented as having been seen by an epilepsy specialist in the previous 12 months. This of course does not mean that they didn't, but how can ongoing management be planned without that knowledge?

Figure 2: Distribution of number of patients who had not seen an epilepsy specialist in the past 12 months across sites



Percentage of patients for whom it is recorded that that they have one of the following listed medical complaints: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Brain tumour	4.6	**7.1**	4.3	**0**	4.7	**0**	4.6	**6.5**
Cerebral palsy	3.3	**7.1**	0.7	**0**	0.4	**0**	2.3	**6.5**
Dementia	5.7	**14.3**	6	**50**	8.8	**0**	6.3	**16.1**
A history of significant head injury	6.5	**7.1**	4.8	**0**	4.8	**0**	5.9	**6.5**
Learning disability	15.3	**28.6**	4.1	**50**	2.7	**0**	11.3	**29**
Stroke	10.1	**21.4**	8.3	**50**	10.9	**0**	10.1	**22.6**

MODE OF TRANSPORT TO EMERGENCY DEPARTMENT: %

	National audit n=3,755	**Your site n=31**
Ambulance 999 via GP	3.6	**3.2**
Ambulance 999 via 'passer by/carer'	85.7	**77.4**
Taxi / car (passenger)	4.7	**6.5**
Other	2.1	**0**
Not known	3.9	**12.9**

Total arriving by ambulance is 89%.

SENIOR REVIEW IN EMERGENCY DEPARTMENT

Is there evidence of senior Emergency Department review, i.e. was the patient seen (or was there a consultation about) by an ST4 or consultant?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Yes	47.2	**64.3**	46.6	**100**	49.4	**100**	47.5	**67.7**
No	30.5	**10.7**	30.9	**0**	26	**0**	29.7	**9.7**
Not recorded	22.3	**25**	22.3	**0**	24.6	**0**	22.8	**22.6**

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	29.8	20.0	25.0	30.0
UPPER QUARTILE	63.7	75.0	77.8	65.0
MAX	100.0	100.0	100.0	100.0

Was this within 4 hours of arrival in the Emergency Department?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,177	**n=18**	n=263	**n=2**	n=343	**n=1**	n=1,784	**n=21**
Yes	85.9	**100**	87.5	**100**	89.8	**100**	86.9	**100**
No	5.4	**0**	3.8	**0**	4.7	**0**	5	**0**
Not recorded	8.7	**0**	8.8	**0**	5.5	**0**	8.1	**0**

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	71.3	100.0	100.0	75.0
UPPER QUARTILE	100.0	100.0	100.0	100.0
MAX	100.0	100.0	100.0	100.0

Less than half of patients were reviewed by a senior in the Emergency Department but when it was done it was usually within 4 hours.

Of those who were seen by a senior in the Emergency Department, was it a consultant?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n= 1,177	**n=18**	n= 263	**n=2**	n= 343	**n=1**	n= 1,784	**n=21**
Yes	31.6	**88.9**	34.2	**100**	29.5	**100**	31.6	**90.5**
No	61.4	**11.1**	57	**0**	60.9	**0**	60.7	**9.5**
Not recorded	6.9	**0**	8.4	**0**	9	**0**	7.5	**0**

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	13.0	0.0	0.0	16.0
UPPER QUARTILE	49.2	65.6	50.0	45.8
MAX	100.0	100.0	100.0	100.0

Of those who were seen by a senior in the Emergency Department, was it an ST4 or above but not a consultant?: %

	(National audit/**Your site)**							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n= 1,177	**n=18**	n= 263	**n=2**	n= 343	**n=1**	n= 1,784	**n=21**
Yes	63.4	**83.3**	59.3	**100**	64.1	**100**	62.9	**85.7**
No	25.6	**16.7**	25.9	**0**	24.5	**0**	25.5	**14.3**
Not recorded	10.5	**0**	14.1	**0**	10.2	**0**	10.9	**0**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	45.6	0.0	33.3	42.3
UPPER QUARTILE	88.3	100.0	100.0	78.8
MAX	100.0	100.0	100.0	100.0

ACUTE SEIZURE MANAGEMENT IN THE COMMUNITY AND ON ARRIVAL TO THE EMERGENCY DEPARTMENT

Percentage of patients for whom it is documented that the following drugs were administered prior to arrival at hospital: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
clobazam	0.4	**3.6**	0	**0**	0	**0**	0.3	**3.2**
diazepam	14.1	**21.4**	6.4	**0**	7.6	**0**	11.7	**19.4**
lorazepam	0.8	**0**	0.2	**0**	0.3	**0**	0.6	**0**
midazolam	4.3	**0**	0.9	**0**	0.6	**0**	3.1	**0**
paraldehyde	0	**0**	0	**0**	0	**0**	0	**0**

Buccal midazolam is recommended as a treatment for prolonged seizure in the community as it is easier to administer and is more dignified for the person with epilepsy. Diazepam may be the most commonly administered drug in the table above as ambulance staff are trained to provide IV services.

Had the seizure stopped by the time of arrival in the emergency room?: %

	National audit n=3,755	**Your site n=31**
Yes	85.2	**93.5**
No	7.9	**0**
Unclear	6.9	**6.5**

National 'yes' figures

MIN	23.3
LOWER QUARTILE	80.0
Q3	94.3
MAX	100.0

Of those whose seizures had not stopped, what treatment was given in the emergency room?: %

	National audit n=296	**Your site n=NA**
IV diazepam	24	**NA**
Rectal diazepam	6.1	**NA**
Buccal midazolam	2.4	**NA**
IV glucose	0	**NA**
IV levetiracetam	1	**NA**
IV lorazapam	59.5	**NA**
IV phenobarbitol	0.3	**NA**
IV phenytoin	34.1	**NA**
IV thiamine / pabrinex	3.4	**NA**
IV valproate	0.7	**NA**
Rectal or intramuscular paraldehyde	0.7	**NA**
None of the above	7.4	**0**

For patients still seizing first line treatments in the Emergency Department were lorazepam (60%), diazepam (24%) and phenytoin (34%). This suggests appropriate management.

INITIAL EMERGENCY DEPARTMENT ASSESSMENT

Was the patient fully conscious upon arrival at the Emergency Department?: %

	National audit n=3,755	**Your site n=31**
Yes	72.4	**67.7**
No	20.5	**32.3**
Don't know	6.1	**0**

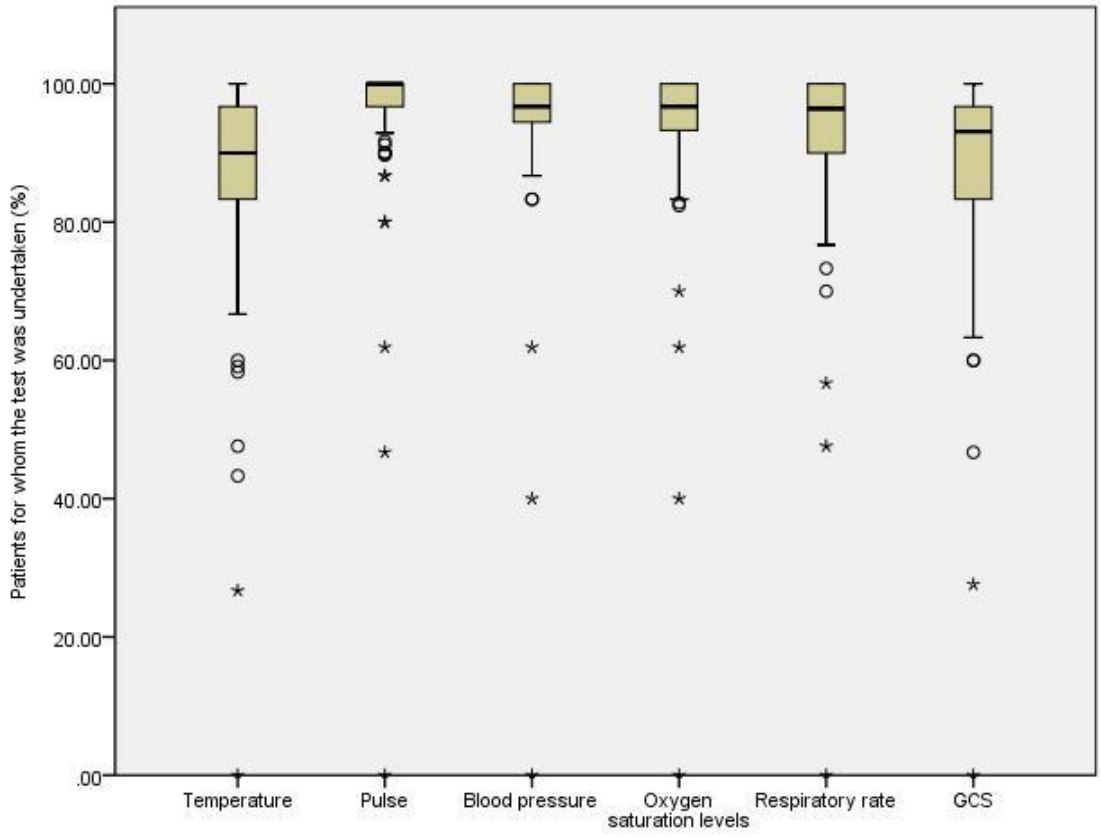
National 'yes' figures

MIN	23.3
LOWER QUARTILE	63.3
UPPER QUARTILE	83.3
MAX	100.0

Percentage of patients for whom the following tests were undertaken in the Emergency Department: %

	National audit n=3,755	**Your site n=31**
Temperature	86.9	**0**
Pulse	95.9	**0**
Blood pressure	95.3	**0**
Oxygen saturation levels	94.4	**0**
Respiratory rate	92.7	**0**
GCS	88	**0**

Figure 3: Distribution of number of patients who had diagnostic tests undertaken in A&E across sites



National averages of temperature being recorded in only 87% and GCS in only 88% cannot be acceptable practice.

What was their temperature?: mean (SD)

	National audit n=3,262		**Your site n=0**	
Temperature (˚C)	36.5	(0.7)	**NA**	**(NA)**

Was the temperature taken within 20 minutes of arrival?: %

	National audit n= 3,262	**Your site n=0**
Yes	69	**NA**
No/Don't know	29.4	**NA**
Missing	1.6	**0.0**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	52.4
UPPER QUARTILE	92.6
MAX	100.0

What was their GCS?:

	National audit n=3,303	**Your site n=0**
Median	15	**NA**
Range	3 to 15	**NA**

	Patients recorded as being conscious on arrival n=2,719	Patients recorded as not being conscious on arrival n=768
GCS recorded (%)	89.8	90.4
Median GCS Score	15	11
IQR	15-15	8-14

Percentage of patients for whom a neuro obs chart was in place in the 4 hours following the patient's arrival at the Emergency Department?: %

	National audit n=3,755	**Your site n=31**
Yes	51.1	**67.7**
No/Don't know	48.6	**32.3**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	28.6
UPPER QUARTILE	75.4
MAX	100.0

	Patients recorded as being conscious on arrival n=2,719	Patients recorded as not being conscious on arrival n=768
Neuro obs chart present (%)	48.0	68.4

Temperatures are not routinely recorded on all patients, and even when not conscious on arrival in the Emergency Department, the use of GCS and neuro-observations is far from routine.

Percentage of patients discharged directly home from the Emergency Department: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Discharged	42.7	**0**	49.1	**0**	37.1	**0**	42.6	**0**

Percentage of patients transferred or admitted to the following departments directly from the Emergency Department?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Intensive Care Unit	1.6	**0**	0.5	**0**	3	**0**	1.7	**0**
Medical ward	7.1	**3.6**	10.1	**0**	9.9	**0**	8.1	**3.2**
Neurology ward	0.7	**0**	0.2	**0**	1	**0**	0.7	**0**
Other ward	2.3	**0**	3.2	**0**	5.6	**0**	3	**0**
Clinical decision unit	6.2	**0**	5	**0**	4	**0**	5.6	**0**
ED observational ward	5.1	**0**	3.9	**0**	4.5	**0**	4.8	**0**
EMU or equivalent	18.6	**0**	15.8	**0**	18.9	**0**	18.3	**0**
Medical decision unit	15.7	**96.4**	11.9	**100**	15.8	**100**	15.2	**96.8**
Discharged	42.7	**0**	49.1	**0**	37.1	**0**	42.6	**0**

Percent of patients (except those who were discharged or for whom the answer to the previous question was missing), who were under the care of the following during admission?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,426	**n=28**	n=285	**n=2**	n=436	**n=1**	n=2,150	**n=31**
Neurologist	3.8	**0**	2.5	**0**	4.4	**0**	3.7	**0**
General physician	76.5	**100**	80.4	**100**	78.4	**100**	77.4	**100**
Other	3.9	**0**	2.8	**0**	7.1	**0**	4.4	**0**
Remained under care of Emergency Department	13.2	**0**	13	**0**	8.9	**0**	12.3	**0**

Most patients are managed by general physicians, i.e. non neurologists. Most admissions are, initially at least, to some form of medical assessment facility but a significant number are managed by the Emergency Department.

ASCERTAINMENT OF EYEWITNESS DESCRIPTION OF SEIZURE

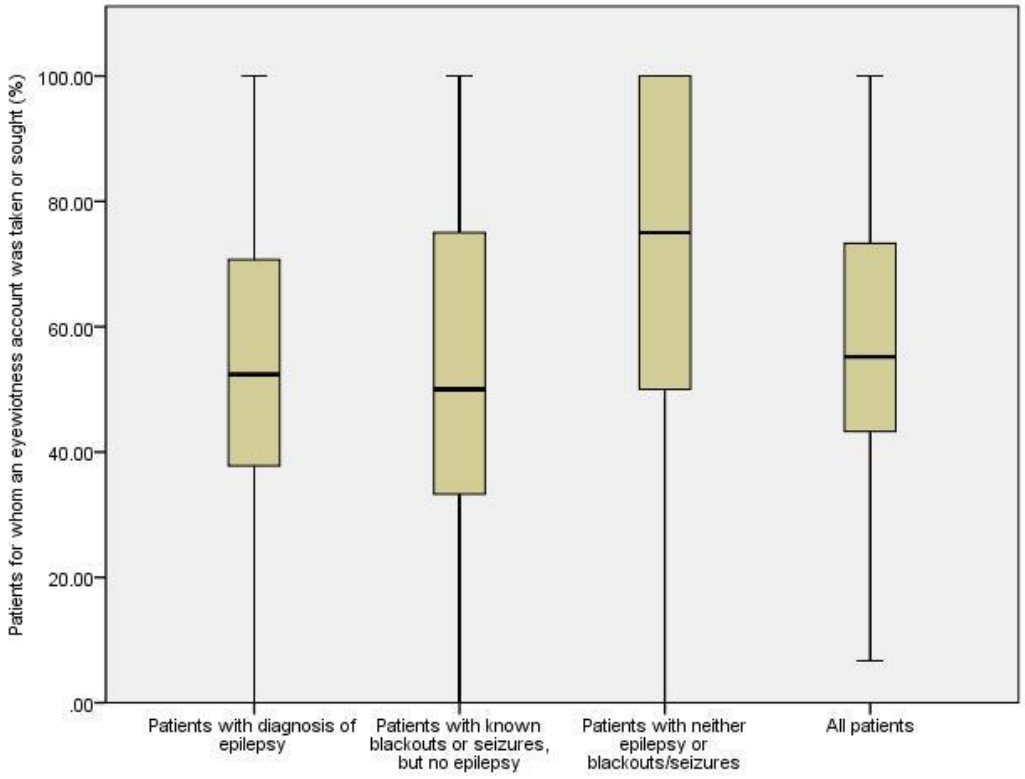
Was an eyewitness to the seizure contacted?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Yes	51.2	**78.6**	51.6	**50**	62.5	**100**	53.3	**77.4**
No, but attempt was made to contact them	5	**0**	2.5	**0**	3.7	**0**	4.4	**0**
No, and no attempt was made to contact them	17.6	**21.4**	18.4	**50**	10.7	**0**	16.4	**22.6**
No, and don't know if any contact was attempted	0.1	**0**	0.7	**0**	0.3	**0**	0.3	**0**
Don't know	26	**0**	26.4	**0**	22.7	**0**	25.5	**0**

National figures for 'good practice', i.e. either of the first two answers in the table above is 'good':

MIN	0.0	0.0	0.0	6.7
LOWER QUARTILE	37.8	33.3	50.0	43.3
UPPER QUARTILE	70.7	75.0	100.0	73.3
MAX	100.0	100.0	100.0	100.0

Figure 4: Distribution of number of patients for whom an eyewitness account was taken or sought across sites



Obtaining a good eyewitness description is vital for distinguishing among differing causes of blackout and for diagnosing seizures. The proportions with an eyewitness account of the seizure is unacceptably low, and especially where there is no prior epilepsy. The range between hospitals shows what can be done.

For those patients where an eyewitness was not contacted, is there a statement that the attack was not observed?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=566	**n=6**	n=122	**n=1**	n=102	**n=0**	n=791	**n=7**
Yes	21.9	**0**	11.5	**0**	25.5	**NA**	20.7	**0**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	0.0
UPPER QUARTILE	42.9	0.0	50.0	37.5
MAX	100.0	100.0	100.0	100.0

ALCOHOL AND ILLICIT DRUG USE

It's a standard government recommendation (as well as good practice) to record alcohol intake in **all** medical histories.

Percentage of patients for whom there is documentation of their general alcohol intake?: %

	(National audit/**Your site)**							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Documentation present	37.1	**10.7**	54.4	**50**	50.2	**0**	42.1	**12.9**

MIN	0.0	0.0	0.0	3.3
LOWER QUARTILE	21.1	29.2	33.3	30.0
UPPER QUARTILE	50.0	75.0	71.4	54.8
MAX	100.0	100.0	100.0	86.7

Of those patients for whom there was documentation of their alcohol intake, how is their drink intake best classified?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=925	**n=3**	n=307	**n=1**	n=349	**n=0**	n=1,582	**n=4**
Excessive	32.5	**0**	53.4	**0**	43.6	**NA**	39.1	**0**
Normal	15.2	**33.3**	11.4	**0**	18.1	**NA**	15.1	**25**
Low	51.8	**66.7**	34.5	**100**	38.1	**NA**	45.4	**75**

The national figures confirm that alcohol is a significant problem.

Percentage of patients for whom it is documented that in the week prior to arrival at the Emergency Department they have been on an alcoholic binge: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Documentation present	10	**0**	22	**0**	14.2	**0**	12.6	**0**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	3.8	0.0	0.0	6.1
UPPER QUARTILE	15.4	33.3	25.0	16.9
MAX	50.0	100.0	100.0	54.6

Percentage of patients for whom there is documentation that they do or do not use illicit drugs?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Documentation present	8	**0**	14.5	**0**	14.1	**0**	10.1	**0**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	3.3
UPPER QUARTILE	12.1	25.0	21.4	14.3
MAX	47.6	77.8	100.0	46.7

Of those for whom there is documentation, are they a user or a non-user?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=200	**n=0**	n=82	**n=0**	n=98	**n=0**	n=380	**n=0**
User	33	**NA**	20.7	**NA**	32.7	**NA**	30.3	**NA**
Non-user	67	**NA**	79.3	**NA**	67.3	**NA**	69.7	**NA**

Of those who are users, which drugs do they use?: % (n)

	National audit n=115	**Your site n=0**
Cannabis	54.8	**NA**
Opiates	36.5	**NA**
Stimulants	24.3	**NA**
Other	3.5	**NA**

Small numbers using illicit drugs make conclusions difficult: how do these figures compare with the general population? How did the drug-provoked subgroup fare in all of this?

NEUROLOGICAL EXAMINATION

All these patients have had a neurological episode and thus **all** should have their nervous system examined and documented as part of the diagnostic assessment – the two tests below are representative of the process.

Percentage of patients with documentation that their fundi were looked at and their plantar reflexes elicited at any time during attendance at the Emergency Department: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Fundi	15.5	**35.7**	17.6	**0**	21.9	**100**	17	**35.5**
Plantars	34.6	**25**	36.4	**0**	47.2	**0**	37.2	**22.6**

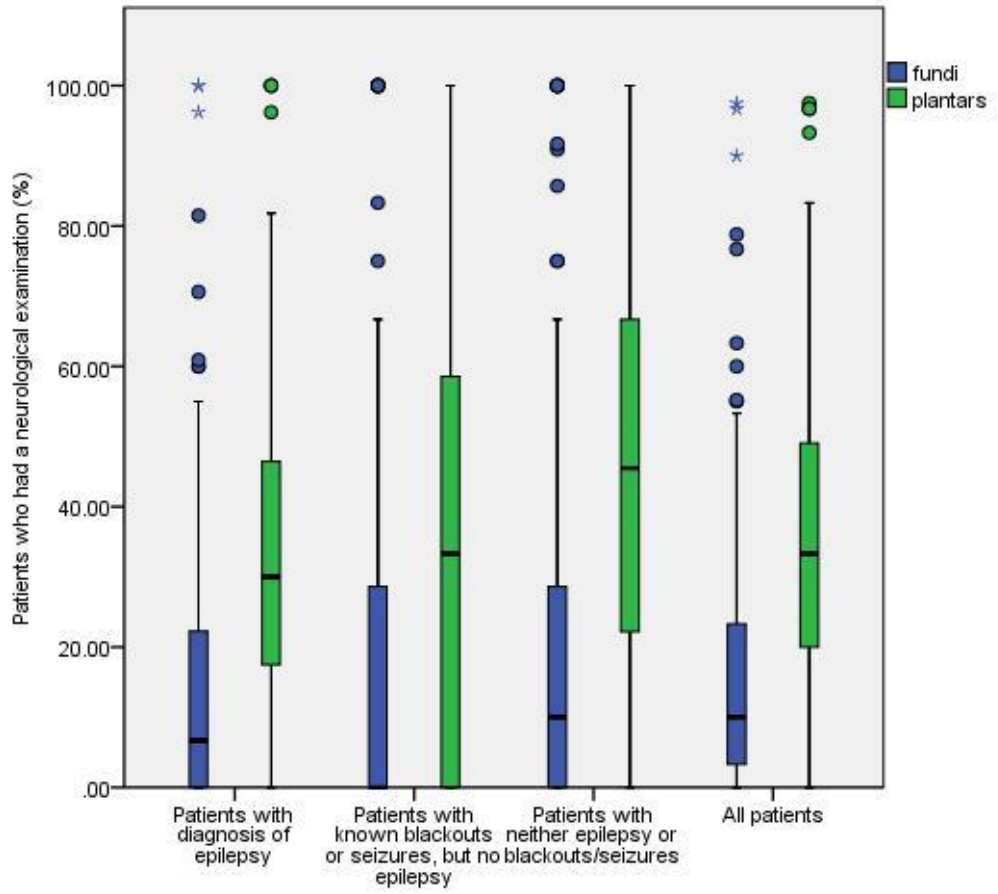
National fundi figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	3.3
UPPER QUARTILE	22.3	28.6	28.6	23.3
MAX	100.0	100.0	100.0	97.5

National plantars figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	17.6	0.0	22.2	20.0
UPPER QUARTILE	46.4	58.6	66.7	49.1
MAX	100.0	100.0	100.0	97.5

Figure 5: Distribution of number of patients who had fundi and plantars examined across sites



These figures are inexcusably low. If there was an enquiry to an individual case there are really no reasons for a neurology examination not to be performed.

Percentage of patients for whom the listed medical investigations were undertaken following attendance in the Emergency Department: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Anti-epileptic drug levels*	22.1	**56.3**	7.6	**NA**	6.1	**NA**	21.1	**56.3**
CT (head)	16.5	**14.3**	24.3	**0**	44.6	**100**	22.9	**16.1**
MRI (head)	1.6	**0**	2.1	**0**	5.2	**0**	2.3	**0**
EEG	2.4	**0**	3.2	**0**	3.3	**0**	2.7	**0**
ECG	54.5	**67.9**	62.6	**0**	71.7	**100**	58.9	**64.5**
Glucose levels / BM	70.8	**100**	75	**50**	74.1	**100**	72	**96.8**

***** 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, phenobarbitol, primidone or sodium valproate.

DISCHARGE AND DEATHS

Did the patient die during their admission?: %

	National audit n=3,755	**Your site n=31**
Yes	1	**0**
No	99	**100**

	(National audit)			
	Patients with diagnosis of epilepsy	Patients with known blackouts or seizures, but no epilepsy	Patients with neither epilepsy or blackouts/seizures	All patients
	n=2,492	n=564	n=695	n=3,755
Yes	0.6 (16 deaths)	0.5 (3 deaths)	2.6 (18 deaths)	1.0 (37 deaths)
No	99.4	99.5	97.4	99.0

Chi-Squared 22.792 (2df) → $p<0.0001$ It appears that the proportion of deaths is higher in the third group. This would be anticipated as this group of patients is more likely to have acute or life-threatening pathologies.

What was the diagnosis at discharge/death?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Blackout with seizure markers, not sure if seizure	0.6	**0**	6	**50**	6.8	**0**	2.5	**3.2**
Syncope/faint	0.2	**0**	0.9	**0**	2.3	**0**	0.7	**0**
First unprovoked seizure	0.2	**0**	5.5	**0**	38.7	**100**	8.1	**3.2**
Unprovoked seizures with history of previous seizures, but no current epilepsy diagnosis	2.8	**3.6**	37.9	**50**	3	**0**	8.1	**6.5**
Seizure in someone with established diagnosis of epilepsy	81.1	**96.4**	5.3	**0**	1.7	**0**	55	**87.1**
Provoked seizure – alcohol induced	6.2	**0**	21.3	**0**	15.5	**0**	10.2	**0**
Provoked seizure – drug induced	0.3	**0**	0.4	**0**	2.7	**0**	0.7	**0**
Provoked seizure – head injury	0.1	**0**	0.5	**0**	2.3	**0**	0.6	**0**
Provoked seizure – acute stroke	0.2	**0**	0.5	**0**	3	**0**	0.7	**0**
Psychogenic non-epileptic attack / pseudoseizure	1.1	**0**	4.4	**0**	1.2	**0**	1.6	**0**
Self-discharged	1.3	**0**	1.2	**0**	1.3	**0**	1.3	**0**
Other	3.4	**0**	9.9	**0**	14.2	**0**	6.4	**0**
Not recorded	2.4	**0**	5.1	**0**	6.2	**0**	3.5	**0**

Percentage of patients who were sent home on any AED: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,476	**n=28**	n=561	**n=2**	n=676	**n=1**	n=3,717	**n=31**
Sent home on AED(s)	70.3	**50**	29.4	**50**	19.2	**0**	54.8	**48.4**

INVESTIGATIONS

Percentage of patients for whom the following investigations were requested as an outpatient following discharge?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,476	**n=28**	n=561	**n=2**	n=676	**n=1**	n=3,717	**n=31**
CT (head)	1.6	**3.6**	4.1	**0**	5.8	**0**	2.7	**3.2**
EEG	2.5	**0**	11.6	**0**	12.3	**0**	5.6	**0**
MRI (head)	2.4	**7.1**	9.3	**0**	11.2	**0**	5	**6.5**
12 lead ECG	0.7	**0**	2.1	**0**	2.1	**0**	1.2	**0**

National figures for all patients

	MIN	LOWER QUARTILE	UPPER QUARTILE	MAX
CT (head)	0.0	0.0	4.1	33.3
EEG	0.0	0.0	6.9	30.0
MRI (head)	0.0	0.0	6.7	30.0
12 lead ECG	0.0	0.0	0.0	13.8

DRIVING AND MANAGEMENT OF SEIZURES

The percentage of patients for whom there is documentation that they were asked as to whether or not they are a driver?: %

(NB The total number of patients in this table is significantly less than for previous questions due to a large amount of missing data.)

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,861	**n=16**	n=474	**n=1**	n=564	**n=1**	n=2,903	**n=18**
Yes	12	**0**	20.5	**0**	26.2	**0**	16.2	**0**
No	88	**100**	79.5	**100**	73.8	**100**	83.8	**100**

Was advice about driving given to the patient?: %

(NB the responses to this question are split based on the answer to the question above regarding whether they were asked if they were a driver).

	National audit							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	Driver Documentation		Driver Documentation		Driver Documentation		Driver Documentation	
	Yes n= 224	No n= 1,630	Yes n=97	No n=375	Yes n= 148	No n=409	Yes n= 469	No n= 2,418
Yes	49.1	1.8	74.2	8	75	13.4	62.5	4.8
No	4.5	24.5	4.1	24.8	3.4	22	4.1	24.1
Don't Know	12.1	63.5	7.2	59.5	7.4	57.7	9.6	61.9
N/A	34.4	10.2	14.4	7.7	14.2	6.8	23.9	9.3

For those who were given advice what was that advice?: %

(NB the responses to this question are split based on the answer to the question above regarding whether they were asked if they were a driver).

	National audit							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	Driver Documentation		Driver Documentation		Driver Documentation		Driver Documentation	
	Yes n= 110	No n= 30	Yes n=72	No n=30	Yes n= 111	No n=55	Yes n= 293	No n= 115
Stop driving	87.3	83.3	90.3	80	89.2	94.5	88.7	87.8
Contact DVLA	54.5	53.3	58.3	60	53.2	50.9	54.9	53.9

- It is not routine in most hospitals to ask patients who have had a seizure about driving – despite the obvious road safety implications for themselves and others.
- When driving status was asked about, significant numbers appear not to have been given advice. However, we do not know which patients were drivers and which were not. It is likely that the majority of those with no history of epilepsy or seizure were holders of a driving license. If driving status was not asked about, **very** few patients had any advice
- In the small number given advice most were told not to drive, but only half were told to inform the DVLA.

Conclusion – the first question re documenting driving is probably the most important indicator question. If the question was not asked it's rare for anything to follow. And it's a simple question that should be documented for **every** patient with a seizure. In epilepsy patients this could be a "breakthrough seizure" that means suspension of driving etc. You **cannot** presume the patient is not driving because of past advice. In the other patient groups – it should be mandatory… but is not.

Was management of future seizures discussed with the patient or carers?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,476	**n=28**	n=561	**n=2**	n=676	**n=1**	n=3,717	**n=31**
Yes	29.4	**39.3**	26.7	**50**	26.8	**100**	28.5	**41.9**
No	17	**10.7**	17.6	**0**	15.4	**0**	16.8	**9.7**
Don't know	53.2	**50**	54.2	**50**	57	**0**	54	**48.4**

National figures for all patients

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	9.1	0.0	0.0	10.0
UPPER QUARTILE	47.5	43.7	50.0	43.3
MAX	90.0	100.0	100.0	86.2

It is best medical practice (GMC good guidance) that the management should always be discussed. The letter to the GP should include what the patient has been told. As each seizure is an indication of treatment failure, these low numbers are worrying. However, the ranges above show it is possible for this to be done for each patient.

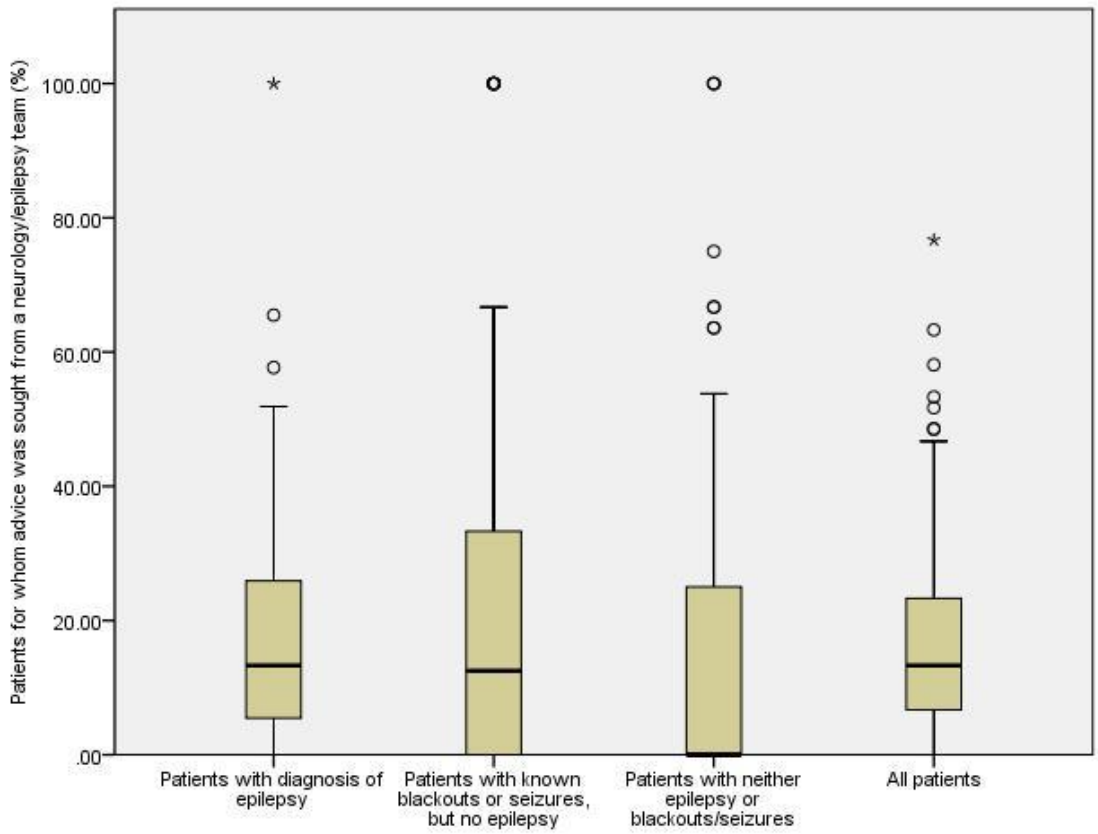
NEUROLOGY/EPILEPSY TEAM ASSESSMENT

Percentage of patients for whom it is documented that at any point in time advice was sought from a neurology / epilepsy team, or an assessment taken by a neurologist or epilepsy specialist: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,492	**n=28**	n=564	**n=2**	n=695	**n=1**	n=3,755	**n=31**
Advice sought	17.3	**3.6**	18.8	**0**	15.8	**0**	17.2	**3.2**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	5.4	0.0	0.0	6.7
UPPER QUARTILE	25.9	33.3	25.0	23.3
MAX	100.0	100.0	100.0	76.7

Figure 6: Distribution of number of patients for whom advice was sought from a neurology/epilepsy team across sites



Where advice was sought, from whom was it sought?: %

	National audit n=647	**Your site n=1**
Epilepsy Specialist Nurse	9.1	**0**
Neurologist/ Paediatric neurologist	86.6	**100**
Neuropsychiatrist	0.9	**0**
Neurosurgeon	2.8	**0**
Paediatrician*	5.1	**0**

*for paediatrician the denominator used is those patients aged 20 or under

The use of specialist input varies massively – but the median figures are **low** – see below with data on referral post visit.

Was the patient referred to any of the following specialists?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n= 2,476	**n=28**	n= 561	**n=2**	n= 676	**n=1**	n= 3,717	**n=31**
Epilepsy Service/First Fit Clinic	4.2	**0**	13	**0**	24.6	**0**	9.3	**0**
Epilepsy Specialist Nurse	5.7	**0**	3	**0**	3.4	**0**	4.9	**0**
GP with special interest in epilepsy (GPSI)	1.9	**35.7**	0.4	**50**	0.3	**100**	1.3	**38.7**
Learning disability psychiatrist	0.9	**0**	0	**0**	0.2	**0**	0.6	**0**
A neurologist at this Trust/Health Board	20.1	**7.1**	23.9	**0**	19.7	**0**	20.6	**6.5**
A neurologist at another Trust/Health Board	7.9	**7.1**	7.1	**0**	2.8	**0**	6.9	**6.5**

Of those with no history of blackouts only 25% were referred to epilepsy/first fit service, 23% to a neurologist and 3% to epilepsy nurse (total 51%).

Of the patients who were referred, did they attend their appointment?

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
Epilepsy Service/First Fit Clinic	n=105 61	**n=0** **NA**	n=73 64.4	**n=0** **NA**	n=166 56	**n=0** **NA**	n=344 59.3	**n=0** **NA**
Epilepsy Specialist Nurse	n=142 47.2	**n=0** **NA**	n=17 52.9	**n=0** **NA**	n=23 73.9	**n=0** **NA**	n=182 51.1	**n=0** **NA**
GP with special interest in epilepsy (GPSI)	n=46 10.9	**n=10** **0**	n=2 0.0	**n=1** **0**	n=2 0.0	**n=1** **0**	n=50 10.0	**n=12** **0**
Learning disability psychiatrist	n=22 22.7	**n=0** **NA**	n=0 NA	**n=0** **NA**	n=1 0	**n=0** **NA**	n=23 21.7	**n=0** **NA**
A neurologist at this Trust/Health Board	n=498 51	**n=2** **0**	n=134 59	**n=0** **NA**	n=133 64.7	**n=0** **NA**	n=765 54.8	**n=2** **0**
A neurologist at another Trust/Health Board	n=196 13.8	**n=2** **50**	n=40 27.5	**n=0** **NA**	n=19 42.1	**n=0** **NA**	n=256 18.4	**n=2** **50**

Even with inadequate referral patterns, the take-up of the service is "patchy".

It is also of interest to look at how many patients had any neurology input during their attendance at hospital or were referred as an outpatient for such, versus those for whom neither of these things happen. For this, we classified patients as fulfilling this criteria if any of the following were true:

- they were transferred to a neurology ward from ED
- they were under the care of a neurologist at some point in their hospital stay
- advice was sought from a neurologist regarding the patient
- they were referred to a neurology specialist as an outpatient

The results are as follows:

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n= 2,476	**n=28**	n= 561	**n=2**	n= 676	**n=1**	n= 3,717	**n=31**
Had some form of neurology input or referral	40.5	**50**	45.0	**50**	45.9	**100**	42.4	**51.6**

Neurological input or referral at any time split by whether the patient has been seen in the past 12 months by a medical specialist*: %

	(National audit)			
	Patients with diagnosis of epilepsy n= 842	Patients with known blackouts or seizures, but no epilepsy n= 108	Patients with neither epilepsy or blackouts/seizures n= 39	All patients n= 991
Seen in past 12 months	63.3	66.7	61.5	63.6

	(National audit)			
	Patients with diagnosis of epilepsy n= 1,650	Patients with known blackouts or seizures, but no epilepsy n= 456	Patients with neither epilepsy or blackouts/seizures n= 656	All patients n= 2,764
Not seen in past 12 months	28.7	39.9	45.3	34.4

*The medical specialists are those who are listed in the question on page 15.

APPENDICES

APPENDIX ONE

NASH Steering Committee

Professor Tony Marson (Joint Study Lead) – University of Liverpool
Professor Mike Pearson (Joint Study lead) – University of Liverpool
Dr John Craig – Representative for Northern Ireland
Dr Colin Dunkley – Representative for the British Paediatric Neurology Association
Ms Melesina Goodwin – Representative for the Epilepsy Nurses Association
Dr Paul Jarman – Representative for the Association of British Neurologists
Dr John Paul Leach – Representative for Scotland
Dr Stephen Nash – Representative for the College of Emergency Medicine
Ms Angela Pullen – Representative for Epilepsy Action
Professor Phil Smith – Representative for Wales and International League Against Epilepsy

Dr Duncan Appelbe – Study IT Manager
Dr Jamie Kirkham – Study Statistician
Dr Pete Dixon – Study Coordinator

APPENDIX TWO

Participating Sites

Aberdeen Royal Infirmary – NHS Grampian
Addenbrookes Hospital – Cambridge University Hospitals NHS Foundation Trust
Airedale General Hospital – Airedale NHS Foundation Trust
Antrim Hospital – Northern Health and Social Care Trust
Arrowe Park Hospital – Wirral University Teaching Hospital NHS Foundation Trust
Basildon University Hospital - Basildon and Thurrock University Hospital NHS Foundation Trust
Basingstoke Hospital – Basingstoke and North Hampshire NHS Foundation Trust
Bedford Hospital – Bedford Hospital NHS Trust
Birmingham Heartlands Hospital – Heart of England NHS Foundation Trust
Bradford Royal Infirmary – Bradford Teaching Hospitals NHS Foundation Trust
Calderdale Royal Hospital – Calderdale and Huddersfield NHS Foundation Trust
Central Middlesex Hospital – North West London Hospitals NHS Trust
Charing Cross Hospital – Imperial College Healthcare NHS Trust
Chelsea & Westminster Hospital - Chelsea & Westminster Hospitals NHS Foundation Trust
Cheltenham General Hospital – Gloucestershire Hospitals NHS Foundation Trust
City Hospital Birmingham – Sandwell and West Birmingham Hospitals NHS Trust
Conquest Hospital – East Sussex Healthcare NHS Trust
Countess of Chester Hospital – Countess of Chester Hospital NHS Foundation Trust
Craigavon Area Hospital – Southern Health and Social Care Trust
Crosshouse Hospital – NHS Ayrshire & Arran
Darent Valley Hospital – Dartford and Gravesham NHS Trust
Derriford Hospital – Plymouth Hospitals NHS Trust
Diana Princess of Wales Hospital – Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Doncaster Royal Infirmary – Doncaster and Bassetlaw Hospitals NHS Foundation Trust
Dorset County Hospital – Dorset County Hospital NHS Foundation Trust
Ealing Hospital – Ealing Hospital NHS Trust
Edinburgh Royal Infirmary – NHS Lothian
Fairfield General Hospital – The Pennine Acute Hospitals NHS Trust
Frenchay Hospital – North Bristol NHS Trust
Frimley Park Hospital – Frimley Park Hospital NHS Foundation Trust
Furness General Hospital – University Hospitals of Morecambe Bay NHS Foundation Trust
Glasgow Royal Infirmary – NHS Greater Glasgow and Clyde
Gloucestershire Royal Hospital – Gloucestershire Hospitals NHS Foundation Trust
Good Hope Hospital – Heart of England NHS Foundation Trust
Horton General Hospital – Oxford University Hospitals NHS Trust
Huddersfield Royal Infirmary – Calderdale and Huddersfield NHS Foundation Trust
Hull Royal Infirmary – Hull and East Yorkshire Hospitals NHS Trust
Ipswich Hospital – The Ipswich Hospital NHS Trust
James Cook University Hospital – South Tees Hospitals NHS Foundation Trust
John Radcliffe Hospital – Oxford University Hospitals NHS Trust
Kent & Sussex Hospital – Maidstone & Tunbridge Wells NHS Trust
Kings College Hospital – Kings College Hospital NHS Foundation Trust
Kings Mill Hospital – Sherwood Forest Hospitals NHS Foundation Trust
Kingston Hospital – Kingston Hospital NHS Trust
Leeds General Infirmary – The Leeds Teaching Hospitals NHS Trust
Leighton Hospital – Mid Cheshire Hospitals NHS Foundation Trust
Lister Hospital – East and North Hertfordshire NHS Trust

Luton & Dunstable Hospital – Luton & Dunstable Hospital NHS Foundation Trust
Manor Hospital – Walsall Healthcare NHS Trust
Milton Keynes General Hospital – Milton Keynes Hospital NHS Foundation Trust
Nevill Hall Hospital – Aneurin Bevan Health Board (Bwrdd Iechyd Aneurin Bevan)
New Cross Hospital – The Royal Wolverhampton Hospitals NHS Trust
Newham General Hospital – Newham University Hospital NHS Trust
Norfolk and Norwich University Hospital – Norfolk and Norwich University Hospitals NHS Foundation Trust
North Manchester General Hospital – The Pennine Acute Hospitals NHS Trust
North Middlesex Hospital – North Middlesex Hospital NHS Trust
Northampton General Hospital – Northampton General Hospital NHS Trust
Peterborough City Hospital – Peterborough and Stamford Hospitals NHS Foundation Trust
Pinderfields General Hospital – The Mid Yorkshire Hospitals NHS Trust
Poole General Hospital – Poole Hospital NHS Foundation Trust
Prince Charles Hospital – Cwm Taf health board (Bwrdd Iechyd Cwm Taf)
Princess Royal Hospital - Haywards Heath – Brighton and Sussex University Hospitals NHS Trust
Princess Royal University Hospital – South London Healthcare NHS Trust
Queen Alexandra Hospital – Portsmouth Hospitals NHS Trust
Queen Elizabeth Hospital King's Lynn – The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
Queen Margaret Hospital – Dunfermline – NHS Fife
Queen's Hospital – Burton – Burton Hospitals NHS Foundation Trust
Queens Hospital – Romford – Barking, Havering and Redbridge University Hospitals NHS Trust
Queen's Medical Centre – Nottingham – Nottingham University Hospitals NHS Trust
Rochdale Infirmary – The Pennine Acute Hospitals NHS Trust
Rotherham Hospital – The Rotherham NHS Foundation Trust
Royal Albert Edward Infirmary – Wrightington, Wigan and Leigh NHS Foundation Trust
Royal Berkshire Hospital – The Royal Berkshire NHS Foundation Trust
Royal Blackburn Hospital –East Lancashire Hospitals NHS Trust
Royal Bournemouth General Hospital –The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
Royal Cornwall Hospital –Royal Cornwall Hospitals NHS Trust
Royal Derby Hospital – Derby Hospitals NHS Foundation Trust
Royal Devon and Exeter Hospital –Royal Devon & Exeter NHS Foundation Trust
Royal Free Hospital – Royal Free Hampstead NHS Trust
Royal Gwent Hospital – Aneurin Bevan Health Board (Bwrdd Iechyd Aneurin Bevan)
Royal Lancaster Infirmary – University Hospitals of Morecambe Bay NHS Foundation Trust
Royal Liverpool University Hospital – The Royal Liverpool and Broadgreen University Hospitals NSH Trust
Royal London Hospital – Barts and The London NHS Trust
Royal Oldham Hospital – The Pennine Acute Hospitals NHS Trust
Royal Surrey Hospital – Royal Surrey County Hospital NHS Foundation Trust
Royal Sussex County Hospital – Brighton and Sussex University Hospitals NHS Trust
Royal United Hospital – Royal United Hospital Bath NHS Trust
Royal Victoria Infirmary – The Newcastle upon Tyne Hospitals NHS Foundation Trust
Russells Hall Hospital – The Dudley Group of Hospitals NHS Foundation Trust
Salford Royal –Salford Royal NHS Foundation Trust
Salisbury District Hospital – Salisbury NHS Foundation Trust
Scarborough General Hospital – Scarborough and North East Yorkshire Healthcare NHS Trust
Scunthorpe General Hospital – Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Solihull Hospital – Heart of England NHS Foundation Trust

South Tyneside District Hospital –South Tyneside NHS Foundation Trust
Southampton General Hospital – University Hospital Southampton NHS Foundation Trust
Southern General Hospital – NHS greater Glasgow and Clyde
Southport District General Hospital – Southport and Ormskirk NHS Trust
St George's Hospital – St George's Healthcare NHS Trust
St James' University Hospital – The Leeds Teaching Hospitals NHS Trust
St Mary's Hospital – Imperial College Healthcare NHS Trust
St Mary's Hospital, IOW – NHS Isle of Wight
St Richard's Hospital – Western Sussex Hospitals NHS Trust
St Thomas' Hospital – Guy's and St Thomas' NHS Foundation Trust
Stafford Hospital – Mid Staffordshire NHS Foundation Trust
Stoke Mandeville Hospital – Buckinghamshire Healthcare NHS Trust
Sunderland Royal Hospital –City Hospitals Sunderland NHS Foundation Trust
The Hillingdon Hospital –The Hillingdon Hospitals NHS Foundation Trust
The Whittington Hospital – Whittington Health NHS Trust
Trafford General Hospital – Trafford Healthcare NHS Trust
Ulster Hospital – South Eastern Health and Social Care Trust
University Hospital Aintree – Aintree University Hospitals NHS Foundation Trust
University Hospital Coventry – University Hospitals Coventry and Warwickshire NHS Trust
University Hospital of Hartlepool – North Tees and Hartlepool NHS Foundation Trust
University Hospital of North Tees – North Tees and Hartlepool NHS Foundation Trust
University Hospital of Wales – Cardiff and Vale University Health Board (Bwrdd Iechyd Prifysgol Caerdydd a'r Fro)
Warrington Hospital – Warrington and Halton Hospitals NHS Foundation Trust
Watford General Hospital – West Hertfordshire Hospitals NHS Trust
West Suffolk Hospital –West Suffolk Hospital NHS Trust
Western Infirmary - Glasgow – NHS Greater Glasgow and Clyde
Weston General Hospital – Weston Area Health NHS Trust
Wexham Park Hospital –Heatherwood and Wexham Park Hospitals NHS Foundation Trust
Whiston Hospital –St Helens & Knowsley Teaching Hospitals NHS Trust
Withybush General Hospital – Hywle Dda Health Board (Bwrdd Iechyd Hywel Dda)
Worthing Hospital – Western Sussex Hospitals NHS Trust
Wycombe General Hospital –Buckinghamshire Healthcare NHS Trust
Wythenshawe Hospital – University Hospital of South Manchester NHS Foundation Trust

APPENDIX THREE

Clinical Proforma Questions

Q1.1 Auditor discipline
Options:
Doctor
Nurse
Other health professional

Q2.2 Age

2.3 Gender
Options:
Male
Female

Q3.1 Is there a statement that the patient is known to have epilepsy?
Options:
Yes
No/Not recorded

Q3.2 Is there documentation that the patient has had previous seizures or blackouts?
Options:
Yes
No/Not recorded

Q3.2a Was the patient's previous seizure or blackout provoked by alcohol?
Options:
Yes
No
Not recorded

Q3.2b Was the patient's previous seizure or blackout provoked by head injury?
Options:
Yes
No
Not recorded

Q3.2c Was the patient's previous seizure or blackout provoked by other?
Options:
Yes
No
Not recorded

Q3.3 On attendance which anti-epileptic drugs was the patient being prescribed?
Options:
Valproate/Epilim/Epilim Chrono/Orlept
Lamotrigine/Lamictal
Carbamazepine/Tegretol/ Tegretol Retard
Levetiracetam/Keppra

Phenytoin/Epanutin
Clobazam/Frisium
Topirimate/Topamax
Diazepam/Valium
Clonazepam/Rivotril/ Rivatril
Pregabalin/Lyrica
Gabapentin/Neurontin
Zonisamide/Zonegran
Oxcarbazepine/Trileptal
Phenobarbital
Lacosmide/Vimpat
Primidone/Mysoline
Ethosuximide/Emeside/ Zarontin
Tiagabine/Gabatril
Vigabatrin/Sabril
Acetazolamide/Diamox
Eslicarbazepine Acetate/ Zebinix
Rufinamide/Inovelon
Oxazepam/Serax

Q3.4a Is it documented that the patient has seen an Epilepsy Specialist Nurse within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.4b Is it documented that the patient has seen a GPSI (neurology, epilepsy or neuropsychiatry) within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.4c Is it documented that the patient has seen a learning disability psychiatrist within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.4d Is it documented that the patient has seen a neurologist within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.4e Is it documented that the patient has seen a paediatrician within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.4f Is it documented that the patient has seen a paediatric neurologist within the previous 12 months?
Options:

Yes
No/Not recorded

Q3.4g Is it documented that the patient has seen a neurosurgeon within the previous 12 months?
Options:
Yes
No/Not recorded

Q3.5a Is the patient recorded as having a brain tumour?
Options:
Yes
No/Not recorded

Q3.5b Is the patient recorded as having cerebral palsy?
Options:
Yes
No/Not recorded

Q3.5c Is the patient recorded as having dementia?
Options:
Yes
No/Not recorded

Q3.5d Is the patient recorded as having a history of significant head injury?
Options:
Yes
No/Not recorded

Q3.5e Is the patient recorded as having a learning disability?
Options:
Yes
No/Not recorded

Q3.5f Is the patient recorded as having a stroke?
Options:
Yes
No/Not recorded

Q4.1 When did the patient arrive in the Emergency Department?
Time
Date

Q4.2 Mode of transport to Emergency Department
Ambulance 999 via GP
Ambulance 999 via 'passer by/carer'
Taxi / car (passenger)
Other – please specify
Not known

Q4.2a If either of the ambulance options are chosen, then when was the ambulance called?
Time

Date

Q4.3 Is there evidence of senior Emergency Department review, i.e. was the patient seen (or was there a consultation regarding the patient)?
Options:
Yes
No
Not recorded

Q4.3a Was this within 4 hours of arrival in the Emergency Department?
Options:
Yes
No
Not recorded

Q4.3b Were they seen by a consultant?
Options:
Yes
No
Not recorded

Q4.3a Were they seen by a ST4 or above?
Options:
Yes
No
Not recorded

Q5.1a Is it documented that clobazam was administered prior to arrival at hospital?
Options:
Yes
No

Q5.1a1 Who was the clobazam administered by?
Options:
Family member/carer
GP
Ambulance staff
Other - please specify

Q5.1b Is it documented that diazepam was administered prior to arrival at hospital?
Options:
Yes
No

Q5.1b1 Who was the diazepam administered by?
Options:
Family member/carer
GP
Ambulance staff
Other - please specify

Q5.1c Is it documented that lorazepam was administered prior to arrival at hospital?
Options:
Yes
No

Q5.1c1 Who was the lorazepam administered by?
Options:
Family member/carer
GP
Ambulance staff
Other - please specify

Q5.1d Is it documented that midazolam was administered prior to arrival at hospital?
Options:
Yes
No

Q5.1d1 Who was the midazolam administered by?
Options:
Family member/carer
GP
Ambulance staff
Other - please specify

Q5.1e Is it documented that paraldehyde was administered prior to arrival at hospital?
Options:
Yes
No

Q5.1b1 Who was the paraldehyde administered by?
Options:
Family member/carer
GP
Ambulance staff
Other - please specify

Q5.2 Had the seizure stopped by the time of arrival in the emergency room?
Options:
Yes
No
Unclear

Q5.2a What treatment was given in the emergency room?
Options:
IV diazepam
Rectal diazepam
Buccal midazolam
IV glucose
IV levetiracetam
IV lorazapam
IV phenobarbitol

IV phenytoin
IV thiamine / pabrinex
IV valproate
Rectal or intramuscular paraldehyde

Q6.1 Was the patient fully conscious upon arrival at the Emergency Department?
Options:
Yes
No
Don't know

Q6.2a Was the patient's temperature taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2a1 What was the patients' temperature?
Options:
Numeric figure

Q6.2a2 Was their temperature taken within 20 minutes of arrival?
Options:
Yes
No/Don't know

Q6.2b Was the patient's pulse taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2c Was the patient's blood pressure taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2d Was the patient's oxygen saturation taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2e Was the patient's respiratory rate taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2f Was the patient's GCS taken in the Emergency Department?
Options:
Taken
Not taken/Don't know

Q6.2f1 What was their GCS score?
Options:
1-15

Q6.3 In the 4 hours following the patient's arrival at the Emergency Department was a neuro obs chart in place?
Options:
Yes
No/Don't know

Q6.4 Where was the patient transferred or admitted to, directly from the Emergency Department?
Options:
Clinical decision unit
ED observational ward
EMU or equivalent
Intensive Care Unit
Medical decision unit
Medical ward
Neurology ward
Other - please specify
Discharged

Q6.4a For all patients except those who were discharged (or for whom the answer to the previous question was missing), who took over the care of the patient during admission?
Options:
Neurologist
General physician
Other
Remained under care of Emergency Department

Q6.4b For patients who were moved to the Intensive Care Unit, what were they treated with?
Options:

Heminevrin	Yes; No; Don't know
Midazolam	Yes; No; Don't know
Phenobarbitol/phenobarbitone	Yes; No; Don't know
Propofol	Yes; No; Don't know
Thiopentone	Yes; No; Don't know
Other - please specify	Yes; No; Don't know

Q6.5 Was an eyewitness to the seizure contacted?
Options:
Yes
No
Don't know

Q6.5a Is there a statement that the attack was not observed?
Options:
Yes
No

Q6.6 Is there documentation that the patient was asked as to whether or not they are a driver?
Options:
Yes
No
Not applicable

Q6.7 Is there documentation of the patients' general alcohol intake?
Options:
Yes
No

Q6.7a How is their drink intake best classified?
Options:
Excessive
Normal
Low

Q6.8 In the week prior to arrival at the Emergency Department is it documented that the patient has been on an alcoholic binge?
Options:
Yes
No

Q6.9 Is there documentation that the patient does or does not use illicit drugs?
Options:
Yes
No

Q6.9a Are they a user or a non-user?
Options:
User
Non-user

Q6.9b Which drugs do they use?
Options:
Cannabis
Opiates
Stimulants
Other - please specify

Q6.10 In the 24 hours prior to arrival at the Emergency Department is it documented that the patients has been using illicit drugs?
Options:
Yes
No

Q6.11a Is there documentation of a fundi examination being undertaken at any time during attendance at the Emergency Department?
Options:
Yes
No

Q6.11b Is there documentation of a plantar examination being undertaken at any time during attendance at the Emergency Department?
Options:
Yes
No

Q7.1 Is it documented that at any point in time advice was sought from a neurology / epilepsy team, or an assessment taken by a neurologist or epilepsy specialist?
Options:
Yes
No

Q7.1a From whom was advice sought?
Options:
Epilepsy Specialist Nurse
Neurologist
Neuropsychiatrist
Neurosurgeon
Paediatrician
Paediatric neurologist

Q8.1a Were antiepileptic drug level investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.1b Were CT (head) investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.1c Were ECG investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.1d Were EEG investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.1e Were glucose levels/BM investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.1f Were MRI (head) investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No

Q8.2 Did the patient die during their admission?
Options:
Yes
No

Q8.2a What was the cause of death?
Options:
Free text entries

Q8.3a Was a CT (head) investigation requested as an outpatient following discharge?
Options:
Yes
No

Q8.3b Was a EEG investigation requested as an outpatient following discharge?
Options:
Yes
No

Q8.3c Was a MRI (head) investigation requested as an outpatient following discharge?
Options:
Yes
No

Q8.3d Was a 12 lead ECG investigation requested as an outpatient following discharge?
Options:
Yes
No

Q9.1 What was the diagnosis at discharge/death?
Options:
Blackout with seizure markers, not sure if seizure
Syncope/faint
First unprovoked seizure
Unprovoked seizures with history of previous seizures, but no current epilepsy diagnosis
Seizure in someone with established diagnosis of epilepsy
Provoked seizure – alcohol induced
Provoked seizure – drug induced
Provoked seizure – head injury
Provoked seizure – acute stroke
Psychogenic non-epileptic attack / pseudoseizure
Self-discharged
Other - please specify
Not recorded

Q9.2 Was the patient sent home on any antiepileptic drugs?
Options:
Yes
No/Don't know

Q9.2a Which drugs were they sent home on?
Options:
Valproate/Epilim/Epilim Chrono/Orlept
Lamotrigine/Lamictal
Carbamazepine/Tegretol/ Tegretol Retard
Levetiracetam/Keppra
Phenytoin/Epanutin
Clobazam/Frisium
Topirimate/Topamax
Diazepam/Valium
Clonazepam/Rivotril/ Rivatril
Pregabalin/Lyrica
Gabapentin/Neurontin
Zonisamide/Zonegran
Oxcarbazepine/Trileptal
Phenobarbital
Lacosmide/Vimpat
Primidone/Mysoline
Ethosuximide/Emeside/ Zarontin
Tiagabine/Gabatril
Vigabatrin/Sabril
Acetazolamide/Diamox
Eslicarbazepine Acetate/ Zebinix
Rufinamide/Inovelon
Oxazepam/Serax

Q9.3 Was advice about driving to the patient given?
Options:
Yes
No
Don't know
Not applicable (patient does not drive)

Q9.3a Was it that they should stop driving?
Options:
Yes
No/Don't know

Q9.3b Was it that they should inform DVLA?
Options:
Yes
No/Don't know

Q9.4 Was the management of future seizures discussed with the patients or carers?
Options:
Yes

No
Don't know

10.1a Was the patient referred to an epilepsy service or first fit clinic?
Options:
Yes
No
Don't know

10.1b Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1c What was the date of their appointment?
Options:
Free text
Date not known

10.1d What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause
Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

10.1e Was the patient referred to an epilepsy specialist nurse?
Options:
Yes
No
Don't know

10.1f Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1g What was the date of their appointment?
Options:
Free text
Date not known

10.1h What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause

Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

10.1i Was the patient referred to a GPSI epilepsy?
Options:
Yes
No
Don't know

10.1j Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1k What was the date of their appointment?
Options:
Free text
Date not known

10.1l What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause
Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

10.1m Was the patient referred to a learning disability psychiatrist?
Options:
Yes
No
Don't know

10.1n Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1o What was the date of their appointment?
Options:
Free text
Date not known

10.1p What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause
Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

10.1q Was the patient referred to a neurologist at this Trust / Health Board?
Options:
Yes
No
Don't know

10.1r Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1s What was the date of their appointment?
Options:
Free text
Date not known

10.1t What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause
Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

10.1u Was the patient referred to a neurologist at another Trust / Health Board?
Options:
Yes
No
Don't know

10.1v Did the patient attend their appointment?
Options:
Yes
No
Don't know

10.1w What was the date of their appointment?
Options:

Free text
Date not known

10.1x What was their diagnosis?
Options:
Blackout of uncertain cause
Blackout with other cardiac cause
Epilepsy
First epileptic seizure
Non epileptic attack disorder (NEAD)
Syncope/fait/low blood pressure
Other - please specify

Institutional Proforma Questions

Q1.1 How many attendances by patients aged 16 or over were there at your hospital ED in the last year?
Options:
Free text

Q1.2 How many patients aged 16 or over attended with a seizure in the full year to March 2010?
Options:
Free text

Q1.3 How many medical emergency admissions of patients aged 16 or over did your hospital admit in the year to March 2010?
Options:
Free text

Q1.4 Of these emergency medical admissions - how many were coded (at discharge) with one of the ICD codes listed in the help text i.e. admitted with a seizure?
Options:
Free text

Q2.1a Does your Trust have a written policy for management of patients with first seizures?
Options:
Yes
No
Under development/intended

Q2.1b Does your Trust have a written policy for management of status epilepticus?
Options:
Yes
No
Under development/intended

Q2.1c Does your Trust have a written policy for the pathway for onward referral of patients presenting with seizures?
Options:
Yes
No
Under development/intended

Q2.2 If a patient's seizure has stopped but the patient needs to be observed or admitted - where would they go to from the ED?
Options:
Observation ward
Medial admissions/assessment unit
General ward
Neurology ward
ITU
Other - please specify

Q3.1 Does your trust have a neurosurgeon on the staff?
Options:
Yes
No

Q3.2 Do you have a neurology ward?
Options:
Yes
No

Q3.2a If Yes - Does it take admissions from ED?
Options:
Yes
No

Q3.3 How many general neurology clinics are conducted per week?
Options:
None
1
2
3
4
More

Q3.4 How many dedicated epilepsy clinics (i.e. a clinic that only sees epilepsy-related problems) are conducted per week?
Options:
None
1
2
3
4
More

Q3.5 Do you have a neurology consultancy service available on the wards?
Options:
Yes
No

Q3.5a If yes; for how many days is that available?
Options:
1-2
3-5

Q3.6 Does your Trust have access to an Epilepsy Specialist Nurse?
Options:
Yes
No

Q3.6a If Yes - How many Epilepsy Specialist Nurses are there?
Options:

Free text

Q3.6b What is their availability, i.e. how soon can an appointment be arranged?
Options:
0-2 weeks
3-4 weeks
5-6 weeks
7+ weeks

Q4.1 Do you have an MRI scanner?
Options:
Yes
No

Q4.1a If yes, what is the waiting time for a routine MRI scan?
Options:
0-2 weeks
3-4 weeks
5-6 weeks
7+ weeks

Q4.2a Do you have access to routine EEGs; - From this Site?
Options:
Yes
No

Q4.2b Do you have access to routine EEGs; - From another Site?
Options:
Yes
No

Q4.3 Which is your tertiary neurology centre?
Options:
Free text

Q4.4 How far away is it?
Options:
0-20 miles
20-50 miles
More

APPENDIX FOUR

ICD10 Codes

ICD10	Description
G40.0	Localization-related (focal)(partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset
G40.1	Localization-related (focal)(partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures
G40.2	Localization-related (focal)(partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures
G40.3	Generalized idiopathic epilepsy and epileptic syndromes
G40.4	Other generalized epilepsy and epileptic syndromes
G40.5	Special epileptic syndromes
G40.6	Grand mal seizures, unspecified (with or without petit mal)
G40.7	Petit mal, unspecified, without grand mal seizures
G40.8	Other epilepsy
G40.9	Epilepsy, unspecified
G41.0	Grand mal status epilepticus
G41.1	Petit mal status epilepticus
G41.2	Complex partial status epilepticus
G41.8	Other status epilepticus
G41.9	Status epilepticus, unspecified