



# National Audit of Seizure Management in Hospitals

St. Elsewhere's Hospital  
Paediatric Clinical Report,  
April 2014



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## FOREWORD

This is the report from a pilot paediatric epilepsy audit, which follows on from two nationwide adult audits, and includes data from over 440 paediatric patients across 15 sites (from 13 Trusts/Health Boards) in north west England and north Wales.

Like the adult audit, the aims of the paediatric 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, patient organisations and NHS managers in the hope that together they can act to effect improvement.

Acute seizures occur at all ages, and in children their causes and outcomes may be different than in adults. Consequently, it was considered appropriate and important that any repeat audit of acute seizure management should also include children. National audits have been undertaken in the outpatient management of children with epilepsy (Epilepsy12 - <http://www.rcpch.ac.uk/epilepsy12>), and the study lead for the paediatric NASH audit (Richard Appleton) participated in a recent prospective national audit of mortality in children with epilepsy and the management of acute prolonged seizures (published in September 2013). This was conducted through the Royal College of Paediatrics and Child Health (RCPCH) and Healthcare Quality Improvement Programme (HQIP). (Child Health Review [CHR] –UK ‘Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies’ - <http://www.hqip.org.uk/assets/NCAPOP-Library/NCAPOP-2013-14/CHRUKModule-B-v5.pdf>). It was considered that NASH 2 would provide additional, emergency data to complement the findings of Epilepsy12 and the CHR-UK Report.

Both adult NASH audits provided comparative data on the process of care and outcomes for individual sites against a benchmark of all other participating UK sites. They identified areas where care and processes are good, and not so good, thus highlighting areas where change, and perhaps investment, are required. They showed:

- that many patients with active epilepsy are not being seen within specialist services, and are not receiving optimal therapy, i.e. opportunities to prevent seizures and thereby avoid acute hospital attendance and admission are being missed.
- when patients were seen, their assessment and management in the ED and on the wards was often sub-optimal; and
- less than half were referred onwards to specialist services able to improve their care plans. This is a large financial burden on the NHS. If more patients get to see epilepsy specialists and receive appropriate regimes and, in addition, appropriate protocols are put in place for acute seizures management, then, quite apart from the benefits to the patients, fewer admissions and fewer ED attendances would bring about large savings, and diminish the burden on clearly overstretched emergency services.

The findings of the NASH2 paediatric audit have shown some similarities, but also some differences, when compared with the adult NASH2 audits. The focus of NASH2 (paediatrics) was on the management of acute seizures in the hospital emergency departments. This was not addressed in Epilepsy12 but was addressed as a component of care in the CHR-UK audit. The conclusions of the CHR-UK Report was that the care (management) of acute seizures in the emergency department and the high-dependency/intensive care units was generally of an acceptable or high standard. In

contrast, the standard of care (management) by the ambulance service was not as good and was often unclear, variable and inconsistent with community and hospital-delivered care. Clearly, the management of acute seizures by the ambulance and paramedic service may impact on the subsequent care of the child in the emergency department and any consequent admission.

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](mailto:info@nashstudy.org.uk)).

We believe that the wide variations in care quality in both NASH1 and NASH2 strongly argues for changes in the way care is delivered. If epilepsy care is to change then action is needed to address the whole spectrum across primary care, secondary and tertiary care, i.e. the whole patient pathway. This requires the active participation of many different individuals and so is likely to need CCGs and specialist commissioners to be actively involved. The paediatric audit is from only 15 sites, but shows similar patterns of variable care quality and suggests that the shortcomings in adult care may apply equally to paediatric units.

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 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 and toward improving care for patients.

Particular thanks are due to the Steering Committee for its helpful comments and advice and to Epilepsy Action, Epilepsy Society and SUDEP Action for providing invaluable advice from the patients' perspective.

Thanks are also due to external funders (Eisai, Viropharma, and UCB Pharma) for supplementing internal Liverpool funding of the audit.



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## EXECUTIVE SUMMARY

The 2011 National Audit of Seizure management in Hospitals (NASH1) was remarkable as the first ever comprehensive audit of this condition in the UK. 127 hospitals with an Emergency Department (ED) across the 4 home countries took part, and, in 2013, 154 hospitals took part in NASH2.

For the paediatric pilot audit, 15 hospitals from across the north west of England and north Wales have taken part and have provided clinical data on 30 consecutive paediatric patients presenting with a seizure (from January 1<sup>st</sup> 2013) detailing both process of care and clinical outcomes. Data were entered via an online system. This opened on June 21<sup>st</sup> 2013 and closed on October 25<sup>th</sup> 2013.

This report gives each site's clinical results benchmarked against all 15 sites (from 13 Trusts/Heath Boards) that completed the audit.

A seizure presenting to the ED 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 be considered 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 regional 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.

### Overall Picture

Two particular findings emerge:

- there is, as was found in the adult audit, a pattern within the data that high performing sites tend to perform well across most variables and *vice versa*; and
- for some data items, the variation between the best performing and least well performing sites is extremely wide. If some are able to achieve these standards, - why can't the rest?

As in the adult NASH audits, we have created a composite variable based on 6 items of care which cover the spectrum of the patient pathway across the patients' care pathway. While there can be some debate as to whether these are the most important 6 items, we use it as a proxy that reflects overall care, but we urge people **not to over interpret** such changes as absolute measures of care quality.

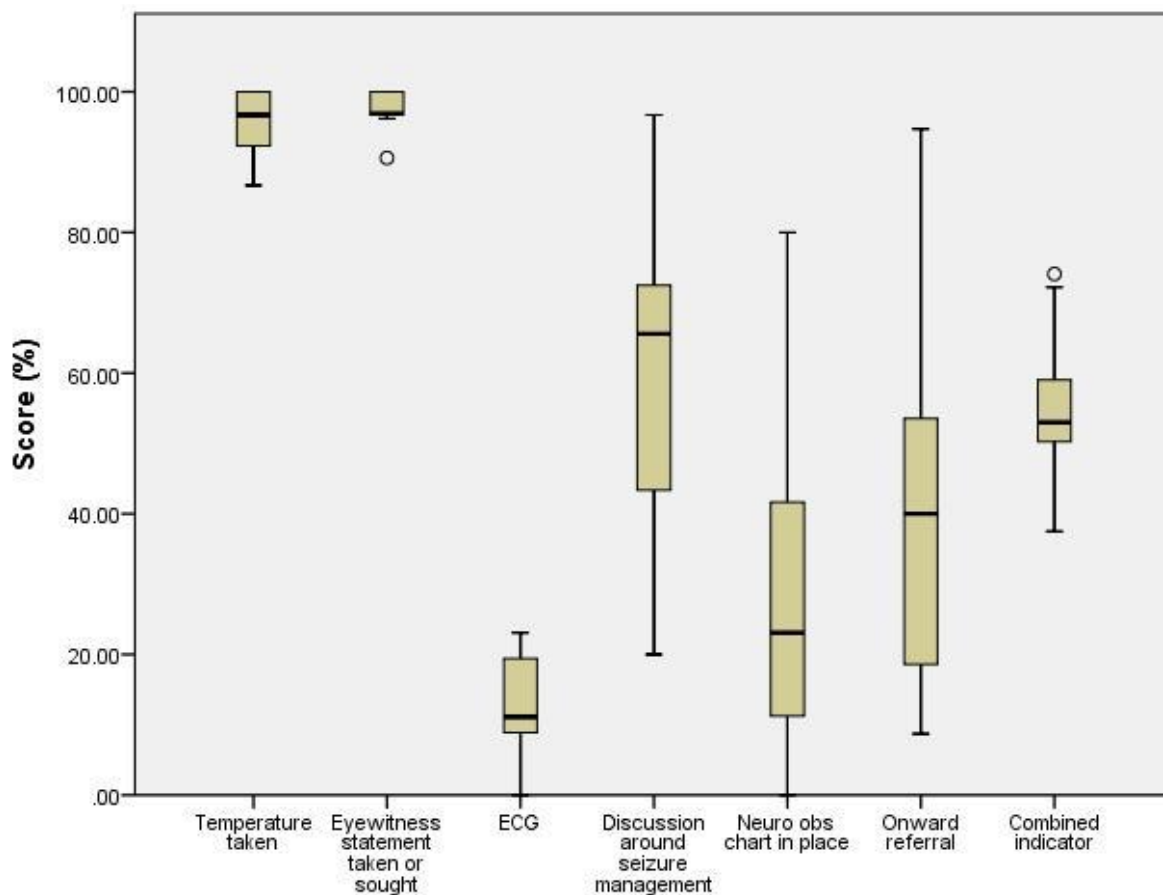
There are other reasons why a given site may have done better or worse which have not been, and cannot be, controlled for in an audit. These include different patient cohorts, different staff in post and differences in the way units are run. Each local unit needs to consider the data and work out for themselves what they can interpret from the data.

The table below shows the regional mean percentage, together with your site's figures.

	Regional mean	Your site
Temperature taken in the ED	95.6	<b>96.7</b>
Eyewitness statement taken or sought	97.8	<b>100</b>
ECG performed	12.7	<b>20</b>
Evidence that the management of future seizures was discussed with the patient or carers	59.4	<b>26.7</b>
A neurological observation chart was completed	27.5	<b>3.3</b>
For those patients whose attendance was not due to a febrile seizure, there was evidence that they were referred on to any of the following: epilepsy service/first fit clinic, epilepsy specialist nurse, neurologist, paediatrician with expertise in epilepsy	55.6	<b>50</b>
Mean of the 6 variables above	59.8	<b>49.4</b>

The graph below shows the variability across all sites.

Figure 1: Key indicators and overall score for all sites



## 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.

NASH data has found similar patterns to that of the national stroke audit which was first done in 1998. The factor that changed stroke care was an attention to the organisation of care. Individuals need a system within which they can operate well and that means asking questions about the care we observe.

There is plenty within the audit to suggest that care could be better. The huge variability between hospitals shows that some can and do provide excellent care. For the other sites, there are plenty of local measures each hospital could consider to improve care.

Suggestions of how to organise epilepsy care are needed since simple exhortations to do things better are unlikely to be enough. Moreover, any system has to include ways in which primary, secondary and tertiary care can combine effectively to ensure patients have optimum control. How this can be achieved is not within the remit of this report, but there are suggestions being made and a recent Dublin paper (Iyer *et. al.*, Epilepsy Research and Treatment, vol. 2012, Article ID 273175, 7 pages, 2012. doi:10.1155/2012/273175) reports a dramatic reduction in hospital stays and re-attendances with their particular system. Such options suggest that better care may even prove to be cheaper care.

## The headline findings of the clinical audit were as follows:

### Clinical Data with Process of Care and Outcomes:

There were a total of 444 admissions registered. 53% of admissions were male and 66% were under 5 years of age.

- 19% of admissions were of patients who were known to have epilepsy
- 23% were of patients who were known to have had previous seizures or blackouts but did not have a known diagnosis of epilepsy; and
- 58% were of patients with no prior history of epilepsy or blackouts/seizures, i.e. this was their first seizure.

## Findings

**Previous ED attendance** – almost 60% of those patients with known epilepsy have had seizures necessitating a visit to ED in the past year

**Current specialist care**– 16% (1 in 6) of children with a diagnosis of epilepsy were recorded as having seen no specialist (including an epilepsy nurse specialist) in the previous 12 months

**Recording of data** – Of those patients who were recorded as not being conscious on arrival, 30% did not have their GCS recorded. The percentage of patients who have their GCS recorded in the group who are recorded as should be 100%, yet this is not done in 30% of cases. In addition, a neuro obs chart was not present in almost 60% of these patients who were not conscious on arrival.

**Evidence of Senior Emergency Department Review** – many patients are managed without a senior review, but of those who are, nearly all are seen within 4 hours of arrival at ED.

**Contacting eyewitnesses** – patients cannot describe their own seizure, so it is encouraging that for over 95% of patients an eyewitness statement was taken, or sought.



**Avoidance of unnecessary investigations** – of those children who arrived at ED after experiencing a febrile seizure, very few underwent the ‘usual’ investigations, i.e. EEG and MRI scans, that are undertaken in the evaluation of children with definite or probable epilepsy.

**Management of future seizures** – less than 60% of children were documented as having the management of future seizures discussed with them and their parent/carers

## Food for Thought

This pilot paediatric audit of almost 450 children has shown that much epilepsy care is sub-optimal, that there is still excessive variability between hospitals, but that some sites demonstrate that good care is possible. This affects primary, secondary and tertiary sectors

- There were opportunities to improve the primary care before the index seizure - more than half of patients might potentially have had the episode prevented with a more modern pharmacological approach, and most were not under specialist review
- Hospital assessment (eyewitness statements, neurological examinations, simple investigations and advice to patients) were hugely variable – but a number of hospitals show that this can be achieved for most, if not all, patients
- Onwards referral for specialist input occurred for less than half of patients with non-febrile seizures, and of those referred many did not attend. Data from Ireland suggests that active management can prevent future seizures and admissions
- Movements now need to be made to address the question of how the care can be changed

### 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/CG137> (epilepsies)

<http://guidance.nice.org.uk/CG109> (TLOC)

## Interpretation of the data in this report

In this report we describe the regional data and local figures in comparison. Because, on average, only 30 cases have been audited at each site a simple comparison of proportions using Chi Squared statistic requires a shift of absolute percentage change **in a single variable** of 30%, e.g. 40% to 70%. Anything less could have happened just by chance in that site.

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 trusts there is an opportunity to make improvements.

It is unlikely that concentrating on one aspect of care alone will solve the overall problem, and a more co-ordinated approach involving primary secondary and tertiary care will be needed to really make a difference.

## BACKGROUND

Epilepsy is common and for those with an established diagnosis, each presentation to an ED represents a “failure” in control. Also, those presenting with a first seizure require appropriate acute management and rapid access to seizures services.

Whilst there are many research studies in epilepsy that have summarised much of the evidence regarding treatment options for patients, little attention have been paid to assessing the organisation and delivery of epilepsy care across the UK. NASH 1 was the first ever national epilepsy audit in the UK and identified unacceptable variation in the quality of care, although some units are able to provide consistently good care given current resources.

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.

The management of epilepsy in children has significantly improved over the past decade at both tertiary but more importantly at secondary care level with the development of the ‘paediatrician with expertise in epilepsy’ and with steadily increasing expansion of these posts in district general hospitals. These paediatricians, often supported by an epilepsy nurse specialist, now provide a designated epilepsy and also ‘fits, faints and funny turns’ service at secondary care level. These secondary care services have been further enhanced with much closer clinical and educational networking with the tertiary care epilepsy specialists (paediatric neurologists) and the recent nationally-commissioned Children’s Epilepsy Surgery Service (CESS).

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 and emails to participants from the adult audit and to other known contacts were sent in to all Trusts/Health Boards in north west England and north Wales which had sites with EDs. 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.

Of the Trusts/Health Boards eligible to take part, 13 participated. Some Trusts had more than one site take part (whilst a small number took part at a Trust-wide level ) with the result that data was collected from 15 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**

The questions used in the audit were mostly the same as those in the adult audit. Feedback from the first audit and input from the steering group led to some new questions being added and some existing questions, and potential answers, being refined. In most instances where answer options were refined they were of a minor nature (e.g. “not documented” being used in NASH2 whereas “not recorded” was the option in NASH1).

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 mysql 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 was recorded in the system, or asked for by the e-forms. 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, 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 21<sup>st</sup> June and 25<sup>th</sup> October 2013. Anonymised data were requested for 30 consecutive patients who:

- a) were aged between one month and 16 years; 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 1<sup>st</sup> January 2013. 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 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.

### **Presentation of results**

The presentation of results is primarily comparative, using the national figures as the comparator. National figures are shown in plain text, with your own site's figures shown in bold. For a number of questions, results are split according to the patients' 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 15 sites within 13 NHS Trusts/Health Boards. 444 attendances at Emergency Departments from January 1<sup>st</sup> 2013 were available for analysis. The median number of attendances per site was 30, range 9-64.

You contributed **30** attendances to the analysis.

### Clinical proforma completed by: %

	National audit n=444	Your site n=30
Doctor	78.8	<b>100</b>
Nurse	10.1	<b>0</b>
Audit staff	7.0	<b>0</b>
Other	4.1	<b>0</b>

## DEMOGRAPHICS

### Age: %

	National audit n=444	Your site n=30
<5	65.5	<b>76.7</b>
5 and over	34.5	<b>23.3</b>

National median = 2 years

**Your site's median = 2 years**

Some of the data in the audit has been analysed (at a regional level) by the two age categories in the table above. For the sake of clarity these are not shown in the individual tables, but are summarised in a separate section towards the end of the report (page 38).

### Gender: %

	National audit n=444	Your site n=30
Males	53.2	<b>56.7</b>
Females	46.8	<b>43.3</b>

There was little difference in the gender make up between those aged under 5 and those aged 5 and over (45.7% female and 49.0% female respectively).

## Does the patient live in the geographical area covered by this Trust?: %

	National audit n=444	Your site n=30
Yes	90.5	<b>100</b>
No/Not documented	9.2	<b>0</b>

### National 'yes' figures

MIN	61.5
LOWER QUARTILE	87.3
UPPER QUARTILE	98.3
MAX	100.0

**COMMENT:** This question was recommended by a number of people in feedback to the NASH1 report. The rationale was that it would enable a more nuanced analysis of the data for certain questions. For instance, if a hospital has a large number of attendances from people who live in a different area, then some of the answers to questions about onward referral would be harder for them to answer. Due to the small number of patients coming from outside the Trusts' areas, we only ran such sub analyses at a regional level, and the differences were found to be minimal for most questions. Were there was a noticeable difference, this will be pointed out in comment sections.

## PREVIOUS SEIZURE HISTORY AND MANAGEMENT

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

	National audit n=444	Your site n=30
Yes	18.5	<b>13.3</b>
No/Not documented	81.3	<b>86.7</b>

### National 'yes' figures

MIN	3.3
LOWER QUARTILE	12.0
UPPER QUARTILE	25.0
MAX	46.7

### Does the patient have a written care plan in place?: %

	National audit n=82	Your site n=4
Yes	48.8	<b>75</b>
No/Not documented	51.2	<b>25</b>

**COMMENT:** This question suggests that 49% of all patients with known epilepsy had a written care plan in place before this episode, which is higher than other data suggests to be the case. We are concerned that this new question may have been misinterpreted (for instance it may have been taken to refer to a rescue care plan, rather than an overall care plan) and welcome comments.

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

	National audit n=444	Your site n=30
Yes	41.7	<b>26.7</b>
No/Not documented	58.3	<b>73.3</b>

### National 'yes' figures

MIN	26.7
LOWER QUARTILE	30.6
UPPER QUARTILE	50.0
MAX	66.7

## 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=82; <5yrs=29, 5 and over=53)
2. Those who are known to have previous seizures or blackouts, but not epilepsy (n=104; <5yrs=63, 5 and over=41)
3. Those who are not known to have either epilepsy or previous seizures or blackouts (n=257; <5yrs=198, 5 and over=59)

NB 1 patient cannot be assigned to these categories because of missing data.

These three patient 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

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

	National audit n=185	Your site n=8
Yes	34.1	<b>0</b>
No	45.4	<b>37.5</b>
Not documented	18.9	<b>62.5</b>

National 'yes' figures	
MIN	0.0
LOWER QUARTILE	20.2
UPPER QUARTILE	44.4
MAX	78.6

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

	National audit n=185	Your site n=8
Yes	11.9	<b>50</b>
No	59.5	<b>0</b>
Not documented	28.1	<b>50</b>

National 'yes' figures	
MIN	0.0
LOWER QUARTILE	2.5
UPPER QUARTILE	19.8
MAX	75.0

The other factors included epilepsy (32%), syncope (27%), febrile convulsion (23%), CNS infection (4.5%), breath holding (4.5%) and not diagnosed (9%).

Questions were also asked as to whether the previous seizures were caused by alcohol or head injury. None of the patients were recorded to have had an alcohol-induced seizure, and a head injury was responsible for causing the previous seizure in 1.1% of patients (your site **0%**).

**COMMENT:** Overall 46.5% (IQR 38.5 to 55.1) recorded one or more known provoking factors.

## Has the patient attended this ED as a result of a seizure in 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Yes	59.8	<b>75</b>	56.7	<b>25</b>	3.1	<b>0</b>	26.1	<b>13.3</b>
No	29.3	<b>25</b>	38.5	<b>75</b>	83.7	<b>95.5</b>	63.1	<b>83.3</b>
Not documented	11.0	<b>0</b>	4.8	<b>0</b>	13.2	<b>4.5</b>	10.8	<b>3.3</b>

### National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	6.3	41.4	0.0	12.9
UPPER QUARTILE	76.4	70.7	2.9	35.5
MAX	100.0	100.0	11.4	60.0

**COMMENT:** This shows that almost 60% of those patients with epilepsy have had seizures necessitating a visit to ED in the past year. A similar proportion with blackouts but no epilepsy are also repeat visitors – hinting that their problems are also not being resolved. This may be explained by sub-optimal care, but it could also be the case that many of these could be patients with refractory epilepsy. If it is the former, this would have huge cost implications for the NHS and wider society, quite part form the impact on patients' health and quality of life.

## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Valproate/Epilim/Epilim Chrono/Orlept	32.9	<b>25</b>	0.0	<b>0</b>	0.0	<b>0</b>	6.1	<b>3.3</b>
Lamotrigine/Lamictal	14.6	<b>25</b>	1.9	<b>0</b>	0.0	<b>0</b>	3.2	<b>3.3</b>
Carbamazepine/Tegretol/ Tegretol Retard	14.6	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	2.7	<b>0</b>
Levetiracetam/Keppra	14.6	<b>25</b>	1.0	<b>0</b>	0.0	<b>0</b>	2.9	<b>3.3</b>
Clobazam/Frisium	6.1	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	1.1	<b>0</b>
Other AED	18.3	<b>0</b>	1.0	<b>0</b>	1.9	<b>0</b>	4.7	<b>0</b>
No AED	26.8	<b>50</b>	96.2	<b>100</b>	98.1	<b>100</b>	84.5	<b>93.3</b>
<b>One or More AED</b>								
Mean	73.2	<b>50</b>	3.8	<b>0</b>	1.9	<b>0</b>	15.5	<b>6.7</b>
Minimum	0.0		0.0		0.0		0.0	
LOWER QUARTILE	56.3		0.0		0.0		8.3	
UPPER QUARTILE	93.8		5.0		0.0		22.0	
Maximum	100.0		100.0		7.7		40.0	



## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
One drug as monotherapy	48.8	25	3.8	0	1.6	0	10.8	3.3
Two or more drugs as polytherapy	24.4	25	0.0	0	0.3	0	4.7	3.3
Not taking AED prior to attendance	26.8	50	96.2	100	98.1	100	84.5	93.3

**COMMENT:** A very small number of 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.

Sodium valproate is the most commonly prescribed AED, taken by 33% of patients with known epilepsy and in two thirds of those cases as monotherapy. It is expected that, in the paediatric population, a broad spectrum drug would be the most widely used rather than, for instance, carbamazepine.

30-40% of patients with epilepsy are refractory, and refractory patients are more likely to attend ED. The high proportion on monotherapy, or no therapy, (which ranges from 0% to 100% across sites) persists which suggests that refractory patients are not getting access to appropriate expertise and to newer treatments. However, another explanation is that children may have been previously treated with polytherapy without benefit but associated with adverse side-effects and consequently the child was maintained on monotherapy.

### Summary of polytherapy when used

Number of AEDs being taken	Percentage of polytherapy patients
2	66.7
3	33.3

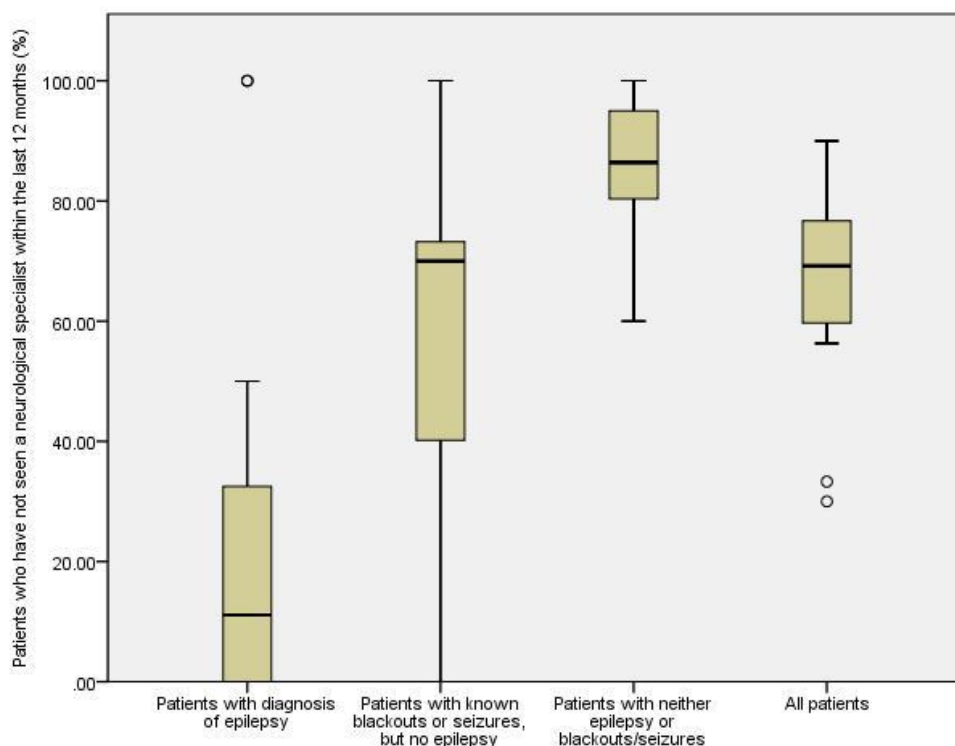
Of the patients with known epilepsy who were taking two AEDs, the most common duo therapy combination (taken by 4 out of 14 patients) was levetiracetam with valproate. All other duo therapy combinations were unique to a single patient.

**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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Hospital Paediatrician	61.0	<b>50</b>	29.8	<b>25</b>	7.2	<b>4.5</b>	23.6	<b>13.3</b>
Epilepsy Specialist Nurse	32.9	<b>0</b>	5.8	<b>0</b>	0.0	<b>0</b>	8.1	<b>0</b>
Community Paediatrician	20.7	<b>50</b>	1.9	<b>0</b>	7.7	<b>13.6</b>	7.2	<b>16.7</b>
Paediatric Neurologist	30.5	<b>25</b>	7.7	<b>0</b>	67.6	<b>0</b>	7.7	<b>3.3</b>
Neurologist	4.9	<b>25</b>	0.0	<b>0</b>	23.6	<b>0</b>	0.9	<b>3.3</b>
Learning disability psychiatrist	2.4	<b>0</b>	0.0	<b>0</b>	0.9	<b>0</b>	0.5	<b>0</b>
GPSI (neurology, epilepsy or neuropsychiatry)	0.0	<b>0</b>	0.0	<b>0</b>	0.5	<b>0</b>	0.0	<b>0</b>
None of the above	15.9	<b>0</b>	61.5	<b>75</b>	86.8	<b>81.8</b>	67.6	<b>70</b>

**COMMENT:** The observation that 16% (1 in 6) children with a diagnosis of epilepsy were recorded as having seen no specialist (including an epilepsy nurse specialist) is of some concern. There is some reassurance in that this figure drops to 8.2% when looking at those patients who have attended the ED as a result of a seizure within the previous 12 months. It is also interesting to note that the overall figure found in the adult audit is 63%.

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



We performed a number of combined analyses of the AED data, previous ED attendance due to a seizure and the use of a medical specialist in the previous 12 months. The results were as follows:

For known epilepsy patients:

	Have attended ED in the previous 12 months	Have not attended ED in the previous 12 months
No AED	18.4%	39.4%
Monotherapy	53.1%	42.4%
Polytherapy	28.6%	18.2%

For known epilepsy patients:

	Have attended ED in previous 12 months	Have not attended ED in previous 12 months
Have seen a specialist in the previous 12 months	91.8%	72.7%

For known epilepsy patients:

	Have seen a specialist in the previous 12 months	Have not seen a specialist in the previous 12 months
No AED	23.2%	46.2%

This shows that:

- Patients who had attended ED after a seizure in the previous 12 months are less likely to be on no therapy
- Patients who had attended ED after a seizure in the previous 12 months are more likely to have seen a medical specialist in the previous year; and
- Patients who had seen a medical specialist in the previous year are less likely to be on no therapy

### Percentage of patients for whom it is recorded that that they have a learning disability or autism spectrum disorder: %

	(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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Learning disability	39.0	<b>75</b>	9.6	<b>0</b>	7.0	<b>9.1</b>	13.5	<b>16.7</b>
Autism spectrum disorder	15.9	<b>0</b>	4.8	<b>0</b>	3.9	<b>0</b>	6.3	<b>0</b>

**COMMENT:** The percentage of known epilepsy patients who had a learning disability is slightly lower than we would have expected.

## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Yes	53.7	<b>25</b>	44.2	<b>50</b>	32.3	<b>50</b>	39.0	<b>46.7</b>
No	32.9	<b>50</b>	39.4	<b>50</b>	55.3	<b>45.5</b>	47.5	<b>46.7</b>
Not recorded	13.4	<b>25</b>	15.4	<b>0</b>	12.5	<b>4.5</b>	13.3	<b>6.7</b>

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	29.2	23.6	14.8	23.2
UPPER QUARTILE	77.5	63.4	46.4	53.3
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=44	n=1	n=46	n=2	n=83	n=11	n=173	n=14
Yes	100.0	<b>100</b>	93.5	<b>100</b>	94.0	<b>100</b>	95.4	<b>100</b>
No	0.0	<b>0</b>	6.5	<b>0</b>	6.0	<b>0</b>	4.6	<b>0</b>
Not recorded	0.0	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>

National 'yes' figures

MIN	100.0	33.3	55.6	53.8
LOWER QUARTILE	100.0	100.0	100.0	100.0
UPPER QUARTILE	100.0	100.0	100.0	100.0
MAX	100.0	100.0	100.0	100.0

**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=44	n=1	n=46	n=2	n=83	n=11	n=173	n=14
Yes	34.1	<b>100</b>	39.1	<b>0</b>	39.8	<b>0</b>	38.2	<b>7.1</b>
No	63.6	<b>0</b>	58.7	<b>100</b>	56.6	<b>90.9</b>	59.0	<b>85.7</b>
Not recorded	2.3	<b>0</b>	2.2	<b>0</b>	3.6	<b>9.1</b>	2.9	<b>7.1</b>

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	4.5	0.0	25.0	33.9
UPPER QUARTILE	31.0	51.4	64.6	57.5
MAX	100.0	60.0	100.0	71.4

**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=44	n=1	n=46	n=2	n=83	n=11	n=173	n=14
Yes	75.0	<b>100</b>	71.7	<b>50</b>	67.5	<b>45.5</b>	70.5	<b>50</b>
No	15.9	<b>0</b>	15.2	<b>0</b>	18.1	<b>0</b>	16.8	<b>0</b>
Not recorded	9.1	<b>0</b>	13.0	<b>50</b>	14.5	<b>54.5</b>	12.7	<b>50</b>

National 'yes' figures

MIN	0.0	0.0	0.0	20.0
LOWER QUARTILE	6.3	50.0	50.0	57.4
UPPER QUARTILE	50.0	100.0	78.3	77.0
MAX	85.7	100.0	100.0	100.0

**COMMENT:** Only 40% of patients were seen by senior ED staff, and this only rises to 52% of those discharged from the ED without admission - an observation that needs to be considered in the light that about half of patients are referred (or their GP is advised to refer) for specialist advice post-seizure. However, it is encouraging that of these who were seen by senior staff, this assessment took place within 4 hours for nearly every patient.

## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
diazepam	13.4	0	13.5	25	9.3	4.5	11.0	6.7
midazolam	28.0	25	1.9	0	0.0	0	5.6	3.3
other (clobazam, lorazepam and paraldehyde)	1.2	0	0.0	0	0.0	0	0.2	0

**COMMENT:** 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. However, midazolam is generally not given by ambulance staff. Hence, 93.9% of the diazepam was administered by ambulance staff and 96% of the midazolam was administered by a family member or teacher.

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

	National audit n=444	Your site n=30
Yes	89.4	100
No	7.7	0
Unclear	2.9	0

National 'yes' figures	
MIN	66.7
LOWER QUARTILE	84.5
Q3	98.2
MAX	100.0

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

	National audit n=34	Your site n=0
IV lorazepam	55.9	NA
IV phenytoin	41.2	NA
Rectal or intramuscular paraldehyde	17.6	NA
Buccal midazolam	14.7	NA
Rectal diazepam	11.8	NA
IV diazepam	8.8	NA
IV phenobarbitol	2.9	NA
IV glucose	0.0	0
IV levetiracetam	0.0	0
IV thiamine / pabrinex	0.0	0
IV valproate	0.0	0
None of the above	11.8	NA

**COMMENT:** The numbers of people being given phenytoin is higher than expected. It is notable that paraldehyde is still being used. Although rectal paraldehyde has been removed as a 'mandatory' drug in national APLS algorithm of the treatment of acute convulsive seizures and status epilepticus, it remains an effective drug –and its use may obviate the child being admitted to intensive care for refractory convulsive status. It would be encouraging to see a move from rectal diazepam to buccal midazolam and this is likely to occur within the next few years.

**INITIAL EMERGENCY DEPARTMENT ASSESSMENT**

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

	National audit n=444	Your site n=30
Yes	81.3	<b>96.7</b>
No	14.4	<b>3.3</b>
Don't know	3.6	<b>0</b>

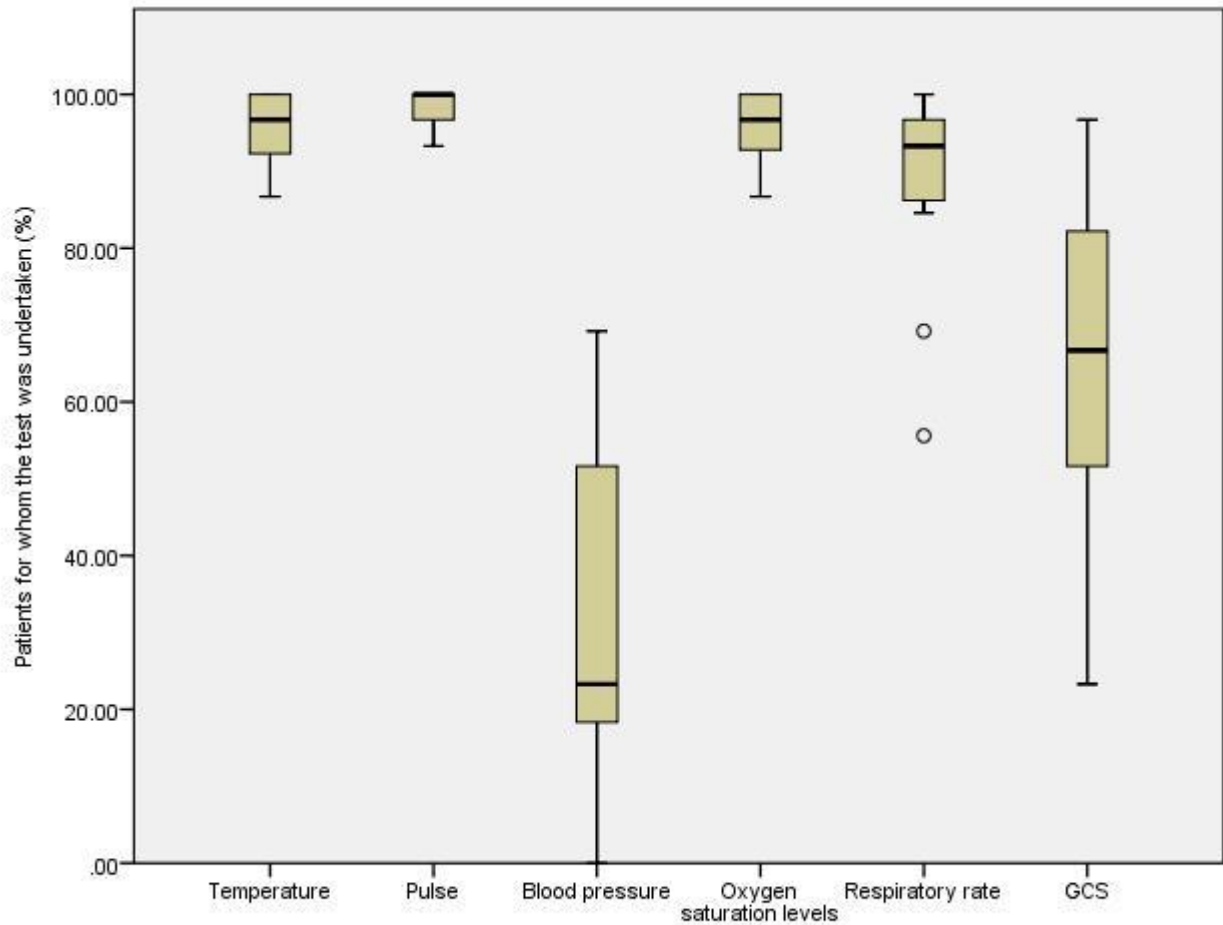
National 'yes' figures

MIN	44.4
LOWER QUARTILE	73.3
UPPER QUARTILE	86.2
MAX	100.0

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

	National audit n=444	Your site n=30
Temperature	96.4	<b>96.7</b>
Pulse	98.0	<b>96.7</b>
Blood pressure	32.4	<b>20</b>
Oxygen saturation levels	96.2	<b>86.7</b>
Respiratory rate	91.4	<b>96.7</b>
GCS	63.3	<b>60</b>

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



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

	National audit n=428	Your site n=29
Yes	79.7	<b>3.4</b>
No	6.1	<b>0</b>
Don't know	13.6	<b>96.6</b>

National 'yes' figures

MIN	3.4
LOWER QUARTILE	83.6
UPPER QUARTILE	98.2
MAX	100.0

**What was their GCS?:**

	National audit n=281	Your site n=18
Median	15	<b>15</b>
Range	3-15	<b>13-15</b>

	Patients recorded as being conscious on arrival n=361	Patients recorded as not being conscious on arrival n=64
GCS recorded (%)	63.4	70.3
Median GCS Score	15	9
IQR	15-15	6-12



**COMMENT:** The number of patients who had their blood pressure taken is lower than would be expected, as is the GCS recording – and there are some *very* low outliers. The percentage of patients who have their GCS recorded in the group who are recorded as not being conscious on arrival should be 100%, yet this is not done in 30% of cases.

### 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=444	Your site n=30
Yes	28.2	<b>3.3</b>
No/Don’t know	71.4	<b>96.7</b>

National ‘yes’ figures	
MIN	0.0
LOWER QUARTILE	11.3
UPPER QUARTILE	41.7
MAX	80.0

	Patients recorded as being conscious on arrival n=361	Patients recorded as not being conscious on arrival n=64
Neuro obs chart present (%)	24.9	42.2

**COMMENT:** As with the recording of GCS (above), a neuro obs chart should be in place for **all** patients who were not conscious on arrival – the figure of 42% is far from this ideal.

### 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
General Paediatric Ward	31.7	<b>75</b>	43.3	<b>100</b>	51.4	<b>90.9</b>	45.9	<b>90</b>
Paediatric Observation / Assessment Unit	13.4	<b>25</b>	11.5	<b>0</b>	16.3	<b>0</b>	14.6	<b>3.3</b>
Paediatric HDU	4.9	<b>0</b>	0.0	<b>0</b>	2.7	<b>0</b>	2.5	<b>0</b>
Medical ward	12.2	<b>0</b>	11.5	<b>0</b>	6.2	<b>9.1</b>	8.6	<b>6.7</b>
Intensive Care Unit	1.2	<b>0</b>	3.8	<b>0</b>	1.9	<b>0</b>	2.3	<b>0</b>
Neurology ward	6.1	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	1.1	<b>0</b>
Medical Decision Unit/ Clinical Decision Unit	6.1	<b>0</b>	8.7	<b>0</b>	7.4	<b>0</b>	7.4	<b>0</b>
ED observational ward	1.2	<b>0</b>	2.9	<b>0</b>	1.6	<b>0</b>	1.8	<b>0</b>
Discharged	23.2	<b>0</b>	18.3	<b>0</b>	12.1	<b>0</b>	15.6	<b>0</b>

**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 n=63		Patients with known blackouts or seizures, but no epilepsy n=85		Patients with neither epilepsy or blackouts/seizures n=226		All patients n=375	
General physician (inc pharmacologist and paediatrician)	82.5	<b>100</b>	94.1	<b>100</b>	93.8	<b>100</b>	92.0	<b>100</b>
Paediatric Neurologist	9.5	<b>0</b>	0.0	<b>0</b>	0.4	<b>0</b>	1.9	<b>0</b>
Remained under care of Emergency Department	1.6	<b>0</b>	2.4	<b>0</b>	0.0	<b>0</b>	0.8	<b>0</b>
Other	6.3	<b>0</b>	3.5	<b>0</b>	5.8	<b>0</b>	5.3	<b>0</b>

**COMMENT:** Most patients are managed by general physicians, i.e. non neurologists, which is as expected in this population.

**Length of stay (days): %**

	(National audit)			
	Patients with diagnosis of epilepsy n=49	Patients with known blackouts or seizures, but no epilepsy n=68	Patients with neither epilepsy or blackouts/seizures n=163	All patients n=281
Mean	1.4	1.3	1.7	1.5
Lower Quartile	1	1	1	1
Upper Quartile	1	1	1	1
Maximum	5	5	20	20

**COMMENT:** The decision to admit the patient will depend on the duration of the seizure, treatment required to terminate it, conscious level following cessation of the seizure, cause of the seizure and parental concern – as well as the time of day the child attended the ED. Clearly, whether the 85% admission rate is completely justified is uncertain and would be an appropriate point for discussion.

## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Yes	96.3	<b>100</b>	95.2	<b>100</b>	96.5	<b>100</b>	96.2	<b>100</b>
No, but attempt was made to contact them	0.0	<b>0</b>	1.9	<b>0</b>	0.8	<b>0</b>	0.9	<b>0</b>
Unwitnessed	1.2	<b>0</b>	1.0	<b>0</b>	0.4	<b>0</b>	0.7	<b>0</b>
No, and no attempt was made to contact them	0.0	<b>0</b>	1.9	<b>0</b>	1.6	<b>0</b>	1.6	<b>0</b>
Don't know	1.2	<b>0</b>	0.0	<b>0</b>	0.8	<b>0</b>	0.7	<b>0</b>

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

MIN	83.3	85.7	82.4	90.6
LOWER QUARTILE	100.0	100.0	98.9	96.7
UPPER QUARTILE	100.0	100.0	100.0	100.0
MAX	100.0	100.0	100.0	100.0

**COMMENT:** Obtaining a good eyewitness description is vital for distinguishing among differing causes of blackout and for diagnosing seizures. Whilst it would be expected that the good practice would be higher than that found in the adult audit (69% for all patients), the very high proportion of 'yes' answers is extremely encouraging.

## ALCOHOL AND ILLICIT DRUG USE

Questions around alcohol and drug use were asked, but tables are not shown as the number of positive responses were so low. Only four of the patients had documentation round their general alcohol intake, all of which were recorded as having low levels of consumption. Similarly, only one case was recorded as having used illicit drugs.

## 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 examined for isolated weakness 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=81	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Fundi	6.1	<b>0</b>	18.3	<b>0</b>	9.7	<b>9.1</b>	11.0	<b>6.7</b>
Isolated Weakness	35.4	<b>0</b>	50.0	<b>0</b>	33.1	<b>0</b>	37.6	<b>0</b>

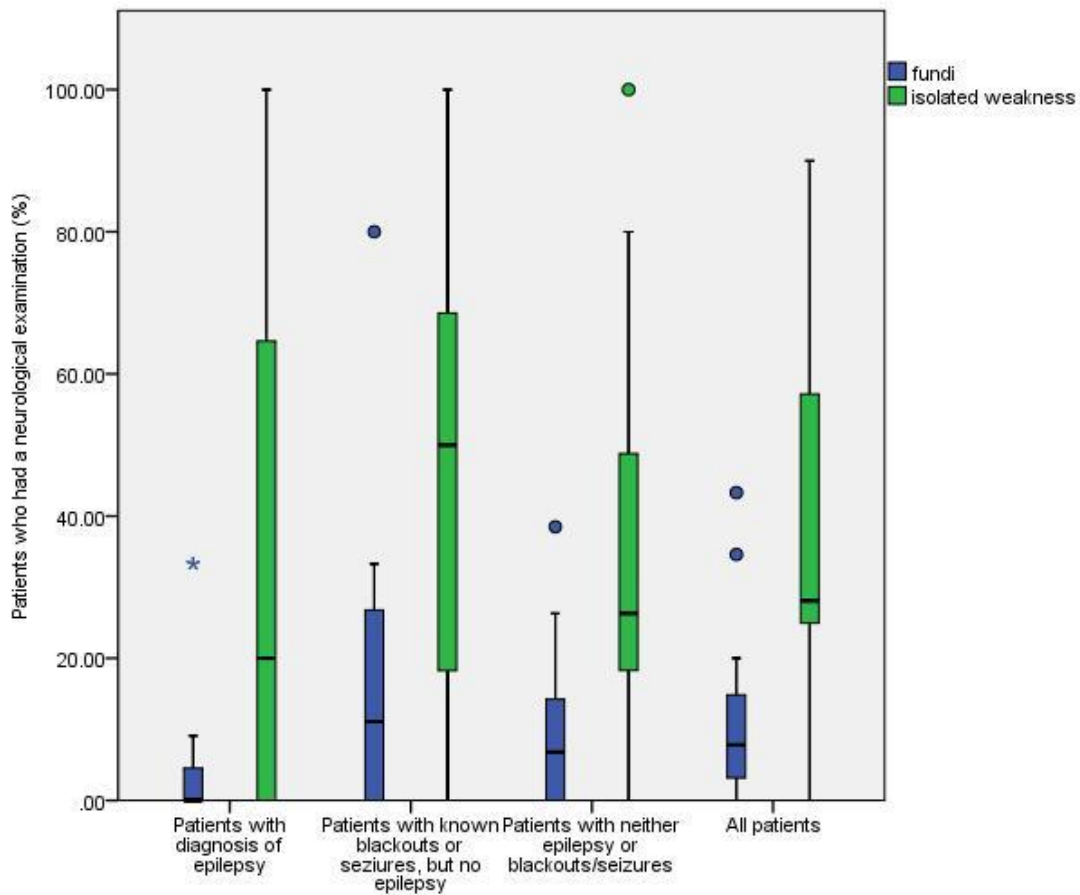
#### National fundi figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	3.1
UPPER QUARTILE	4.5	26.8	14.2	14.8
MAX	33.3	80.0	38.5	43.3

#### National isolated weakness figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	18.3	18.3	24.9
UPPER QUARTILE	64.6	68.6	48.8	57.1
MAX	100.0	100.0	100.0	90.0

Figure 4: Distribution of number of patients who had fundi and isolated weakness examined across sites



**COMMENT:** The low figure for fundoscopy is likely to reflect the difficulty of performing this in children. However, it should also be noted that the national average for all patients in the adult audit was only 14%. Conversely, it is encouraging that the figure for isolated weakness is as high as it is. However the wide variation between sites shown in the box plot indicates that this could be higher.

**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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Glucose levels / BM	62.2	<b>50</b>	61.5	<b>75</b>	59.1	<b>68.2</b>	60.4	<b>66.7</b>
ECG	4.9	<b>25</b>	18.3	<b>25</b>	11.7	<b>18.2</b>	11.9	<b>20</b>
Anti-epileptic drug levels*	12.2	<b>100</b>	NA	<b>NA</b>	0.0	<b>NA</b>	11.6	<b>100</b>
CT (head)	6.1	<b>0</b>	4.8	<b>0</b>	5.1	<b>4.5</b>	5.2	<b>3.3</b>
EEG	2.4	<b>0</b>	2.9	<b>25</b>	2.7	<b>13.6</b>	2.7	<b>13.3</b>
MRI (head)	1.2	<b>0</b>	1.9	<b>0</b>	1.9	<b>4.5</b>	1.8	<b>3.3</b>

\* 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 (carbamazepine, phenytoin, phenobarbitol, primidone and sodium valproate).

A sub-analysis of those patients who were diagnosed with a febrile seizure shows the following:

	(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=3	n=0	n=47	n=4	n=170	n=18	n=221	n=22
Glucose levels / BM	0.0	<b>0</b>	53.2	<b>75</b>	58.2	<b>66.7</b>	56.6	<b>68.2</b>
ECG	0.0	<b>0</b>	4.3	<b>25</b>	4.7	<b>16.7</b>	4.5	<b>18.2</b>
CT (head)	0.0	<b>0</b>	0.0	<b>0</b>	2.9	<b>5.6</b>	2.3	<b>4.5</b>
EEG	0.0	<b>0</b>	2.1	<b>25</b>	1.2	<b>11.1</b>	1.4	<b>13.6</b>
MRI (head)	0.0	<b>0</b>	2.1	<b>0</b>	0.6	<b>0</b>	0.9	<b>0</b>

**COMMENT:** It is encouraging that the number of children with a febrile seizure who underwent EEG, CT and MRI scans was low as this group do not merit these investigations. The exceptions would be those in whom there is a high index of suspicion of meningitis or encephalitis or who present with a complex febrile seizure (defined as lasting >15 minutes or focal or followed by a focal neurological deficit) and particularly if difficult to terminate. A blood glucose or BM level should be measured in most children (and ideally all children) who present to an ED with a 'seizure' – whether febrile, epileptic or uncertain. All children that present with a convulsive (tonic, clonic or tonic-clonic) seizure should also have an ECG.

## DISCHARGE AND DEATHS

No patients died during their admission.

### What was the diagnosis at 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Febrile Seizure	3.7	<b>0</b>	45.2	<b>100</b>	66.1	<b>81.8</b>	49.8	<b>73.3</b>
Seizure in someone with established diagnosis of epilepsy	85.4	<b>75</b>	2.9	<b>0</b>	0.0	<b>0</b>	16.4	<b>10</b>
First unprovoked seizure	0.0	<b>0</b>	6.7	<b>0</b>	21.4	<b>13.6</b>	14.0	<b>10</b>
Unprovoked seizures with history of previous seizures, but no current epilepsy diagnosis	6.1	<b>25</b>	31.7	<b>0</b>	2.7	<b>0</b>	10.1	<b>3.3</b>
Blackout with seizure markers, not sure if seizure	0.0	<b>0</b>	3.8	<b>0</b>	0.8	<b>0</b>	1.4	<b>0</b>
Syncope/faint	0.0	<b>0</b>	1.9	<b>0</b>	1.9	<b>0</b>	1.6	<b>0</b>
Psychogenic non-epileptic attack / pseudoseizure	0.0	<b>0</b>	1.0	<b>0</b>	0.0	<b>0</b>	0.2	<b>0</b>
Provoked seizure - head injury	0.0	<b>0</b>	1.0	<b>0</b>	0.0	<b>0</b>	0.2	<b>0</b>
Provoked seizure - other	1.2	<b>0</b>	1.0	<b>0</b>	2.7	<b>0</b>	2.0	<b>0</b>
Status epilepticus	1.2	<b>0</b>	1.0	<b>0</b>	0.0	<b>0</b>	0.5	<b>0</b>
Other - Hypoglycaemic seizure	0.0	<b>0</b>	0.0	<b>0</b>	0.4	<b>0</b>	0.2	<b>0</b>
Other - Hyponatraemic seizure	0.0	<b>0</b>	0.0	<b>0</b>	0.4	<b>0</b>	0.2	<b>0</b>
Other - Infantile spasms	1.2	<b>0</b>	0.0	<b>0</b>	0.4	<b>0</b>	0.5	<b>0</b>
Other - Non-epileptic	0.0	<b>0</b>	1.0	<b>0</b>	1.2	<b>0</b>	0.9	<b>0</b>
Self-discharged	0.0	<b>0</b>	0.0	<b>0</b>	0.4	<b>4.5</b>	0.2	<b>3.3</b>
Not recorded	1.2	<b>0</b>	1.0	<b>0</b>	1.2	<b>0</b>	1.1	<b>0</b>
Uncertain	0.0	<b>0</b>	1.9	<b>0</b>	0.4	<b>0</b>	0.7	<b>0</b>

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

NB The analysis for this question is based on those patients who were diagnosed with something other than a febrile seizure.

	(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=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Sent home on AED(s)	77.2	<b>50</b>	10.5	<b>NA</b>	1.1	<b>25</b>	30.5	<b>37.5</b>

	(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=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Change in drug	25.3	<b>50</b>	5.3	<b>NA</b>	1.1	<b>25</b>	10.8	<b>37.5</b>
Change in dose	21.5	<b>25</b>	0.0	<b>0</b>	0.0	<b>0</b>	7.6	<b>12.5</b>
Any change	44.3	<b>75</b>	5.3	<b>NA</b>	1.1	<b>25</b>	17.5	<b>50</b>

National 'any change' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	29.2	0.0	0.0	9.5
UPPER QUARTILE	58.3	0.0	0.0	27.4
MAX	100.0	20.0	25.0	50.0

**COMMENT:** It is very rare for changes to an AED to be made in ED without some input from the child's usual consultant (general paediatrician or paediatric neurologist). Consequently, one explanation for the high figures in the above table would be that this question is not being interpreted correctly.

## 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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
EEG	3.7	<b>0</b>	16.3	<b>0</b>	6.2	<b>9.1</b>	8.1	<b>6.7</b>
MRI (head)	7.3	<b>0</b>	8.7	<b>0</b>	3.9	<b>9.1</b>	5.6	<b>6.7</b>
12 lead ECG	0.0	<b>0</b>	1.9	<b>0</b>	1.9	<b>0</b>	1.6	<b>0</b>
CT (head)	0.0	<b>0</b>	0.0	<b>0</b>	0.4	<b>0</b>	0.2	<b>0</b>



National figures for all patients

	MIN	LOWER QUARTILE	UPPER QUARTILE	MAX
EEG	0.0	6.5	10.6	20.0
MRI (head)	0.0	3.2	6.7	23.3
12 lead ECG	0.0	0.0	3.2	11.1
CT (head)	0.0	0.0	0.0	3.6

A sub-analysis of those patients who were diagnosed with a febrile seizure shows the following:

	(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=3	n=22	n=47	n=22	n=170	n=22	n=221	n=22
EEG	0.0	<b>0</b>	0.0	<b>0</b>	1.2	<b>5.6</b>	1.0	<b>4.5</b>
MRI (head)	0.0	<b>0</b>	0.0	<b>0</b>	1.2	<b>5.6</b>	1.0	<b>4.5</b>
12 lead ECG	0.0	<b>0</b>	0.0	<b>0</b>	0.6	<b>0</b>	0.5	<b>0</b>
CT (head)	0.0	<b>0</b>	0.0	<b>0</b>	0.6	<b>0</b>	0.5	<b>0</b>

**COMMENT:** Very few children who were diagnosed as having experienced a febrile seizure underwent the 'usual' investigations that are undertaken in the evaluation of children with definite or probable epilepsy (EEG and MRI scans). This is as expected. For the few children that did undergo an EEG or MRI scan (or both) as an outpatient, this may have been because the febrile seizure was complex. The audit did not collect data on whether the febrile seizure was simple or complex.

**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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Yes	54.9	<b>25</b>	61.5	<b>0</b>	59.1	<b>31.8</b>	58.8	<b>26.7</b>
No	9.8	<b>75</b>	13.5	<b>100</b>	19.8	<b>68.2</b>	16.4	<b>73.3</b>
Don't know	34.1	<b>0</b>	25.0	<b>0</b>	21.0	<b>0</b>	24.5	<b>0</b>

MIN	11.1	0.0	11.8	20.0
LOWER QUARTILE	29.2	46.4	38.5	43.4
UPPER QUARTILE	69.7	87.5	81.7	72.5
MAX	100.0	100.0	94.7	96.7

**COMMENT:** It is best medical practice (GMC good guidance) that the management should always be discussed. For children who attend the ED but who are not admitted, all GPs are notified using a coding-generated proforma letter that their patient attended the ED. There is an ability to add a comment for the GP on the front of the casualty card, though this isn't often used. The proforma letter is brief, computer-generated, and does not include any details on a specific management plan. Depending on the ED doctor and the clinical situation, a formal letter might be dictated and sent to the child's GP about the attendance and what the family were told about the episode (in this case,

seizure) and what to do if there was a recurrence. 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 clearly show it is possible for this practice to be undertaken for all patients.

## NEUROLOGY/EPILEPSY TEAM ASSESSMENT

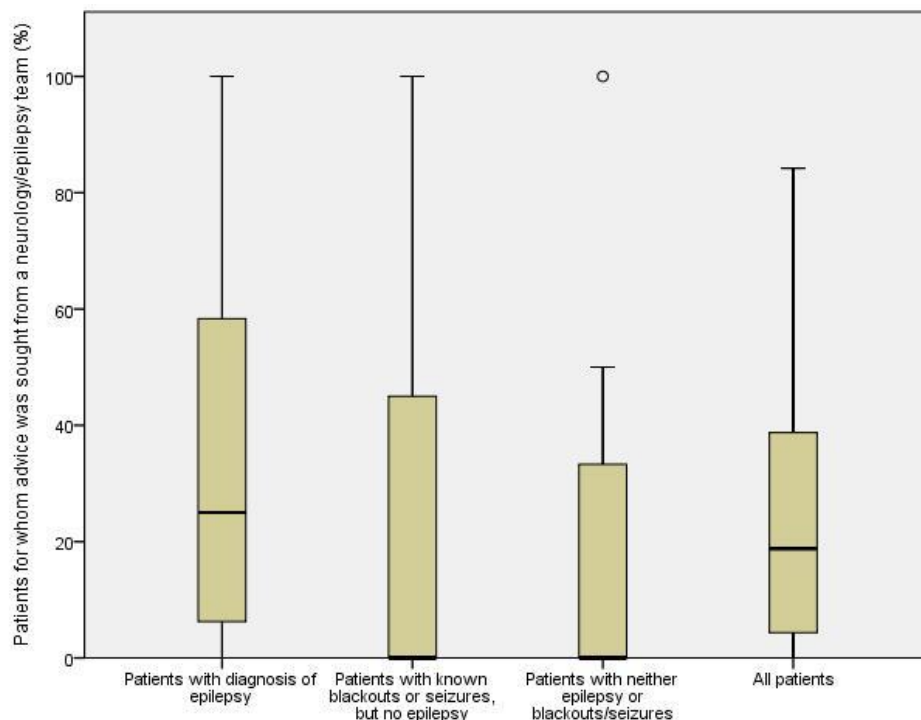
### Percentage of patients for whom it is documented that at any point in time advice was sought from a neurology / epilepsy team, or an assessment taken by a neurologist or epilepsy specialist: %

NB This analysis for this question is based on those patients who were diagnosed with something other than a febrile seizure.

	(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=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Advice sought	34.2	<b>25</b>	24.6	<b>NA</b>	12.6	<b>50</b>	23.3	<b>37.5</b>

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	6.3	0.0	0.0	4.3
UPPER QUARTILE	58.3	47.5	33.3	38.8
MAX	100.0	100.0	100.0	84.2

Figure 5: 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=52	Your site n=3
Paediatric neurologist	46.2	<b>33.3</b>
Paediatrician	34.6	<b>33.3</b>
Epilepsy Specialist Nurse	15.4	<b>0</b>
Neurologist	3.8	<b>33.3</b>

**COMMENT:** The use of specialist input varies massively – but we are encouraged that the figure for those patients known to have epilepsy is as high as it is (and compares favourably with the 21% found in the adult audit), especially when many sites would not have a resident (paediatric) neurologist.

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

NB This analysis for this question is based on those patients who were diagnosed with something other than a febrile seizure.

	(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=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Paediatrician	32.9	<b>50</b>	28.1	<b>NA</b>	34.5	<b>25</b>	32.3	<b>37.5</b>
Paediatrician with training and expertise in epilepsy	32.9	<b>25</b>	29.8	<b>NA</b>	13.8	<b>50</b>	24.7	<b>37.5</b>
Epilepsy Specialist Nurse	24.1	<b>0</b>	14.0	<b>NA</b>	8.0	<b>0</b>	15.2	<b>0</b>
A neurologist at this Trust/Health Board	13.9	<b>25</b>	12.3	<b>NA</b>	2.3	<b>0</b>	9.0	<b>12.5</b>
A neurologist at another Trust/Health Board	5.1	<b>0</b>	3.5	<b>NA</b>	2.3	<b>25</b>	3.6	<b>12.5</b>
Epilepsy Service/First Fit Clinic	10.1	<b>0</b>	5.3	<b>NA</b>	2.3	<b>0</b>	5.8	<b>0</b>
Learning disability psychiatrist	2.5	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	0.9	<b>0</b>
GP with special interest in epilepsy (GPSI)	0.0	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>	0.0	<b>0</b>
Referral to any of the above services	78.5	<b>75</b>	64.9	<b>NA</b>	46.0	<b>50</b>	62.3	<b>62.5</b>

**COMMENT:** The average figures for referral for both patients with epilepsy and those with previous blackouts or seizures are in the region of what would be expected (and much higher than those found in the adult audit of 36% and 51% respectively). However, as with many of the items in the audit, those average values mask a large amount of variation between sites, as can be seen in figure 6 below. It is the practice in many sites that a child will not automatically be referred on following their first seizure; consequently we would expect the referral rates to be lower for the first seizure group.

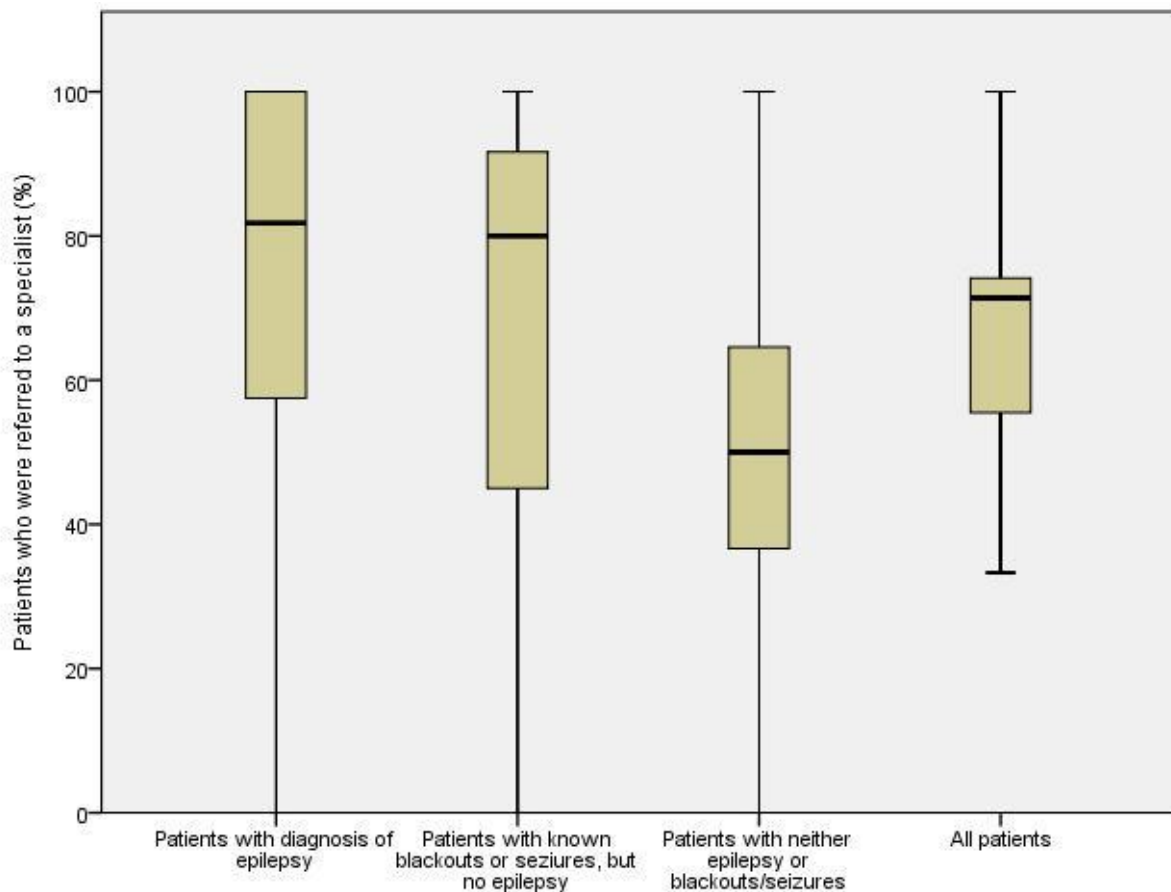
Feedback from NASH1 indicated that some hospitals were unable to make consultant-consultant referrals, but needed to go via their local GPs. Therefore, for NASH2 we added a question asking if a letter was sent to the GP (50.2% of all cases - see below) and if that letter advised the GP to refer on (2.7% of letters). We, unfortunately, have no data to know if the GP responded but we have assumed that they did and so those figures have been added to figures in the previous table to obtain the overall referral rates below .

	(National audit/ <b>Your site</b> )							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Any referral (including GP requested ones)	78.5	<b>75</b>	68.4	<b>NA</b>	49.4	<b>50</b>	64.6	<b>62.5</b>

National 'yes' figures

MIN	0.0	25.0	0.0	33.3
LOWER QUARTILE	57.5	50.0	36.7	55.5
UPPER QUARTILE	100.0	95.8	64.6	74.2
MAX	100.0	100.0	100.0	100.0

Figure 6: Distribution of number of patients for whom a referral was made across sites



## Of the patients who were referred, did they attend their appointment?: n/%

	(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=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Paediatrician	n=26 57.7	n=2 <b>50</b>	n=16 43.8	n=0 <b>NA</b>	n=30 36.7	n=1 <b>0</b>	n=72 50.0	n=3 <b>33.3</b>
Paediatrician with training and expertise in epilepsy	n=26 53.8	n=1 <b>0</b>	n=17 52.9	n=0 <b>NA</b>	n=12 41.7	n=2 <b>0</b>	n=55 50.9	n=3 <b>0</b>
Epilepsy Specialist Nurse	n=19 63.2	n=0 <b>NA</b>	n=8 62.5	n=0 <b>NA</b>	n=7 28.6	n=0 <b>NA</b>	n=34 55.9	n=0 <b>NA</b>
A neurologist at this Trust/Health Board	n=11 81.8	n=1 <b>0</b>	n=7 27.3	n=0 <b>NA</b>	n=2 50.0	n=0 <b>NA</b>	n=20 65.0	n=1 <b>0</b>
A neurologist at another Trust/Health Board	n=4 25.0	n=0 <b>NA</b>	n=2 0.0	n=0 <b>0</b>	n=2 50.0	n=1 <b>0</b>	n=8 25.0	n=1 <b>0</b>
Epilepsy Service/First Fit Clinic	n=8 62.5	n=0 <b>NA</b>	n=3 100.0	n=0 <b>NA</b>	n=2 50.0	n=0 <b>NA</b>	n=13 69.2	n=0 <b>NA</b>
Learning disability psychiatrist	n=2 50.0	n=0 <b>NA</b>	n=0 NA	n=0 <b>NA</b>	n=0 NA	n=0 <b>NA</b>	n=2 50.0	n=0 <b>NA</b>

**COMMENT:** The uptake of referrals can only be described as 'patchy'. The DNA rate is higher than what would have been expected, and is of some concern.

## Was an A&E discharge letter provided to the patient's GP following attendance at ED?: %

	(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=82	n=4	n=104	n=4	n=257	n=22	n=444	n=30
Yes	52.4	<b>50</b>	50.0	<b>75</b>	49.4	<b>72.7</b>	50.2	<b>70</b>
No	22.0	<b>25</b>	17.3	<b>25</b>	24.1	<b>22.7</b>	22.1	<b>23.3</b>
Don't know	25.6	<b>25</b>	32.7	<b>0</b>	26.5	<b>4.5</b>	27.7	<b>6.7</b>

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	42.5	3.8
UPPER QUARTILE	100.0	100.0	82.5	96.8
MAX	100.0	100.0	100.0	100.0

**COMMENT:** This should be done for all patients, and for many hospitals in England, this is a CQUIN target for hospital-primary care communication. It may be useful for you to compare this with local data that should be available. This was a question where some difference was seen between

patients who lived in the Trust's area and those who came from outside (52.7% vs. 26.8% respectively). This suggests the latter group of children may be being disadvantaged. It is also of interest to look at how many patients had any neurology input during their attendance at hospital or were referred for an outpatient neurology opinion *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 (NB This analysis for this question is based on those patients who were diagnosed with something other than a febrile seizure.)

	(National audit/ <b>Your site</b> )							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=79	n=4	n=57	n=0	n=87	n=4	n=223	n=8
Had some neurology input acutely or as an outpatient referral	84.8	<b>100</b>	68.4	<b>NA</b>	50.6	<b>75</b>	67.3	<b>87.5</b>

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

NB This analysis for this question is based on those patients who were diagnosed with something other than a febrile seizure.

	(National audit)			
	Patients with diagnosis of epilepsy n=79	Patients with known blackouts or seizures, but no epilepsy n=57	Patients with neither epilepsy or blackouts/seizures n=87	All patients n=223
Seen in prior 12 months	89.6	81.5	80.0	86.0
Not seen in prior 12 months	58.3	56.7	41.8	47.7

\*The medical specialists are those who are listed in the question on page 17.

**COMMENT:** There is a substantial cohort of patients who are not receiving specialist neurological input. However, it is important to note that not every child with epilepsy needs to be referred to and seen by (or even discussed with) a paediatric neurologist; first because not all the epilepsies in childhood will need specialist advice from a paediatric neurologist and second because the vast majority of secondary care units (where these children will present to) will not have a paediatric neurologist on their consultant staff. All children with epilepsy will be under regular supervision and

review by a paediatrician and in the majority, by a paediatrician with expertise in epilepsy. This is significantly different than in adult practice where most adults with epilepsy would be diagnosed and managed by their GP.

## SUB-ANALYSIS BY AGE CATEGORY

As mentioned on page 12, the responses to certain questions were analysed (at a global level) in terms of the age of the patient. The results are summarised below:

	<5 years n=291	5 years and over n=153
The patient is known to have epilepsy	10.0	34.6
The patient has had previous blackouts or seizures	31.3	61.4
For those patients who had had a previous seizure/blackout (<5 years n=91, 5 years and over n=94), it was provoked by a fever	54.9	13.8
The patient has not seen a medical specialist in the previous 12 months	75.6	47.7
There is evidence of senior ED review	39.5	37.9
Percent of patients discharged	14.8	17.0
Eyewitness statement was taken or sought	99.3	94.1
CT (head) undertaken following attendance in ED	2.7	9.8
ECG recorded following attendance in ED	6.5	22.2

**COMMENT:** Where there are differences in the two groups highlighted above, these are in line with what would be expected. It is unsurprising that a large proportion of the older group have epilepsy and had experienced previous seizures, as there has been more time in which these could have evolved. A much smaller proportion of the older group would have had a previous seizure / blackout provoked by a fever, assuming that many in that group would have had a previous febrile seizure (by definition, febrile seizures should be diagnosed in children aged 5 and over). The fact that a smaller proportion of the younger group had not seen a medical specialist in the preceding year is as would be predicted, reflecting the fact that many, if not the majority, of this group would have experienced a febrile seizure or other non-epileptic event (e.g. reflex anoxic seizure, breath holding attack) and this would not have automatically necessitated a review by a medical specialist. Few children of any age (as shown above) would need to undergo a CT brain scan after attendance in the ED. The larger proportion in the 5 and over group might reflect a possible traumatic insult (accidental or non-accidental) or possible encephalitis/meningitis as a trigger for the presenting episode. With regards to ECGs, most of the younger children would have had a febrile seizure or reflex anoxic seizure which would not automatically justify an ECG. However, ideally, all children that present with a 'blackout', including a probable reflex anoxic seizure, should undergo an ECG to exclude a potentially treatable cardiac arrhythmia.

It is encouraging that the proportion of children who had received a senior ED review, had been accompanied by someone who was able to give an eyewitness account of the episode and were subsequently discharged are broadly similar, as there are no reasons for these observations and actions to be undertaken differently for patients of different ages.

## CONCLUSIONS

This is the end of the formal data presentation. It is for each hospital to determine how they can best respond to these data, and we are aware you may have further questions. Some you can resolve by reviewing your own data (which we have previously sent to you as an Excel spreadsheet) but other questions may suggest a need for further analyses of the national data.

We cannot promise instant responses as we have limited resources, but we would like to hear your feedback and will respond to specific requests when we can. These data (in aggregate form) will be shared with the Health Quality Improvement Partnership (HQIP) along with others, and will hopefully be used by many to raise not only the emergency, but the overall standard of epilepsy care and subsequently to improve the quality of life for people with epilepsy.



## 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

Professor Phil Smith – Representative for Wales and International League Against Epilepsy

Dr Adrian Boyle – Representative for the College of Emergency Medicine

Dr Richard Appleton – Representative for pilot paediatric NASH study

Dr Greg Rogers – GP with Special Interest in Epilepsy

Ms Angela Pullen – Representative for Epilepsy Action

Mr Graham Faulkner - Representative for Epilepsy Society

Ms Jane Hanna - Representative for SUDEP Action

Dr Duncan Appelbe – Study IT Manager

Dr Jamie Kirkham – Study Statistician

Dr Pete Dixon – Study Coordinator

Ms Karen Billington – Study Administrator

## APPENDIX TWO

### Participating Sites

Alder Hey Children's Hospital – Alder Hey Children's NHS Foundation Trust  
Arrowe Park Hospital – Wirral University Teaching Hospital NHS Foundation Trust  
Blackpool Victoria Hospital – Blackpool Teaching Hospitals NHS Trust  
Countess of Chester Hospital – Countess of Chester Hospital NHS Foundation Trust  
Cumberland Infirmary – North Cumbria University Hospitals NHS Trust  
East Lancashire Hospitals NHS Trust – East Lancashire Hospitals NHS Trust  
Furness General Hospital – University Hospitals of Morecambe Bay NHS Foundation Trust  
Glan Clwyd Hospital – Betsi Cadwaladr University Health Board (Bwrdd Iechyd Prifysgol Betsi Cadwaladr)  
Royal Bolton Hospital – The Bolton NHS Foundation Trust  
Royal Lancaster Infirmary – University Hospitals of Morecambe Bay NHS Foundation Trust  
Royal Manchester Children's Hospital – Central Manchester University Hospitals NHS Foundation Trust  
Warrington Hospital – Warrington & Halton Hospitals NHS Foundation Trust  
West Cumberland Hospital – North Cumbria University Hospitals NHS Trust  
Whiston Hospital – St Helens & Knowsley NHS Trust  
Wythenshawe Hospital – The 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**

#### **Q2.3 Gender**

Options:

Male

Female

#### **Q2.4 Does the patient live in the geographical location covered by this trust?**

Options:

Yes

No/Not documented

#### **Q3.1 Is there a statement that the patient is known to have epilepsy?**

Options:

Yes

No/Not documented

#### **Q3.2 Does the patient have a written care plan in place?**

Options:

Yes

No/Not documented

#### **Q3.3 Is there documentation that the patient has had previous seizures or blackouts?**

Options:

Yes

No/Not documented

#### **Q3.3a Was the patient's previous seizure or blackout provoked by alcohol?**

Options:

Yes

No

Not documented

#### **Q3.3b Was the patient's previous seizure or blackout provoked by head injury?**

Options:

Yes

No

Not documented

**Q3.3b Was the patient's previous seizure or blackout provoked by fever?**

Options:

Yes

No

Not documented

**Q3.3d Was the patient's previous seizure or blackout provoked by other?**

Options:

Yes (if yes – please specify)

No

Not documented

**Q3.4 Has the patient attended this Emergency Department as a result of a seizure in the previous 12 months?**

Yes

No

Not documented

**Q3.5 On attendance which anti-epileptic drugs was the patient being prescribed?**

Options:

Carbamazepine/Tegretol/ Tegretol Retard

Lamotrigine/Lamictal

Levetiracetam/Keppra

Phenytoin/Epanutin

Sodium Valproate/Epilim/Epilim Chrono/Orlept

Acetazolamide/Diamox

Clobazam/Frisium

Clonazepam/Rivotril/ Rivatril

Diazepam/Valium

Eslicarbazepine Acetate/ Zebinix

Ethosuximide/Emeside/ Zarontin

Gabapentin/Neurontin

Lacosamide/Vimpat

Oxcarbazepine/Trileptal

Oxazepam/Serax

Perampanel/Fycompa

Pregabalin/Lyrica

Phenobarbital

Primidone/Mysoline

Retigabine/Trobalt

Rufinamide/Inovelon

Stiripentol/Diacomit

Sulthiame/Ospolot

Tiagabine/Gabatril

Topiramate/Topamax

Vigabatrin/Sabril

Zonisamide/Zonegran

**Q3.6a Is it documented that the patient has seen an Epilepsy Specialist Nurse within the previous 12 months?**

Options:

Yes  
No  
Not documented

**Q3.6b Is it documented that the patient has seen a GPSI (neurology, epilepsy or neuropsychiatry) within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.6c Is it documented that the patient has seen a learning disability psychiatrist within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.6d Is it documented that the patient has seen a neurologist within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.6e Is it documented that the patient has seen a hospital paediatrician within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.6f Is it documented that the patient has seen a community paediatrician within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.6g Is it documented that the patient has seen a paediatric neurologist within the previous 12 months?**

Options:  
Yes  
No  
Not documented

**Q3.7a Is the patient recorded as having a learning disability?**

Options:  
Yes  
No/Not documented

**Q3.7a Is the patient recorded as having an autism spectrum disorder?**

Options:

Yes

No/Not documented

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

Date

**Q4.2 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 documented

**Q4.2a Was this within 4 hours of arrival in the Emergency Department?**

Options:

Yes

No

Not documented

**Q4.2b Were they seen by a consultant?**

Options:

Yes

No

Not documented

**Q4.2a Were they seen by a ST4 or above?**

Options:

Yes

No

Not documented

**Q5.1a Is it documented that diazepam (rectal or IV) was administered prior to arrival at hospital?**

Options:

Yes

No

**Q5.1a1 Who was the diazepam administered by?**

Options:

Family member/carer

GP

Ambulance staff

Other - please specify

**Q5.1b Is it documented that midazolam was administered prior to arrival at hospital?**

Options:

Yes

No

**Q5.1b1 Who was the midazolam administered by?**

Options:

Family member/carer

GP

Ambulance staff

Other - please specify

**Q5.1c Is it documented that an other drug (oral clobazam, iv lorazepam or paraldehyde) was administered prior to arrival at hospital?**

Options:

Yes

No

**Q5.1c1 Who was the other drug 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 lorazepam

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  
Paediatric neurologist  
General physician  
Other  
Remained under care of Emergency Department

**Q6.4b For all patients except those who were discharged (or for whom the answer to the previous question was missing), how long was the patient admitted for?**

Options:  
Days  
Hours

**Q6.4c For patients who were moved to the Intensive Care Unit, what were they treated with?**

Options:  
Chlormethiazole 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  
Event unwitnessed

**Q6.5a If no to the above, is there a statement that an attempt was made to contact an eyewitness?**

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 patient's general alcohol intake?**

Options:  
Yes

No

**Q6.7a How is their drink intake best classified?**

Options:  
Excessive  
Moderate  
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 an isolated weakness 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

Don't know

**Q8.1b Were CT (head) investigations undertaken following attendance in the Emergency Department?**

Options:

Yes

No

Don't know

**Q8.1c Were ECG investigations undertaken following attendance in the Emergency Department?**

Options:

Yes

No

Don't know

**Q8.1d Were EEG investigations undertaken following attendance in the Emergency Department?**

Options:

Yes

No

Don't know

**Q8.1e Were glucose levels/BM investigations undertaken following attendance in the Emergency Department?**

Options:

Yes

No

Don't know

**Q8.1f Were MRI (head) investigations undertaken following attendance in the Emergency Department?**

Options:

Yes  
No  
Don't know

**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  
Don't know

**Q8.3b Was a EEG investigation requested as an outpatient following discharge?**

Options:  
Yes  
No  
Don't know

**Q8.3c Was a MRI (head) investigation requested as an outpatient following discharge?**

Options:  
Yes  
No  
Don't know

**Q8.3d Was a 12 lead ECG investigation requested as an outpatient following discharge?**

Options:  
Yes  
No  
Don't know

**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:

Carbamazepine/Tegretol/ Tegretol Retard

Lamotrigine/Lamictal

Levetiracetam/Keppra

Phenytoin/Epanutin

Sodium Valproate/Epilim/Epilim Chrono/Orlept

Acetazolamide/Diamox

Clobazam/Frisium

Clonazepam/Rivotril/ Rivatril

Diazepam/Valium

Eslicarbazepine Acetate/ Zebinix

Ethosuximide/Emeside/ Zarontin

Gabapentin/Neurontin

Lacosamide/Vimpat

Oxcarbazepine/Trileptal

Oxazepam/Serax

Perampanel/Fycompa

Pregabalin/Lyrica

Phenobarbital

Primidone/Mysoline

Retigabine/Trobalt

Rufinamide/Inovelon

Stiripentol/Diacomit

Sulthiame/Ospolot

Tiagabine/Gabatril

Topirimate/Topamax

Vigabatrin/Sabril

Zonisamide/Zonegran

**Q9.3 Was the management of future seizures discussed with the patients or carers?**

Options:

Yes

No

Not documented

**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

**10.1y Was the patient referred to an alcohol/drug liaison service?**

Options:

Yes

No

Don't know

**10.1z Did the patient attend their appointment?**

Options:

Yes

No

Don't know

**10.1aa What was the date of their appointment?**

Options:

Free text

Date not known

**10.1bb 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

**10.1cc Was the patient referred to a paediatrician?**

Options:

Yes

No

Don't know

**10.1dd Did the patient attend their appointment?**

Options:

Yes

No

Don't know

**10.1ee What was the date of their appointment?**

Options:

Free text

Date not known

**10.1ff 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

**10.1gg Was the patient referred to a paediatrician with training and expertise in epilepsy?**

Options:

Yes  
No  
Don't know

**10.1hh Did the patient attend their appointment?**

Options:

Yes  
No  
Don't know

**10.1ii What was the date of their appointment?**

Options:

Free text  
Date not known

**10.1jj 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

**Q10.2 Was an A&E discharge letter provided to the patient's GP following their attendance at ED?**

Options:

Yes  
No  
Don't know

**Q10.2a Did the letter ask their GP to arrange onward referral?**

Options:

Yes  
No  
Don't know

## 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
R56.0	Febrile convulsions
R56.1	Post traumatic seizures
R56.8	Unspecified convulsions

## **APPENDIX FIVE**

It was established that NASH 2 could assist with reporting on the following NICE Quality Statements for Epilepsy (Adults).

Statement 1: Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Statement 2: Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Statement 4: Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Statement 5: Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Statement 6: Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Statement 7: Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Statement 8: Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.