UNIVERSITY OF LIVERPOOL

National Audit of Seizure Management in Hospitals

St. Elsewhere's Hospital

Clinical Report, April 2014

Eisai Ltd.

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VIROPHARMA

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FOREWORD

This is the second UK-wide epilepsy audit and includes data from over 4,500 adult patients across 154 sites (from 132 Trusts/Health Boards) in England, Wales, Scotland and Northern Ireland.

The aims of the original 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.

The first NASH audit, 2 years ago, provided comparative data on the process of care and outcomes for individual sites against a benchmark of all other participating UK sites. It identified areas where care and processes are good, and areas where care and processes are poorer, thus highlighting areas where change, and perhaps investment, are required. It 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. There is a large financial burden on the NHS. If more patients got to see epilepsy specialists and had appropriate regimes and appropriate protocols 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.

All participating hospitals have had feedback reports with comparative data, and we ran 7 regional meetings to discuss the data. NASH2 using similar methodology asks what may have changed over 2 years . The questionnaire is very similar to the first audit but with some additions, improvements and subtractions based on the feedback received.

NASH1 was based on the 2004 NICE guidelines and NASH2 relates also to the revision "NICE CG137 (January 2012)". Epilepsy is the first neurological condition to be given its Quality Standards by NICE and the data from NASH2 provide some information for 7 of the 9 standards (see Appendix Five).

The most positive conclusion from NASH 2 is that there has been a small, but statistically significant, shift toward better care across the country. However, this must be balanced by observations that there continues to be a very wide range of care quality between hospital. A few centres have scored very highly showing that quality care is possible - but many have not. Each of the criticisms made of overall care 2 years ago, can be repeated again based on the current data.

Individual hospitals returned data on 30 patients each so the comparisons between years must be interpreted with some care. For individual variables, a change in score of up to 30% can be within the limits of statistical chance - so it’s important not to get over concerned with one or two items. The pattern of care across *multiple variables* is a better way of assessing the care standards and there are many hospitals where the opportunity, and need, for improvement is very obvious.

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).

We believe that showing care is still far from optimal across the country reinforces the need for change. 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.

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

We are grateful to everyone who has helped with the project and appreciate the very considerable amount of time and effort that has gone into obtaining local data. We hope that all participants will feel it has been worthwhile and that the audit represents a significant step in raising the profile of epilepsy and toward improving care for patients.

Particular thanks are due to the steering committee for their helpful comments and advice and to the Epilepsy Action, Epilepsy Society and SUDEP Action who have provided invaluable advice from the patient's perspective.

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




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January 2014

P.S. For Information: there is a smaller paediatric pilot version of this audit from 15 hospitals across northwest England and north Wales that will be reported on separately. We will supply email versions of this to you in a few weeks time.

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. The data have been fed back and trusts have had time to reflect on the results. Now, two years on, the data collection has continued using the same proforma (with minor modifications) offering the chance to assess if patterns of care have changed and, if not, to consider how things might be changed for the future.

For NASH2, 154 hospitals have taken part and, again, have provided clinical data on at least 30 consecutive adult patients presenting with a seizure (from January 1st 2013) detailing both process of care and clinical outcomes. Data were entered via an online system. This opened on June 12th 2013 and closed on September 30th 2013.

This report gives each site's clinical results benchmarked against all 154 UK sites (from 132 Trusts/Heath Boards) that completed the audit. A second report will shortly be produced that examines the available resources and organisation of care.

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

Overall Picture

Three particular findings emerge:

- it is encouraging that across the national cohort there are small but significant improvements from NASH1, but these are probably at a level at which patients will not perceive change
- there is, as was found in the first audit, a pattern within the data that high performing sites tend to perform well across most variables and *vice versa*; and
- the variation between the best performing and least well performing sites is extremely wide. If some can achieve these standards - why can't the others do so too?

At the regional feedback meetings which followed NASH1, there was a general agreement that an aggregated overall measure might be useful, but some debate about the validity of our choices. However while our 7 variable selection may not be ideal, it does cover the spectrum of the patient pathway and in absence of a better alternative, we have repeated the exercise here.

The overall rise in this statistic from 52% to 60% for the 101 sites who took part in both NASH1 and NASH2 is encouraging but there are still 18% of NASH2 sites who score below 50% on this measure. Can this be acceptable?

In the introduction to the NASH1 report, we created a composite variable based on 7 items of care across the patients' care pathway. While there can be some continued debate as to whether these are the most important 7 items, we use it again to illustrate the changes over the 2 year period. In the NASH1 report and in our follow-up regional meetings we invited you to comment on this selection, and while a few comments have been made no one has yet suggested a better composite selection that reflects overall care.

Probably the most comment at the regional meetings concerned the recording of a neurological examination within either the ED dept or (for those admitted) the ward stay. Some ED physicians felt that recording plantar responses or examining fundi was not an essential part of the ED role, while some neurologists argued it was essential part of a patient assessment after a neurological event. The judgement as to which is correct is not for us to decide - it must await a guidelines revision - but the fact that there is such a disagreement on a relatively simple aspect of care shows that there is a need for professional discussions to provide agreement as to what best care should be.

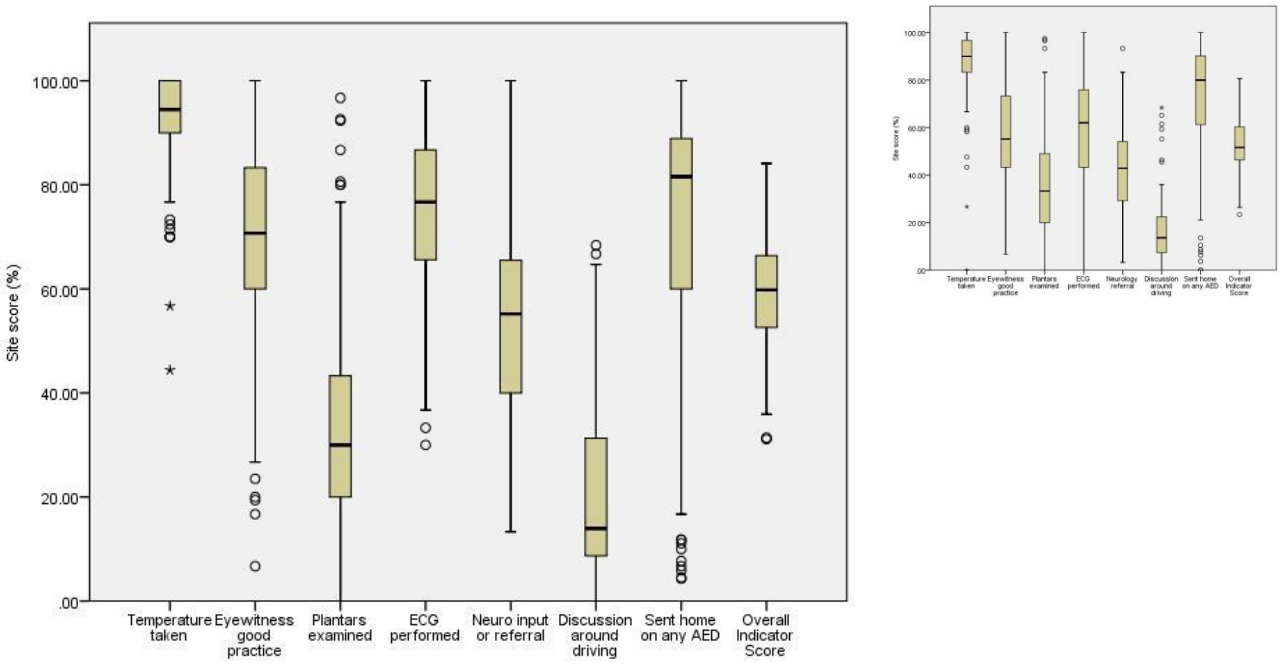
For many of the variables there was agreement that the items should be performed and that the overall proportions observed in the audit were not acceptable. An example is the follow up by specialists where we accepted the widest possible definition of specialist, yet less than half of patients were referred on to specialist services for further assessment.

The table below shows the national mean percentage of cases for the 101 sites involved in both rounds of the audit, together with your site's figures from NASH2.

	National mean – NASH1	National mean – NASH2	**Your site – NASH2**
Temperature taken in the ED	86.4	91.6	**93.3**
Eyewitness statement taken or sought	55.8	66.9	**60**
Plantars examined	35.2	36.7	**40**
ECG performed	56.8	74.8	**63.3**
The patient had some neurology input during their attendance, or was referred to a neurologist as an outpatient	42.7	55.5	**40**
Discussion around driving took place with the patient	16.0	22.1	**4.2**
Sent home on at least one anti-epileptic drug (NB only applied to patients known to have epilepsy)	71.8	68.6	**33.3**
Mean of the 7 variables above	52.1	59.5	**47.7**

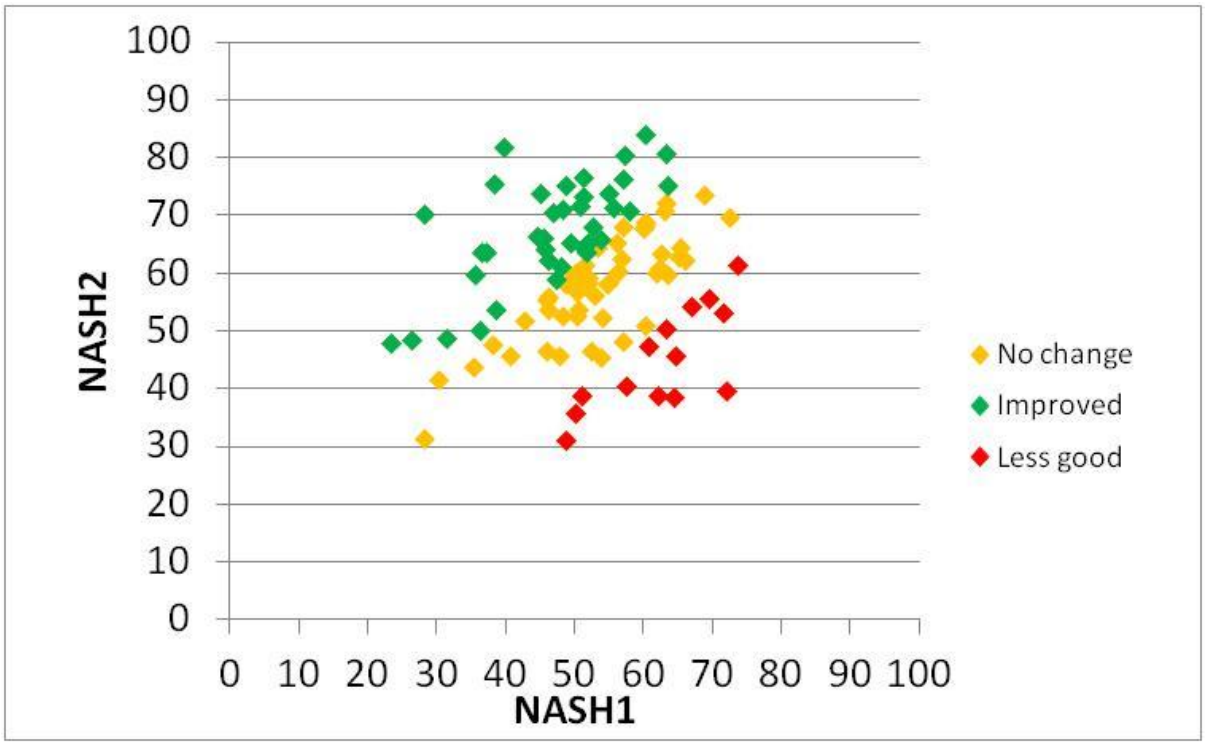
Five of the 7 variables exhibit a small, but significant, improvement overall, but the scatter of data within hospitals for each of the 7 data items remains high. The two graphs below show the variability across all sites. The average of the 7 variables (right hand most box and whisker) has a narrower, but still wide, range. With more data included the confidence interval is also less (+/- 11%), so there is less "wriggle room" to argue that the whole is down to "bad luck".

Figure 1: Key indicators and overall score for all sites taking part in NASH2 (inset graph shows equivalent from NASH1)



Applying this composite to each local site and plotting NASH2 against NASH1 yields the graph below. Sites in green have performed significantly better than last time while those in red are statistically worse. From this representation it is clear that there are more hospitals that have performed better, but we urge people **not to over interpret** such changes as absolute measures of care quality.

Figure 2: Comparisons of key indicator scores for NASH1 and NASH2 for those sites who participated in both audits



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 changes 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.

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.

The NASH2 data replicate the performance of 2011 and indeed this is a similar situation that applied to the stroke audit which was first done in 1998 with the second audit following in 2000. 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.

In NASH1 we observed:

- that many patients are on therapy that could be improved upon i.e. many of these seizures were unnecessary
- that the assessment and management was often less than ideal; and
- that onward referral to the teams able to diagnose and control the disease often does not happen

All of these issues are present again in NASH2 - more so in some hospitals than others.

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.

Once again there was similar variability in stroke care in 2000 and the key was better organisation of care - in that instance based around stroke units. 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 4,544 admissions registered. 57% of admissions were male and the median age was 45 years.

- 61% of admissions were of patients who were known to have epilepsy
- 17% were of patients who were known to have had previous seizures or blackouts but did not have a known diagnosis of epilepsy; and

- 22% were of patients with no prior history of epilepsy or blackouts/seizures, i.e. this was their first seizure.

Findings

Notwithstanding the observation of a small overall improvement in many of the variables there were still many problems. These principle findings remain the same as those in the first NASH report:

Anti Epileptic Drugs (AEDs) prior to the event – the 60% of patients presenting to the Emergency Department who are already on AEDs include many on monotherapy and often with older drugs. - a clear opportunity to improve control with modified therapy
Evidence of Senior Emergency Department Review – many patients are managed without a senior review
Contacting eyewitnesses – patients cannot describe their own seizure yet in many hospitals it is clearly not routine to seek a witness of the event
Documentation of whether the patient is a driver – Driving should be documented and advice given – especially where it is a first event. This is not happening at many sites.
Documentation of alcohol intake – DoH guidance recommends alcohol use should be documented in all, and especially where it is a known provoking factor for the event, but it is often not happening.
Recording of data – recording temperature, and recording GCS, should be routine , but there are some sites where it is not.
Neurological examination – despite a loss of consciousness, a full neurological examination including plantar reflex and fundi examination are not performed for most patients.
Obtaining expert epilepsy help – despite the most generous definitions, but more than half of patients did not get such an assessment.
Drugs on discharge –many appear to not be sent home on the medication one might have expected

Food for Thought

This second UK national audit has confirmed that much epilepsy care is sub-optimal, that there is still excessive variability between hospitals, and yet 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 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 and of those referred many did not attend. Data from Ireland suggests that active management can prevent future seizures and admissions
- Now the results have been confirmed in a second audit this situation cannot be acceptable to patients. 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/CG20 (epilepsies)
http://guidance.nice.org.uk/CG109 (TLOC)

Interpretation of the data in this report

Across the UK there were 127 sites describing 3,759 patients in 2011 and 154 reporting 4,544 in 2013.

At the UK level, with large numbers, a relatively small percentage change of 2.5% in a particular variable will reach statistical significance. Thus an increase in the proportion having their temperature measured on arrival from 89.0% to 91.5% is statistically significant. If similar changes in the same direction are also seen in related variables, the confidence that something has changed is increased.

Direct comparisons have been made using the whole of each cohort and repeated using only the 101 sites who completed both NASH1 and NASH2. For simplicity in this report we describe the changes in the whole of each cohort. However, patterns in the whole cohort and in the 101 sites are very similar and conclusions are the same. Wherever a change is noted "significant", the statistics apply to both forms of analysis

There has been a small improvement in many of the variables reported upon between NASH1 and NASH2. This is encouraging, but the wide variability between hospitals remains, and whether patients could perceive the benefits of these small improvements is unclear.

Using local data

In this report we describe the national 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.

National audits can change care and practice. Previous experience of the study team in audits of myocardial infarction, stroke, carotid endarterectomy, evidence-based prescribing, COPD, lung cancer, continence, inflammatory bowel disease, blood transfusion, and palliative care have shown them to be successful in improving services as the results have been fed back to sites.
NASH seeks to identify any variation in patient care and identify some of the resource and organisational factors that may account for this. The national audit data provides a first national benchmark against which clinical teams can compare themselves now, and monitor future change. The comparative performance data in this report should therefore provide a means of raising the standards of epilepsy care nationwide.

METHOD

Organisation and monitoring

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

Recruitment

Letters to the Chief Executives and Heads of Clinical Audit, and emails to participants from NASH1, were sent in February 2013 to all Trusts/Health Boards in England, Scotland, Wales and Northern Ireland 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.

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

Of the Trusts/Health Boards eligible to take part, 132 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 154 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 NASH1. 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). For purposes of comparing the results from each audit, these have been considered to be analogous.

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 were 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 12th June and 30th September 2013. Anonymised data were requested for 30 consecutive patients who:

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

The start date for these presentations was chosen as 1st 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. Results from the NASH1 audit are shown in red and in parentheses. For a number of questions, results are split according to the patients' known history of epilepsy and seizures. An annotated example table is shown below. Variation between sites is summarised for certain questions by use of box plots and/or inter quartile ranges.

Figure 3: Example of a table used in the report

Patient type

Percentage of patients for whom it is recorded that that they have a learning disability: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=16**	n=767	**n=8**	n=1,011	**n=6**	n=4,544	**n=30**
Learning disability	18.3 (15.3)	**25.0 (15.0)**	5.3 (4.1)	**12.5 (4.0)**	4.1 (2.7)	**0.0 (0.0)**	12.9 (11.3)	**16.7 (10.5)**

Number of patients in the analysis (national figure are in plain text, your site's figures are in bold)

Mean percentage (NASH2 results are in black, NASH1 figures are in red)

PATIENT DATA

Patient Data were received from 154 sites within 132 NHS Trusts/Health Boards.

4,544 attendances at Emergency Departments from January 1st 2013 were available for analysis. The median number of attendances per site was 30, range 9-40.

You contributed **30** attendances to the analysis.
St. Eleswhere's Hospital took part in both NASH1 and NASH2.

Clinical proforma completed by: %

	National audit n=4,544	**Your site n=30**
Doctor	84.0 (81.9)	**100 (100)**
Audit staff	3.6 (5.5)	**0 (0)**
Nurse	9.7 (11.0)	**0 (0)**
Other	2.8 (1.6)	**0 (0)**

DEMOGRAPHICS

Gender: %

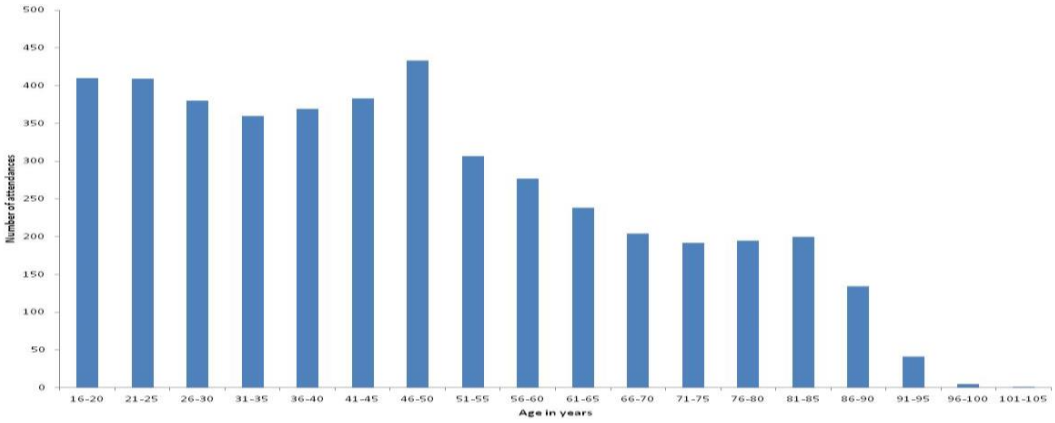
	National audit n=4,544	**Your site n=30**
Males	57.4 (57.0)	**56.7 (51.6)**
Females	42.6 (43.0)	**43.3 (48.4)**

Age: %

	National audit n=4,544	**Your site n=30**
<45	49.0 (51.6)	**53.3 (32.3)**
45-65	29.5 (29.8)	**36.7 (32.3)**
>65	21.4 (18.6)	**10 (35.5)**

National median = 45 (IQR 30-62). Your site's median **= 42.5** (IQR 30.8 – 55.8)

Figure 4: Age distribution of cases contributing to NASH2



COMMENT: The demographics for NASH1 and NASH2 are similar – not surprising given the starting point of was a consecutive series of patients arriving at ED.

NEW FOR NASH2: Does the patient live in the geographical area covered by this Trust?: %

	National audit n=4,544	**Your site n=30**
Yes	91.4	**100**
No/Not documented	8.6	**0**

National 'yes' figures

MIN	33.3
LOWER QUARTILE	89.0
UPPER QUARTILE	100.0
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. We ran such sub analysis on a number of the questions and the differences were found to be minimal both at both a national and individual site level. These sub-analyses are therefore not shown in this report.

PREVIOUS SEIZURE HISTORY AND MANAGEMENT

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

	National audit n=4,544	**Your site n=30**
Yes	60.7 (66.4)	**40 (90.3)**
No/Not documented	39.2 (33.5)	**60 (9.7)**

National 'yes' figures

MIN	23.1
LOWER QUARTILE	50.0
UPPER QUARTILE	73.3
MAX	93.3

NEW FOR NASH2: Does the patient have a written care plan in place?: %

	National audit n=2,759	**Your site n=12**
Yes	28.1	**25**
No/Not documented	71.7	**75**

COMMENT: This question suggests that 28% of all patients 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 and welcome comments.

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

	National audit n=4,544	**Your site n=30**
Yes	73.9 (76.2)	**66.7 (87.1)**
No/Not documented	25.9 (23.8)	**33.3 (12.9)**

National 'yes' figures

MIN	26.7
LOWER QUARTILE	64.2
UPPER QUARTILE	83.3
MAX	96.7

Nationally, 61% had epilepsy and 74% had previous seizures or blackouts.

CLASSIFICATION OF PATIENTS

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

1. Those who are known to have epilepsy (n=2,759)
2. Those who are known to have previous seizures or blackouts, but not epilepsy (n=767)
3. Those who are not known to have either epilepsy or previous seizures or blackouts (n=1,011)

NB 7 patients cannot be assigned to these categories because of missing data

These three groups will be used throughout the rest of this report.

Distribution of patient classes between audits:

	Patients with diagnosis of epilepsy	Patients with known blackouts or seizures, but no epilepsy	Patients with neither epilepsy or blackouts/seizures
NASH1	66%	15%	18%
NASH2	61%	12%	22%

COMMENT: This second round of NASH has fewer patients labelled as having prior epilepsy. We know of no reason for this change, and, although statistically significant, it may yet be due to chance.

NB some 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 alcohol?: %

	National audit n=3,360	**Your site n=20**
Yes	14.0 (13.7)	**30 (0)**
No	53.2 (51.8)	**70 (48.1)**
Not documented	31.1 (33.6)	**0 (51.9)**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	6.4
UPPER QUARTILE	20.5
MAX	53.8

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

	National audit n=3,360	**Your site n=20**
Yes	5.1 (4.4)	**5 (3.7)**
No	60.1 (58.5)	**95 (55.6)**
Not documented	32.9 (36.1)	**0 (40.7)**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	0.0
UPPER QUARTILE	8.3
MAX	22.2

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

	National audit n=3,360	**Your site n=20**
Yes	20.4 (20.7)	**50 (55.6)**
No	42.6 (38.7)	**25 (7.4)**
Not documented	36.6 (39.8)	**25 (37.0)**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	10.0
UPPER QUARTILE	27.1
MAX	83.3

COMMENT: 14.0% had a history of alcohol-related seizure.
Overall 36.3% (IQR 23.1 to 45.8) recorded one or more known provoking factors.
In each of the three tables above, it seems that there are fewer cases of no documentation compared to the first audit - a small but useful improvement in the process.

NEW FOR NASH2: 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=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Yes	45.1	**25**	40.8	**22.2**	3.9	**22.2**	35.1	**23.3**
No	39.9	**33.3**	48.8	**33.3**	83.2	**55.6**	51.0	**40**
Not documented	14.9	**41.7**	10.4	**44.4**	12.9	**22.2**	13.6	**36.7**

National 'yes' figures

MIN	0.0	0.0	0.0	3.3
LOWER QUARTILE	33.3	25.0	0.0	26.7
UPPER QUARTILE	57.1	50.0	0.0	45.8
MAX	100.0	100.0	100.0	87.1

COMMENT: This shows that almost half of those patients with epilepsy have had seizures necessitating a visit to ED in the past year. Many of those with blackouts but no epilepsy are also repeat visitors – hinting that their problems are also not being resolved. This has huge cost implications for the NHS and society 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=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Valproate/Epilim/Epilim Chrono/Orlept	33.9 (35.9)	**8.3 (35.7)**	6.4 (6.6)	**0 (0)**	1.9 (2.3)	**0 (0)**	22.1 (25.3)	**3.3 (32.3)**
Lamotrigine/Lamictal	21.1 (21.4)	**16.7 (7.1)**	3.0 (2.8)	**0 (0)**	0.4 (0.9)	**0 (0)**	13.4 (14.8)	**6.7 (6.5)**
Carbamazepine/Tegretol/ Tegretol Retard	17.8 (19.0)	**0 (21.4)**	2.3 (4.6)	**0 (0)**	0.2 (0.3)	**0 (0)**	11.3 (13.4)	**0 (19.4)**
Levetiracetam/Keppra	21.7 (19.1)	**8.3 (14.3)**	3.9 (2.8)	**0 (0)**	0.5 (0.1)	**0 (0)**	13.9 (13.2)	**3.3 (12.9)**
Phenytoin/Epanutin	10.1 (12.1)	**8.3 (7.1)**	2.0 (3.4)	**11.1 (0)**	0.6 (2.3)	**0 (0)**	6.6 (9.0)	**6.7 (6.5)**
Clobazam/Frisium	6.3 (5.5)	**0 (0)**	0.0 (0.5)	**11.1 (0)**	0.1 (0.0)	**0 (0)**	3.9 (3.8)	**3.3 (6.5)**
Other AED	17.5 (15.0)	**16.7 (25)**	4.4 (2.8)	**0 (0)**	2.1 (2.4)	**0 (0)**	11.8 (10.9)	**6.7 (22.6)**
No AED	18.1 (15.7)	**58.3 (14.3)**	80.3 (80.9)	**88.9 (100)**	95.0 (92.4)	**100 (100)**	45.8 (39.7)	**80 (22.6)**
One or More AED								
Mean	81.9 (84.3)	**41.7 (85.7)**	19.7 (19.1)	**11.1 (0)**	5.0 (7.6)	**0 (0)**	54.2 (60.3)	**20 (77.4)**
Minimum	0.0		0.0		0.0		3.3	
LOWER QUARTILE	76.9		0.0		0.0		46.7	
UPPER QUARTILE	91.3		27.9		0.0		63.3	
Maximum	100.0		100.0		66.7		90.0	

COMMENT: Overall, prior drug treatment shows no significant differences between NASH1 and NASH2, suggesting no significant changes in primary care management over the past 2 years.

Summary of Polytherapy

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
One drug as monotherapy	48.2 (49.4)	**33.3 (50)**	17.3 (15.6)	**0 (0)**	4.5 (6.9)	**0 (0)**	33.2 (36.4)	**13.3 (45.2)**
Two or more drugs as polytherapy	33.7 (34.8)	**8.3 (35.7)**	2.3 (3.5)	**11.1 (0)**	0.6 (0.7)	**0 (0)**	21.0 (23.9)	**6.7 (32.3)**
Not taking AED prior to attendance	18.1 (15.7)	**58.3 (14.3)**	80.3 (80.9)	**88.9 (100)**	95.0 (92.4)	**100 (100)**	45.8 (39.7)	**80 (22.6)**

COMMENT: Sodium valproate remains the most commonly prescribed AED, taken by 34% of patients with known epilepsy and often as monotherapy – thus 18.8% are on valproate as monotherapy and 3.3 % are on phenyotin as monotherapy.

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 25% to 100% across sites) persists which suggests that refractory patients are not getting access to appropriate expertise and to newer treatments. Therefore, there remains an opportunity to intervene with more modern or additional treatment to prevent future seizures. The range of drug prescription pre presentation remains uncomfortably wide.

Summary of polytherapy when used

Number of AEDs being taken	Percentage of polytherapy patients
2	64.4
3	25.5
4	8.1
5	1.6
6	0.3
7	0.1

Most popular duo polytherapy combinations (those in over 5% of cases)	Percentage of polytherapy patients
LEV/VPA	7.4
LTG/VPA	7.4
LEV/LTG	6.3
CBZ/VPA	5.3

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

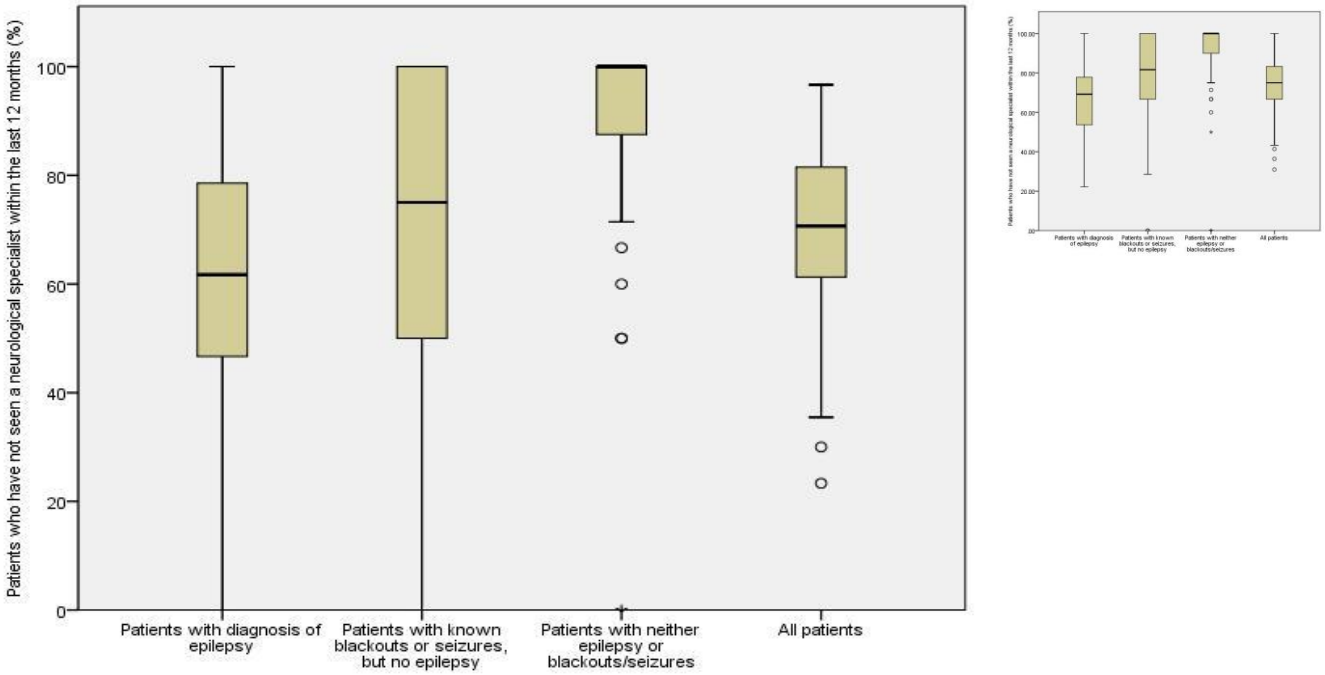
Percentage of patients for whom it is documented that they have seen one of the listed medical specialists within the previous 12 months: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Epilepsy Specialist Nurse	9.6 (5.5)	**0 (3.6)**	1.4 (0.7)	**0 (0)**	0.1 (0.0)	**0 (0)**	6.1 (3.8)	**0 (3.2)**
GPSI (neurology, epilepsy or neuropsychiatry)	1.9 (1.2)	**0 (14.3)**	1.6 (0.7)	**0 (50)**	0.4 (0.3)	**0 (0)**	1.5 (1.0)	**0 (16.1)**
Learning disability psychiatrist	1.4 (1.1)	**0 (0)**	0.8 (0.5)	**0 (0)**	0.2 (0.6)	**0 (0)**	1.0 (0.9)	**0 (0)**
Neurologist/paediatric neurologist	31.5 (29.9)	**8.3 (32.1)**	26.0 (16.7)	**22.2 (0)**	4.4 (3.5)	**0 (0)**	24.5 (23.0)	**10 (29.0)**
Paediatrician*	14.1 (8.8)	**NA (0)**	6.2 (3.2)	**0 (NA)**	0.0 (0.0)	**0 (NA)**	9.8 (6.3)	**0 (0)**
Neurosurgeon	2.0 (2.3)	**0 (0)**	3.1 (2.1)	**0 (0)**	2.5 (1.7)	**0 (0)**	2.3 (2.1)	**0 (0)**
None of the above	62.9 (66.2)	**91.7 (53.6)**	70.0 (80.9)	**77.8 (50)**	93.1 (94.4)	**100 (100)**	70.9 (73.6)	**90 (54.8)**

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

COMMENT: The proportion of epilepsy patients who have seen an epilepsy specialist in the previous 12 months has risen (statistically significant). However, there were still 63% who had not, despite over 50% having had a seizure-related ED attendances in the previous year. The variation between trusts is as wide as can be seen below.

Figure 5: Distribution of number of patients who had not seen an epilepsy specialist in the past 12 months across sites (inset graph shows results from NASH1)



Percentage of patients for whom it is recorded that that they have a learning disability: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Learning disability	18.3 (15.3)	**8.3 (28.6)**	5.3 (4.1)	**0 (50)**	4.1 (2.7)	**22.2 (0)**	12.9 (11.3)	**10 (29.0)**

SENIOR REVIEW IN EMERGENCY DEPARTMENT

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Yes	57.5 (47.2)	**16.7 (64.3)**	59.2 (46.6)	**44.4 (100)**	58.6 (49.4)	**33.3 (100)**	58.0 (47.5)	**30 (67.7)**
No	26.1 (30.5)	**75 (10.7)**	25.4 (30.9)	**55.6 (0)**	24.4 (26.0)	**55.6 (0)**	25.6 (29.7)	**63.3 (9.7)**
Not recorded	15.8 (22.3)	**8.3 (25)**	14.9 (22.3)	**0 (0)**	16.5 (24.6)	**11.1 (0)**	15.8 (22.8)	**6.7 (22.6)**

National 'yes' figures

MIN	5.0	0.0	0.0	6.7
LOWER QUARTILE	42.1	40.0	40.0	43.4
UPPER QUARTILE	73.3	80.0	80.0	70.0
MAX	100.0	100.0	100.0	100.0

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,586	**n=2**	n=454	**n=4**	n=592	**n=3**	n=2,636	**n=9**
Yes	89.5 (85.9)	**100 (100)**	89.2 (57.5)	**75 (100)**	86.7 (89.8)	**66.7 (100)**	88.8 (86.9)	**77.8 (100)**
No	4.9 (5.4)	**0 (0)**	5.1 (3.8)	**0 (0)**	5.6 (4.7)	**0 (0)**	5.1 (5.0)	**0 (0)**
Not recorded	5.5 (8.7)	**0 (0)**	5.7 (8.8)	**25 (0)**	7.8 (5.5)	**33.3 (0)**	6.0 (8.1)	**22.2 (0)**

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	85.7	83.3	84.5	84.4
UPPER QUARTILE	100.0	100.0	100.0	100.0
MAX	100.0	100.0	100.0	100.0

COMMENT: It is an encouraging move in the right direction that significantly more patients were seen by a senior clinician in NASH2. However, 43% of those discharged from the ED without admission were seen only by junior medical staff - 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.

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
diazepam	13.3 (14.1)	**0 (21.4)**	7.0 (6.4)	**0 (0)**	6.5 (7.6)	**11.1 (0)**	10.7 (11.7)	**3.3 (19.4)**
midazolam	4.2 (4.3)	**0 (0)**	0.5 (0.9)	**0 (0)**	0.1 (0.6)	**0 (0)**	2.7 (3.1)	**0 (0)**
other (clobazam, lorazepam or paraldehyde)	1.1 (1.2)	**0 (3.6)**	0.3 (0.2)	**0 (0)**	0.5 (0.3)	**0 (0)**	0.8 (1.0)	**0 (3.2)**

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. Diazepam

may be the most commonly administered drug in the table above as ambulance staff are trained to provide IV services. There has been no change in the use of these drugs between the two NASH audits.

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

	National audit n=4,544	**Your site n=30**
Yes	86.6 (85.2)	**93.3 (93.5)**
No	9.1 (7.9)	**3.3 (0)**
Unclear	4.2 (6.9)	**3.3 (6.5)**

National 'yes' figures

MIN	40.0
LOWER QUARTILE	83.3
Q3	93.3
MAX	100.0

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

	National audit n=412	**Your site n=1**
IV diazepam	38.1 (24.0)	**100 (NA)**
Rectal diazepam	6.1 (6.1)	**0 (NA)**
Buccal midazolam	1.0 (2.4)	**0 (NA)**
IV lorazapam	42.7 (59.5)	**0 (NA)**
IV phenytoin	35.4 (34.1)	**0 (NA)**
None of the above	10.4 (8.4)	**0 (NA)**

COMMENT: For patients still seizing first line treatments in the Emergency Department were lorazepam (43%), diazepam (38%) and phenytoin (35%). There has been a significant shift from IV lorazepam to IV diazepam from NASH1, which is surprising as lorazepam is recommended.

INITIAL EMERGENCY DEPARTMENT ASSESSMENT

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

	National audit n=4,544	**Your site n=30**
Yes	74.8 (72.4)	**83.3 (67.7)**
No	20.7 (20.5)	**13.3 (32.3)**
Don't know	3.6 (6.1)	**3.3 (0)**

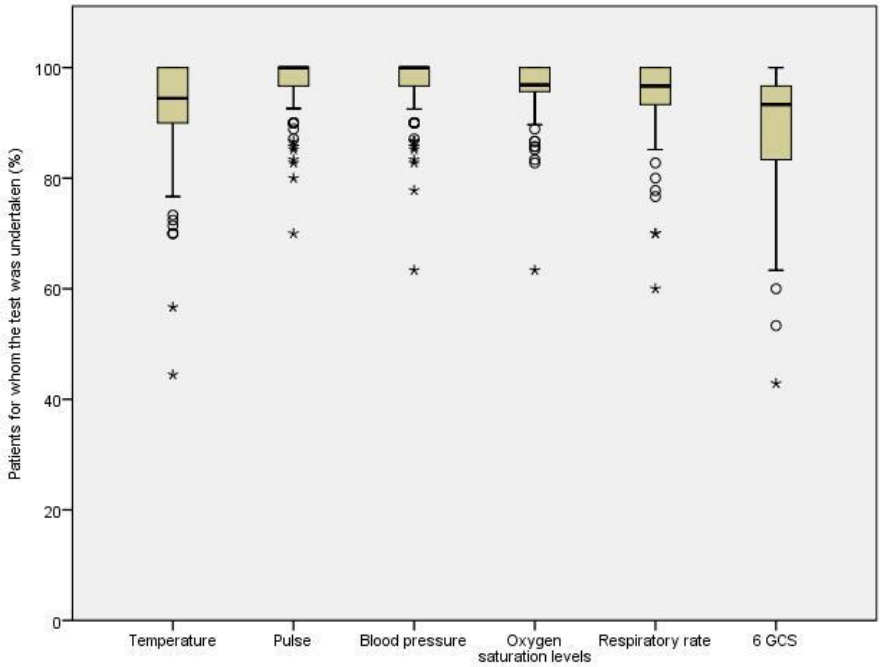
National 'yes' figures

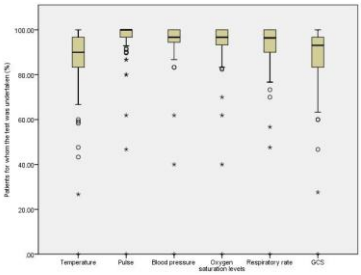
MIN	33.3
LOWER QUARTILE	66.7
UPPER QUARTILE	83.3
MAX	100.0

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

	National audit n=4,544	**Your site n=30**
Temperature	92.3 (86.9)	**93.3 (0)**
Pulse	97.5 (95.9)	**93.3 (0)**
Blood pressure	97.0 (95.3)	**93.3 (0)**
Oxygen saturation levels	96.7 (94.4)	**93.3 (0)**
Respiratory rate	95.7 (92.7)	**93.3 (0)**
GCS	89.8 (88.0)	**93.3 (0)**

Figure 6: Distribution of number of patients who had diagnostic tests undertaken in A&E across sites (inset graph shows results from NASH1)





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

	National audit n=4,192	**Your site n=28**
Yes	75.2 (69.0)	**100 (NA)**
No	11.2	**0**
Don't know	13.1	**0**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	61.0
UPPER QUARTILE	93.1
MAX	100.0

What was their GCS?:

	National audit n=4,079	**Your site n=28**
Median	15 (15)	**15 (NA)**
Range	3 to 15 (3 to 15)	**7 to 15 (NA)**

	Patients recorded as being conscious on arrival n=3,401	Patients recorded as not being conscious on arrival n=942
GCS recorded (%)	91.0 (89.8)	92.1 (90.4)
Median GCS Score	15 (15)	11 (11.0)
IQR	15-15 (15-15)	8-14 (8-14)

COMMENT: Not recording simple measures like temperature cannot be acceptable practice, so it is good to note a significant improvement in this. However, national averages are still lower than they should be (temperature being recorded in only 92% and GCS in only 90% of cases cannot be considered a success) and there are some very low outliers.

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=4,544	**Your site n=30**
Yes	50.2 (51.1)	**83.3 (67.7)**
No/Don't know	48.9 (48.6)	**16.7 (32.3)**

National 'yes' figures

MIN	0.0
LOWER QUARTILE	26.7
UPPER QUARTILE	73.3
MAX	100.0

	Patients recorded as being conscious on arrival n=3,401	Patients recorded as not being conscious on arrival n=942
Neuro obs chart present (%)	46.1 (48.0)	67.6 (68.4)

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

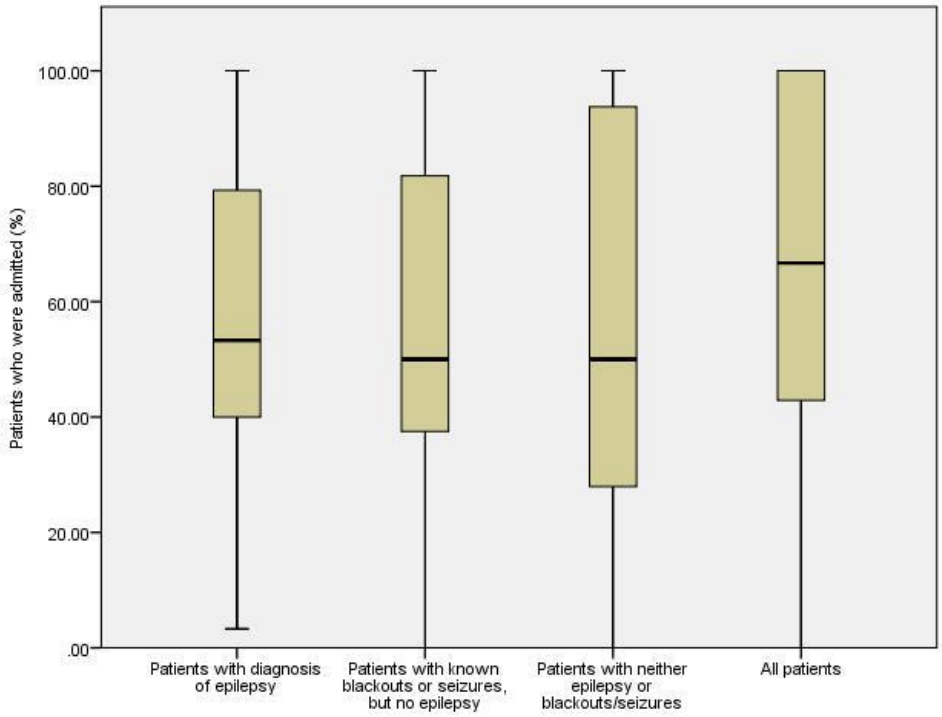
Percentage of patients discharged directly home from the Emergency Department: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Discharged	43.8 (42.7)	**16.7 (0)**	48.4 (49.1)	**55.6 (0)**	34.6 (37.1)	**44.4 (0)**	42.5 (42.6)	**36.7 (0)**

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Intensive Care Unit	1.7 (1.6)	**0 (0)**	1.3 (0.5)	**0 (0)**	2.2 (3.0)	**0 (0)**	1.7 (1.7)	**0 (0)**
Medical ward	11.0 (7.1)	**8.3 (3.6)**	11.5 (10.1)	**0 (0)**	14.3 (9.9)	**11.1 (0)**	11.8 (8.1)	**6.7 (3.2)**
Neurology ward	1.2 (0.7)	**0 (0)**	0.4 (0.2)	**0 (0)**	1.1 (1.0)	**0 (0)**	1.0 (0.7)	**0 (0)**
Other ward	2.5 (2.3)	**0 (0)**	2.6 (3.2)	**0 (0)**	2.6 (5.6)	**0 (0)**	2.5 (3.0)	**0 (0)**
Clinical decision unit	5.3 (6.2)	**0 (0)**	3.3 (5.0)	**0 (0)**	6.8 (4.0)	**0 (0)**	5.3 (5.6)	**0 (0)**
ED observational ward	3.4 (5.1)	**50 (0)**	3.0 (3.9)	**11.1 (0)**	2.6 (4.5)	**11.1 (0)**	3.2 (4.8)	**26.7 (0)**
EMU or equivalent	18.5 (18.6)	**0 (0)**	16.3 (15.8)	**0 (0)**	19.0 (18.9)	**0 (0)**	18.2 (18.3)	**0 (0)**
Medical decision unit	12.2 (15.7)	**25 (96.4)**	13.3 (11.9)	**33.3 (100)**	16.4 (15.8)	**33.3 (100)**	13.3 (15.2)	**30 (96.8)**
Discharged without admission	43.8 (42.7)	**16.7 (0)**	48.4 (49.1)	**55.6 (0)**	34.6 (37.1)	**44.4 (0)**	42.5 (42.6)	**36.7 (0)**

Figure 7: Distribution of number of patients who were admitted across sites



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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,541	**n=10**	n=396	**n=4**	n=657	**n=5**	n=2,598	**n=19**
Neurologist	5.2 (3.8)	**0 (0)**	2.8 (2.5)	**25 (0)**	5.2 (4.4)	**0 (0)**	4.8 (3.7)	**5.3 (0)**
General physician	77.9 (76.5)	**40 (100)**	82.1 (80.4)	**50 (100)**	78.8 (78.4)	**80 (100)**	78.8 (77.4)	**52.6 (100)**
Other	4.1 (3.9)	**0 (0)**	5.6 (2.8)	**0 (0)**	5.3 (7.1)	**0 (0)**	4.6 (4.4)	**0 (0)**
Remained under care of Emergency Department	11.2 (13.2)	**60 (0)**	7.8 (13.0)	**25 (0)**	9.6 (8.9)	**20 (0)**	10.3 (12.3)	**42.1 (0)**

COMMENT: Most patients are managed by general physicians, i.e. non neurologists. Most admissions are, initially at least, to some form of medical assessment facility but a significant number are managed by the Emergency Department, which was also found in NASH1.

Length of stay (days): %

	(National audit)			
	Patients with diagnosis of epilepsy n=1,459	Patients with known blackouts or seizures, but no epilepsy n=375	Patients with neither epilepsy or blackouts/seizures n=621	All patients n=2,456
Mean	1	1	1	1
Lower Quartile	1	1	1	1
Upper Quartile	3	3	5	4
Maximum	100	100	85	100

COMMENT: HES data shows that seizures account for about 1.5% of all general medical emergency admissions to acute hospitals and that they occupy a significant number of bed days. Do 57% of patients presenting with a seizure require to be admitted, and if so for how long?

ASCERTAINMENT OF EYEWITNESS DESCRIPTION OF SEIZURE

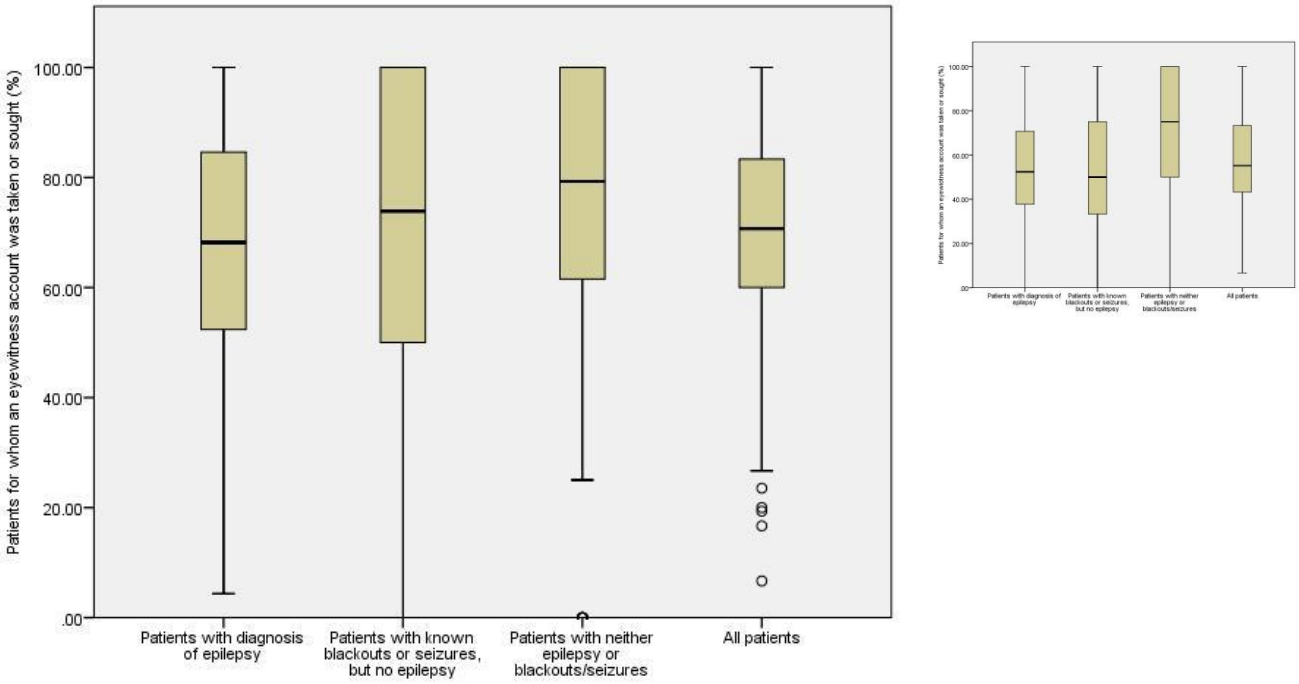
Was an eyewitness to the seizure contacted?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Yes	58.1 (51.2)	**41.7** **(78.6)**	62.7 (51.6)	**66.7** **(50)**	70.8 (62.5)	**44.4** **(100)**	61.8 (53.3)	**50** **(77.4)**
No, but attempt was made to contact them	0.8 (5.0)	**0** **(0)**	1.7 (2.5)	**22.2** **(0)**	0.7 (3.7)	**0** **(0)**	0.9 (4.4)	**6.7** **(0)**
Unwitnessed	7.3 (NA)	**0** **(NA)**	4.8 (NA)	**0** **(NA)**	3.6 (NA)	**11.1** **(NA)**	6.1 (NA)	**3.3** **(NA)**
No, and no attempt was made to contact them	13.3 (17.6)	**50** **(21.4)**	13.8 (18.4)	**0** **(50)**	7.8 (10.7)	**22.2** **(0)**	12.1 (16.4)	**26.7** **(22.6)**
Don't know	20.2 (26.0)	**8.3** **(0)**	16.8 (26.4)	**11.1** **(0)**	16.8 (22.7)	**22.2** **(0)**	18.9 (25.5)	**13.3** **(0)**

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

MIN	4.3	0.0	0.0	6.7
LOWER QUARTILE	52.4	50.0	61.8	60.0
UPPER QUARTILE	84.6	100.0	100.0	83.3
MAX	100.0	100.0	100.0	100.0

Figure 8: Distribution of number of patients for whom an eyewitness account was taken or sought across sites (inset graph shows results from NASH1)



COMMENT: Obtaining a good eyewitness description is vital for distinguishing among differing causes of blackout and for diagnosing seizures. This question differs slightly from NASH1 in that we added an option to say that the seizure was unwitnessed. This therefore increases the proportion of patients for whom an eyewitness statement was taken or tried to be taken. However, it is encouraging to note that there is a significant rise in the 'yes' answers from NASH1. The inter-site scatter remains uncomfortably wide.

ALCOHOL AND ILLICIT DRUG USE

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Documentation present	37.2 (37.1)	**25 (10.7)**	53.8 (54.4)	**66.7 (50)**	48.0 (50.2)	**22.2 (0)**	42.4 (42.1)	**36.7 (12.9)**

MIN	0.0	0.0	0.0	3.3
LOWER QUARTILE	21.2	33.3	25.0	30.0
UPPER QUARTILE	47.8	75.0	66.7	53.3
MAX	100.0	100.0	100.0	100.0

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,026	**n=3**	n=413	**n=6**	n=485	**n=2**	n=1,927	**n=11**
Excessive	31.6 (32.5)	**33.3 (0)**	43.3 (53.4)	**33.3 (0)**	33.2 (43.6)	**50 (NA)**	34.6 (39.1)	**36.4 (0)**
Moderate	8.6 (15.2)	**66.7 (33.3)**	12.6 (11.4)	**50 (0)**	13.4 (18.1)	**0 (NA)**	10.6 (15.1)	**45.5 (25)**
Low	59.5 (51.8)	**0 (66.7)**	44.1 (34.5)	**16.7 (100)**	53.2 (38.1)	**50 (NA)**	54.5 (45.4)	**18.2 (75)**

COMMENT: The national figures confirm that alcohol is a significant problem.

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Documentation present	10.0 (10.0)	**16.7 (0)**	16.9 (22.0)	**11.1 (0)**	13.1 (14.2)	**22.2 (0)**	11.9 (12.6)	**16.7 (0)**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	3.9	0.0	0.0	3.9
UPPER QUARTILE	14.7	31.0	20.0	16.7
MAX	45.5	100.0	100.0	35.1

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Documentation present	8.3 (8.0)	**0 (0)**	13.4 (14.5)	**0 (0)**	13.9 (14.1)	**11.1 (0)**	10.4 (10.1)	**3.3 (0)**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	3.3
UPPER QUARTILE	12.5	20.0	25.0	13.3
MAX	59.4	100.0	100.0	61.5

Of the 474 patients for whom documentation around drug use was present, 36% were drug users (**your site: 100%**). Of those, the most frequent drug used was cannabis (51.2%) with stimulants and opiates both being taken by 27.1% of patients. Nationally, 2.4% of patients (**your site: 3.3%**) were recorded to have taken an illicit drug in the 24 hours prior to arrival at the ED.

COMMENT: There has been little change in the proportions associated with engaging in illicit drug use from NASH1. Some sites have much bigger problems than others, reflecting their catchment area.

NEUROLOGICAL EXAMINATION

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Fundi	12.6 (15.5)	**50 (35.7)**	15.6 (17.6)	**55.6 (0)**	18.5 (21.9)	**55.6 (100)**	14.4 (17.0)	**53.3 (35.5)**
Plantars	30.0 (34.6)	**25 (25)**	35.9 (36.4)	**55.6 (0)**	41.7 (47.2)	**44.4 (0)**	33.6 (37.2)	**40 (22.6)**

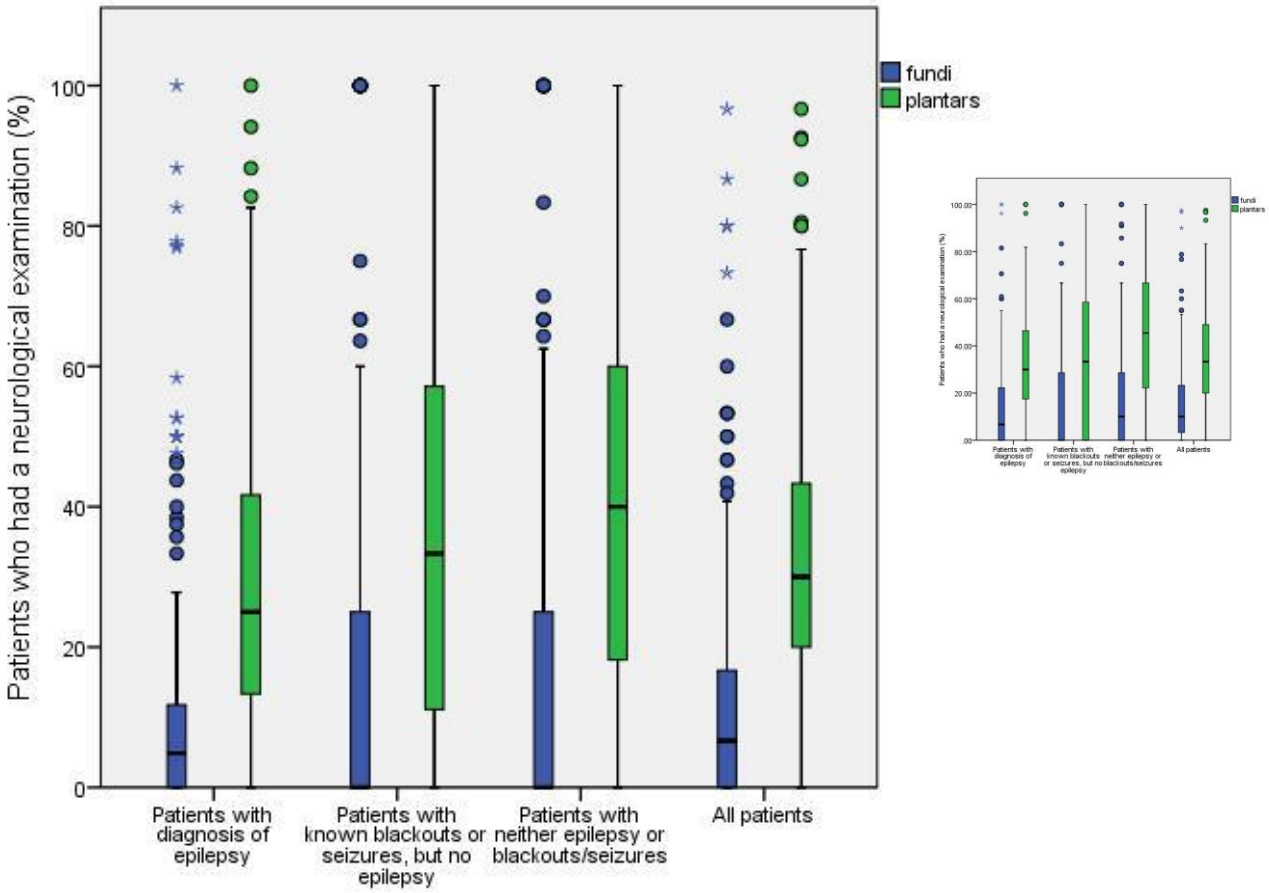
National fundi figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	0.0	0.0	0.0	0.0
UPPER QUARTILE	11.6	25.0	25.0	16.7
MAX	100.0	100.0	100.0	96.7

National plantars figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	13.3	14.3	20.0	20.0
UPPER QUARTILE	41.5	58.6	60.0	43.3
MAX	100.0	100.0	100.0	96.7

Figure 9: Distribution of number of patients who had fundi and plantars examined across sites (inset graph shows results from NASH1)



COMMENT: In the 2011 NASH report, we stated:

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

This comment caused more reaction than any others – ranging from those arguing that a full neurological examination is not required in the ED to those who believe it is mandatory. The extreme range of scores shown in figure 6 confirms the lack of concordance. Whilst most feedback did agree that a clinical neurological examination should be done for patients with a suspected first seizure, the observed range is as wide as for the other patient groups. We suggest that this is an issue that needs to be dealt with by a guidelines committee.

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Anti-epileptic drug levels*	24.3 (22.1)	**100 (56.3)**	16.7 (7.6)	**0 (NA)**	16.0 (6.1)	**NA (NA)**	23.8 (21.1)	**66.7 (56.3)**
CT (head)	21.6 (16.5)	**8.3 (14.3)**	31.8 (24.3)	**22.2 (0)**	54.3 (44.6)	**33.3 (100)**	30.6 (22.9)	**20 (16.1)**
MRI (head)	2.1 (1.6)	**0 (0)**	3.3 (2.1)	**0 (0)**	7.5 (5.2)	**0 (0)**	3.5 (2.3)	**0 (0)**
EEG	2.3 (2.4)	**0 (0)**	2.2 (3.2)	**0 (0)**	3.7 (3.3)	**0 (0)**	2.6 (2.7)	**0 (0)**
ECG	68.6 (54.5)	**41.7 (67.9)**	79.3 (62.6)	**77.8 (0)**	86.8 (71.7)	**77.8 (100)**	74.5 (58.9)	**63.3 (64.5)**
Glucose levels / BM	81.5 (70.8)	**83.3 (100)**	83.1 (75.0)	**88.9 (50)**	86.5 (74.1)	**88.9 (100)**	82.9 (72.0)	**86.7 (96.8)**

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

COMMENT: There has been an significant increase in the proportion of first seizure patients having an ECG which is recommended for all patients. There has also been a significant increase the number of CT head scans, with a wide range across sites (one site performed a CT for 75% of these patients). One would question the need for a CT head scan in 21.6% of people with an established epilepsy diagnosis, . This suggests inefficient use of resources and the possibility of multiple exposures to x rays for repeat attendees.

DISCHARGE AND DEATHS

Did the patient die during their admission?: %

	National audit n=4,544	**Your site n=30**
Yes	0.9	**0**
No	98.7	**100**

	(National audit)			
	Patients with diagnosis of epilepsy n=2,759	Patients with known blackouts or seizures, but no epilepsy n=767	Patients with neither epilepsy or blackouts/seizures n=1,011	All patients n=4,544
Yes	0.9 (19 deaths)	0.4 (3 deaths)	1.8 (18 deaths)	0.9 (40 deaths)
No	99.0	99.2	97.7	98.7

COMMENT: the proportion of deaths is higher in the group of patients without an established diagnosis (Chi-Squared 12.68 (2df) → $p<0.01$). This would be anticipated as this group of patients is more likely to have acute or life-threatening pathologies.

The mean age of those dying was markedly older, i.e. mean 76 yrs vs. 45 yrs overall.
Causes of death in the 19 with epilepsy included 11 pneumonia/sepsis, 3 "vascular" and 2 cancer, and in the 18 with no prior epilepsy 6 pneumonia/sepsis, 5 "vascular", and 2 cancer. In each group there was one patient where seizures were implicated as a cause of death.

What was the diagnosis at discharge/death?: %

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
First unprovoked seizure	0.4 (0.2)	**0 (0)**	6.8 (5.5)	**0 (0)**	45.6 (38.7)	**55.6 (100)**	11.5 (8.1)	**16.7 (3.2)**
Unprovoked seizures with history of previous seizures, but no current epilepsy diagnosis	3.1 (2.8)	**16.7 (3.6)**	41.5 (37.9)	**55.6 (50)**	3.2 (3.0)	**0 (0)**	9.6 (8.1)	**23.3 (6.5)**
Seizure in someone with established diagnosis of epilepsy	77.2 (81.1)	**58.3 (96.4)**	4.3 (5.3)	**0 (0)**	1.1 (1.7)	**0 (0)**	47.9 (55.0)	**23.3 (87.1)**
Provoked seizure – alcohol induced	7.3 (6.2)	**16.7 (0)**	19.0 (21.3)	**33.3 (0)**	13.1 (15.5)	**11.1 (0)**	10.6 (10.2)	**20 (0)**
Provoked seizure – drug induced	0.5 (0.3)	**0 (0)**	1.8 (0.4)	**0 (0)**	2.9 (2.7)	**11.1 (0)**	1.2 (0.7)	**3.3 (0)**
Provoked seizure – head injury	0.4 (0.1)	**0 (0)**	0.9 (0.5)	**0 (0)**	1.2 (2.3)	**0 (0)**	0.7 (0.6)	**0 (0)**
Provoked seizure – acute stroke	0.3 (0.2)	**0 (0)**	1.0 (0.5)	**0 (0)**	2.8 (3.0)	**0 (0)**	1.0 (0.7)	**0 (0)**
Blackout with seizure markers, not sure if seizure	0.5 (0.6)	**0 (0)**	3.9 (6.0)	**0 (50)**	5.4 (6.8)	**11.1 (0)**	2.2 (2.5)	**3.3 (3.2)**
Syncope/faint	0.2 (0.2)	**0 (0)**	1.6 (0.9)	**0 (0)**	2.7 (2.3)	**0 (0)**	1.0 (0.7)	**0 (0)**
Psychogenic non-epileptic attack / pseudoseizure	1.7 (1.1)	**8.3 (0)**	5.0 (4.4)	**0 (0)**	1.5 (1.2)	**0 (0)**	2.2 (1.6)	**3.3 (0)**
Self-discharged	1.2 (1.3)	**0 (0)**	0.5 (1.2)	**0 (0)**	0.8 (1.3)	**0 (0)**	1.0 (1.3)	**0 (0)**
Other	5.9 (3.4)	**0 (0)**	11.6 (9.9)	**11.1 (0)**	16.9 (14.2)	**11.1 (0)**	9.3 (6.4)	**6.7 (0)**
Not recorded	1.1 (2.4)	**0 (0)**	1.7 (5.1)	**0 (0)**	2.4 (6.2)	**0 (0)**	1.5 (3.5)	**0 (0)**

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Sent home on AED(s)	71.8 (70.8)	**33.3 (50)**	30.0 (29.4)	**11.1 (50)**	20.2 (19.2)	**11.1 (0)**	53.3 (54.8)	**20 (48.4)**

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,649	**n=12**	n=757	**n=9**	n=986	**n=9**	n=4,398	**n=30**
Change in drug	32.1	**66.7**	22.7	**11.1**	20.0	**11.1**	27.8	**33.3**
Change in dose	13.9	**0**	4.1	**0**	0.6	**0**	9.2	**0**
Any change	43.4	**66.7**	26.6	**11.1**	20.4	**11.1**	35.3	**33.3**

National 'any change' figures

MIN	0.0	0.0	0.0	3.3
LOWER QUARTILE	23.2	0.0	0.0	23.3
UPPER QUARTILE	60.0	40.0	33.3	48.1
MAX	100.0	100.0	100.0	86.7

COMMENT: Almost 30% of patients with an established diagnosis of epilepsy were not sent home on AED treatment, despite presenting with another seizure. While restarting AED treatment will not be appropriate for all patients, this finding is a concern given that a significant proportion of patients were neither seen by or referred onto an epilepsy specialist. However, we do not know whether those said to be going home without AEDs are in fact simply being asked to continue with their existing medications. The proportion in whom drugs are altered is independent of whether they are or are not under neuro follow up.

INVESTIGATIONS

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
CT (head)	1.5 (1.6)	**0 (3.6)**	4.2 (4.1)	**0 (0)**	4.4 (5.8)	**22.2 (0)**	2.6 (2.7)	**6.7 (3.2)**
EEG	3.0 (2.5)	**0 (0)**	13.7 (11.6)	**0 (0)**	14.0 (12.3)	**0 (0)**	7.2 (5.6)	**0 (0)**
MRI (head)	3.3 (2.4)	**0 (7.1)**	11.3 (9.3)	**0 (0)**	15.1 (11.2)	**0 (0)**	7.2 (5.0)	**0 (6.5)**
12 lead ECG	0.5 (0.7)	**0 (0)**	2.9 (2.1)	**0 (0)**	3.3 (2.1)	**0 (0)**	1.5 (1.2)	**0 (0)**

National figures for all patients

	MIN	LOWER QUARTILE	UPPER QUARTILE	MAX
CT (head)	0.0	0.0	3.4	21.4
EEG	0.0	0.0	10.3	35.7
MRI (head)	0.0	0.6	10.7	34.5
12 lead ECG	0.0	0.0	3.3	17.4

DRIVING AND MANAGEMENT OF SEIZURES

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=1,969	**n=10**	n=631	**n=8**	n=785	**n=6**	n=3,381	**n=24**
Yes	11.6 (12.0)	**0 (0)**	25.4 (20.5)	**0 (0)**	34.8 (26.2)	**16.7 (0)**	19.6 (16.2)	**4.2 (0)**
No	88.4 (88.0)	**100 (100)**	74.6 (79.5)	**100 (100)**	65.2 (73.8)	**83.3 (100)**	80.4 (83.8)	**95.8 (100)**

Was advice about driving given to the patient?: %

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

	National audit							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	Driver Documentation		Driver Documentation		Driver Documentation		Driver Documentation	
	Yes n=228	No n=1,741	Yes n=160	No n=471	Yes n=273	No n=512	Yes n=663	No n=2,728
Yes	54.4 (49.1)	2.0 (1.8)	67.5 (74.2)	7.4 (8.0)	77.3 (75.0)	12.3 (13.4)	67.1 (62.5)	4.8 (4.8)
No	3.1 (4.5)	28.5 (24.5)	1.9 (4.1)	25.5 (24.8)	1.8 (3.4)	22.7 (22.0)	2.3 (4.1)	26.9 (24.1)
Don't Know	9.2 (12.1)	61.1 (63.5)	8.1 (7.2)	63.7 (59.5)	5.5 (7.4)	56.6 (57.7)	7.4 (9.6)	60.7 (61.9)
N/A	32.9 (34.4)	7.9 (10.2)	22.5 (14.4)	2.5 (7.7)	15.0 (14.2)	8.0 (6.8)	22.9 (23.9)	7.0 (9.3)

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

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

	National audit							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	Driver Documentation		Driver Documentation		Driver Documentation		Driver Documentation	
	Yes n=124	No n=34	Yes n=108	No n=35	Yes n=211	No n=63	Yes n=445	No n=132
Stop driving	85.5 (87.3)	85.3 (83.3)	92.6 (90.3)	91.4 (80.0)	90.0 (89.2)	92.1 (94.5)	89.4 (88.7)	90.2 (87.8)
Contact DVLA	61.3 (54.5)	58.8 (53.3)	50.9 (58.3)	54.3 (60.0)	61.1 (53.2)	50.8 (50.9)	58.7 (54.9)	53.8 (53.9)

COMMENT: This is most important for first seizure cases. Data are similar to NASH1.

- It is not routine in most hospitals to ask patients who have had a seizure about driving – despite the obvious road safety implications for themselves and others
- When driving status was asked about, significant numbers appear not to have been given advice; and
- In the small number given advice most were told not to drive, but only half were told to inform the DVLA

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Yes	28.0 (29.4)	**16.7 (39.3)**	26.8 (26.7)	**11.1 (50)**	26.7 (26.8)	**22.2 (100)**	27.5 (28.5)	**16.7 (41.9)**
No	14.1 (17.0)	**0 (10.7)**	15.5 (17.6)	**0 (0)**	15.6 (15.4)	**11.1 (0)**	14.6 (16.8)	**3.3 (9.7)**
Not documented	57.4 (53.2)	**83.3 (50)**	57.4 (54.2)	**88.9 (50)**	57.5 (57.0)	**66.7 (0)**	57.4 (54.0)	**80 (48.4)**

National figures for all patients

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	9.5	0.0	0.0	10.5
UPPER QUARTILE	38.4	38.8	42.9	36.4
MAX	100.0	100.0	100.0	100.0

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

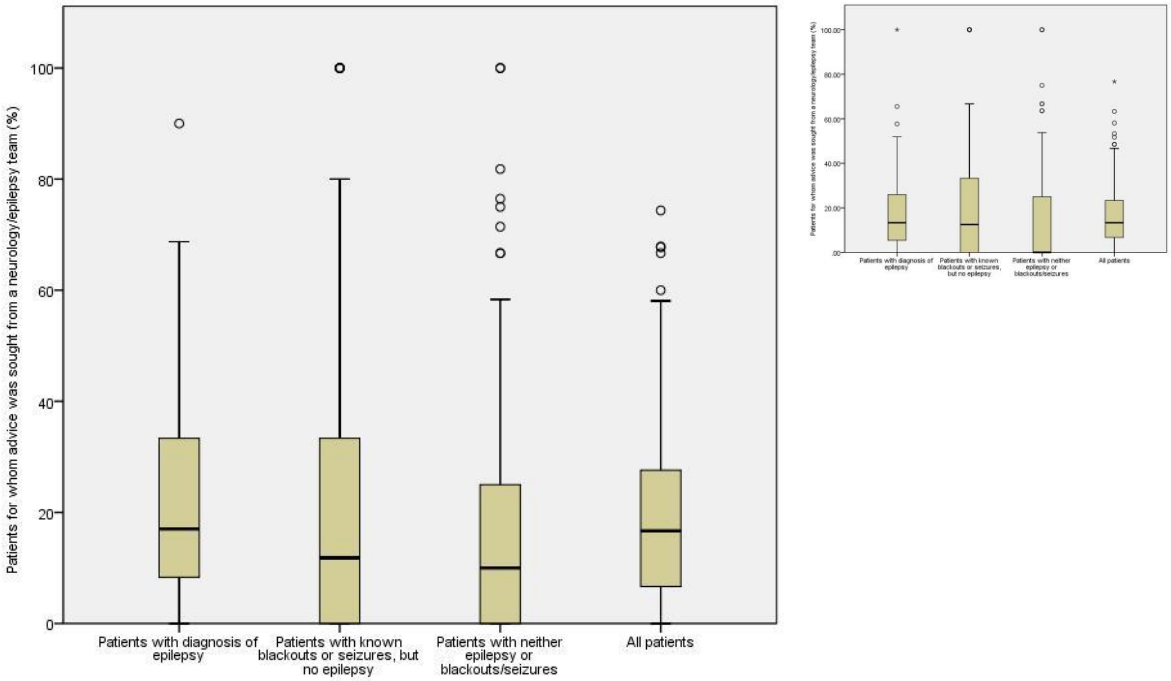
NEUROLOGY/EPILEPSY TEAM ASSESSMENT

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,759	**n=12**	n=767	**n=9**	n=1,011	**n=9**	n=4,544	**n=30**
Advice sought	20.9 (17.3)	**8.3 (3.6)**	18.6 (18.8)	**11.1 (0)**	18.6 (15.8)	**11.1 (0)**	20.0 (17.2)	**10 (3.2)**

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	8.3	0.0	0.0	6.7
UPPER QUARTILE	32.8	33.3	25.0	27.5
MAX	90.0	100.0	100.0	74.4

Figure 10: Distribution of number of patients for whom advice was sought from a neurology/epilepsy team across sites (inset graph shows results from NASH1)



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

	National audit n=909	**Your site n=3**
Epilepsy Specialist Nurse	9.9 (9.1)	**0 (0)**
Neurologist/ Paediatric neurologist	84.2 (86.6)	**100 (100)**
Neuropsychiatrist	0.3 (0.9)	**0 (0)**
Neurosurgeon	5.1 (2.8)	**0 (0)**
Paediatrician*	3.5 (5.1)	**NA (0)**

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

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

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Epilepsy Service/First Fit Clinic	6.1 (4.2)	**0 (0)**	20.5 (13.0)	**0 (0)**	29.4 (24.6)	**22.2 (0)**	13.7 (9.3)	**6.7 (0)**
Epilepsy Specialist Nurse	6.9 (5.7)	**0 (0)**	3.8 (3.0)	**0 (0)**	3.1 (3.4)	**0 (0)**	5.5 (4.9)	**0 (0)**
GP with special interest in epilepsy (GPSI)	1.1 (1.9)	**16.7 (35.7)**	0.5 (0.4)	**0 (50)**	0.3 (0.3)	**0 (100)**	0.8 (1.3)	**6.7 (38.7)**
Learning disability psychiatrist	0.5 (0.9)	**0 (0)**	0.7 (0.0)	**0 (0)**	0.2 (0.2)	**0 (0)**	0.5 (0.6)	**0 (0)**
A neurologist at this Trust/Health Board	20.3 (20.1)	**8.3 (7.1)**	22.2 (23.9)	**44.4 (0)**	19.4 (19.7)	**22.2 (0)**	20.4 (20.6)	**23.3 (6.5)**
A neurologist at another Trust/Health Board	5.6 (7.9)	**8.3 (7.1)**	6.7 (7.1)	**0 (0)**	3.0 (2.8)	**11.1 (0)**	5.2 (6.9)	**6.7 (6.5)**
NEW FOR NASH2 Alcohol/drug liaison service	3.1 (NA)	**0 (NA)**	8.8 (NA)	**0 (NA)**	6.3 (NA)	**0 (NA)**	4.8 (NA)	**0 (NA)**
Referral to any of the above services	36.2 (35.4)	**33.3 (50)**	51.2 (40.5)	**44.4 (50)**	48.4 (42.0)	**44.4 (100)**	41.4 (37.3)	**40 (51.6)**

COMMENT: Onward referral continues to be the exception rather than the rule even for those with a presumed first seizure. We have added in the alcohol referrals but still less than half get referred.

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 (75.6% of all cases - see below) and if that letter advised the GP to refer on

(17.6% of letters). We have no data to know if the GP responded but even if that is considered an alternative to direct referral, and allowing for double counting, then the total referral rates remain below 50%.

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Any referral (including GP requested ones)	43.6	**33.3**	59.0	**44.4**	54.9	**44.4**	48.7	**40**

National 'yes' figures

MIN	0.0	0.0	0.0	13.3
LOWER QUARTILE	26.7	40.8	37.5	36.7
UPPER QUARTILE	59.0	80.0	75.0	61.9
MAX	100.0	100.0	100.0	100.0

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

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
Epilepsy Service/First Fit Clinic	n=168 58.3	**n=0 NA**	n=156 51.3	**n=0 NA**	n=290 48.6	**n=2 0**	n=615 52.0	**n=2 0**
Epilepsy Specialist Nurse	n=189 54.0	**n=0 NA**	n=29 48.3	**n=0 NA**	n=31 64.5	**n=0 NA**	n=249 54.6	**n=0 NA**
GP with special interest in epilepsy (GPSI)	n=31 3.2	**n=2 0**	n=4 0.0	**n=0 NA**	n=3 0.0	**n=0 NA**	n=38 2.6	**n=2 0**
Learning disability psychiatrist	n=14 7.1	**n=0 NA**	n=5 0.0	**n=0 NA**	n=2 50.0	**n=0 NA**	n=21 9.5	**n=0 NA**
A neurologist at this Trust/Health Board	n=554 47.7	**n=1 0**	n=169 47.9	**n=4 0**	n=192 57.8	**n=2 0**	n=915 49.8	**n=7 0**
A neurologist at another Trust/Health Board	n=152 9.9	**n=1 0**	n=51 19.6	**n=0 NA**	n=30 13.3	**n=1 0**	n=233 12.4	**n=2 0**
Alcohol/drug liaison service	n=84 23.8	**n=0 NA**	n=67 23.9	**n=0 NA**	n=62 32.3	**n=0 NA**	n=215 26.0	**n=0 NA**

COMMENT: The uptake of referrals can only be described as "patchy". If half of patients are referred, and only half of those are seen, that implies that 75% of patients with seizures presenting to ED are not being seen by specialists; but who else is likely to take on reviewing or managing these patients?

NEW FOR NASH2: 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=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Yes	75.3	**0**	79.0	**0**	73.9	**0**	75.6	**0**
No	11.6	**25**	9.6	**0**	10.9	**0**	11.1	**10**
Don't know	12.8	**75**	11.2	**100**	14.5	**100**	12.9	**90**

National 'yes' figures

MIN	0.0	0.0	0.0	0.0
LOWER QUARTILE	65.2	62.5	60.0	63.2
UPPER QUARTILE	100.0	100.0	100.0	96.7
MAX	100.0	100.0	100.0	100.0

COMMENT: For many hospitals in England, this is a CQUIN target for hospital-primary care communication, and it may be useful for you to compare this with local data that should be available.

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

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

The results are as follows:

	(National audit/**Your site**)							
	Patients with diagnosis of epilepsy		Patients with known blackouts or seizures, but no epilepsy		Patients with neither epilepsy or blackouts/seizures		All patients	
	n=2,732	**n=12**	n=761	**n=9**	n=988	**n=9**	n=4,487	**n=30**
Had some form of neurology input or referral	48.8 (40.5)	**33.3**	63.3 (45.0)	**44.4**	60.6 (45.9)	**44.4**	53.9 (42.4)	**40**

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

	(National audit)			
	Patients with diagnosis of epilepsy n=2,732	Patients with known blackouts or seizures, but no epilepsy n=761	Patients with neither epilepsy or blackouts/seizures n=988	All patients n=4,487
Seen in prior 12 months	64.4	73.1	61.8	65.8
Not seen in prior 12 months	31.2	53.0	54.3	41.6

*The medical specialists are those who are listed in the question on page 21.

COMMENT: There is a substantial cohort of patients who are not getting specialist neurological input.

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 along with others, and will hopefully be used by many to raise the overall standard of epilepsy care and improve lives 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

Addenbrookes Hospital - Cambridge University Hospitals NHS Foundation Trust
Antrim Area Hospital - Northern Health and Social Care Trust
Arrowe Park Hospital - Wirral University Teaching Hospital NHS Foundation Trust
Barnsley Hospital - Barnsley Hospital NHS Foundation Trust
Bedford Hospital - Bedford Hospital NHS Trust
Birmingham Heartlands Hospital - Heart Of England NHS Foundation Trust
Bradford Royal Infirmary - Bradford Teaching Hospitals NHS Foundation Trust
Bristol Royal Infirmary - University Hospitals Bristol NHS Foundation Trust
Central Middlesex Hospital - North West London Hospitals NHS Trust
Charing Cross Hospital - Imperial College Healthcare NHS Trust
Chelsea & Westminster Hospital - Chelsea and Westminster Hospital NHS Foundation Trust
Cheltenham General Hospital - Gloucestershire Hospitals NHS Foundation Trust
Chesterfield Royal Hospital - Chesterfield Royal Hospital NHS Foundation Trust
Colchester General Hospital - Colchester Hospital University NHS Foundation Trust
Conquest Hospital - East Sussex Healthcare NHS Trust
Countess of Chester Hospital - Countess of Chester Hospital NHS Foundation Trust
Craigavon Area Hospital - Southern Health and Social Care Trust
Crosshouse Hospital - NHS Ayrshire and Arran
Croydon University Hospital - Croydon Health Services NHS Trust
Cumberland Infirmary - North Cumbria University Hospitals NHS Trust
Darent Valley Hospital - Dartford and Gravesham NHS Trust
Darlington Memorial Hospital - County Durham and Darlington NHS Foundation Trust
Derriford Hospital - Plymouth Hospitals NHS Trust
Diana Princess of Wales Hospital - Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Doncaster Royal Infirmary - Doncaster and Bassetlaw Hospitals NHS Foundation Trust
Dorset County Hospital - Dorset County Hospital NHS Foundation Trust
Dumfries and Galloway Royal Infirmary - NHS Dumfries and Galloway
Ealing Hospital - Ealing Hospital NHS Trust
East Lancashire NHS Trust
Fairfield General - Pennine Acute Hospitals NHS Trust
Forth Valley Royal Hospital - NHS Forth Valley
Frenchay Hospital - North Bristol NHS Trust
Friarage Hospital - South Tees Hospitals NHS Foundation Trust
Frimley Park Hospital - Frimley Park Hospital NHS Foundation Trust
Furness General Hospital - University Hospitals of Morecambe Bay NHS Foundation Trust
George Eliot Hospital - George Eliot Hospital NHS Trust
Good Hope Hospital - Heart of England NHS Foundation Trust
Great Western Hospital - Great Western Hospitals NHS Foundation Trust
Harrogate District Hospital - Harrogate and District NHS Foundation Trust
Hinchingbrooke Hospital - Hinchingbrooke Health Care NHS Trust
Homerton University Hospital - Homerton University Hospital NHS Foundation Trust
Horton General - Oxford University Hospitals NHS Trust
Huddersfield Royal Infirmary - Calderdale and Huddersfield NHS Foundation Trust
Hull Royal Infirmary - Hull and East Yorkshire Hospitals NHS Trust
Ipswich Hospital - Ipswich Hospital NHS Trust
James Cook University Hospital - South Tees Hospitals NHS Foundation Trust
John Radcliffe Hospital - Oxford University Hospitals NHS Trust

Kettering General Hospital - Kettering General Hospital NHS Foundation Trust
Kings College Hospital - King's College Hospital NHS Foundation Trust
Kings Mill Hospital - Sherwood Forest Hospitals NHS Foundation Trust
Kingston Hospital - Kingston Hospital NHS Trust
Lagan Valley Hospital - South Eastern Health and Social Care Trust
Leeds General Infirmary - Leeds Teaching Hospitals NHS Trust
Lister Hospital - East and North Hertfordshire NHS Trust
Luton & Dunstable Hospital - Luton and Dunstable Hospital NHS Foundation Trust
Macclesfield District Hospital - East Cheshire NHS Trust
Maidstone Hospital - Maidstone and Tunbridge Wells NHS Trust
Manchester Royal Infirmary - Central Manchester University Hospitals NHS Foundation Trust
Manor Hospital - Walsall Healthcare NHS Trust
Medway Maritime Hospital - Medway NHS Foundation Trust
Mid Yorkshire Hospitals NHS Trust
Milton Keynes General Hospital - Milton Keynes Hospital NHS Foundation Trust
Morriston Hospital - Abertawe Bro Morgannwg University Health Board (Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg)
Musgrove Park Hospital - Taunton and Somerset NHS Foundation Trust
Newham General Hospital - Barts Health NHS Trust
Norfolk and Norwich University Hospital - Norfolk and Norwich University Hospitals NHS Foundation Trust
North Devon District Hospital - Northern Devon Healthcare NHS Trust
North Manchester General Hospital - Pennine Acute Hospitals NHS Trust
North Tees and Hartlepool NHS Foundation Trust
Northampton General Hospital - Northampton General Hospital NHS Trust
Northern General Hospital - Sheffield Teaching Hospitals NHS Foundation Trust
Northwick Park Hospital - North West London Hospitals NHS Trust
Peterborough City Hospital - Peterborough and Stamford Hospitals NHS Foundation Trust
Pilgrim Hospital - United Lincolnshire Hospitals NHS Trust
Poole General Hospital - Poole Hospital NHS Foundation Trust
Princess Alexandra Hospital - The Princess Alexandra Hospital NHS Trust
Princess of Wales Hospital - Abertawe Bro Morgannwg University Health Board (Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg)
Princess Royal University Hospital - South London Healthcare NHS Trust
Queen Alexandra Hospital - Portsmouth Hospitals NHS Trust
Queen Elizabeth Hospital King's Lynn - The Queen Elizabeth Hospital, King's Lynn NHS Foundation Trust
Queen Elizabeth Hospital- Woolwich - South London Healthcare NHS Trust
Rotherham Hospital - The Rotherham NHS Foundation Trust
Royal Albert Edward Infirmary - Wrightington, Wigan and Leigh NHS Foundation Trust
Royal Alexandra Hospital - NHS Greater Glasgow and Clyde
Royal Berkshire Hospital - Royal Berkshire NHS Foundation Trust
Royal Bolton Hospital - Bolton NHS Foundation Trust
Royal Bournemouth General Hospital - The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
Royal Cornwall Hospital - Royal Cornwall Hospitals NHS Trust
Royal Derby Hospital - Derby Hospitals NHS Foundation Trust
Royal Devon and Exeter Hospital - Royal Devon and Exeter NHS Foundation Trust
Royal Free Hospital - Royal Free London NHS Foundation Trust
Royal Gwent Hospital, Newport - Aneurin Bevan Health Board (Bwrdd Iechyd Aneurin Bevan)
Royal Infirmary of Edinburgh - NHS Lothian

Royal Lancaster Infirmary - University Hospitals of Morecambe Bay NHS Foundation Trust
Royal Liverpool University Hospital - Royal Liverpool and Broadgreen University Hospitals NHS Trust
Royal London Hospital - Barts Health NHS Trust
Royal Oldham Hospital - Pennine Acute Hospitals NHS Trust
Royal Preston Hospital - Lancashire Teaching Hospitals NHS Foundation Trust
Royal Sussex County Hospital - Brighton and Sussex University Hospitals Trust
Royal United Hospital - Royal United Hospital Bath NHS Trust
Royal Victoria Hospital - Belfast - Belfast Health and Social Care Trust
Royal Victoria Infirmary - The Newcastle Upon Tyne Hospitals NHS Foundation Trust
Russells Hall Hospital - The Dudley Group NHS Foundation Trust
Salford Royal - Salford Royal NHS Foundation Trust
Salisbury District Hospital - Salisbury NHS Foundation Trust
Sandwell and West Birmingham Hospitals NHS Trust
Scunthorpe General Hospital - Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Shrewsbury and Telford Hospital NHS Trust
Solihull Hospital - Heart of England NHS Foundation Trust
South Tyneside District Hospital - South Tyneside NHS Foundation Trust
South West Acute Hospital - Western Health and Social Care Trust
Southampton General Hospital - University Hospital Southampton NHS Foundation Trust
Southport District General Hospital - Southport and Ormskirk Hospital NHS Trust
St George's Hospital - St George's Healthcare NHS Trust
St James' University Hospital - Leeds Teaching Hospitals NHS Trust
St John's Hospital, Livingston - NHS Lothian
St Mary's Hospital, IOW - Isle of Wight NHS Trust
St Richard's Hospital - Western Sussex Hospitals NHS Trust
St Thomas' Hospital - Guy's and St Thomas' NHS Foundation Trust
St. Peter’s Hospital - Ashford and St Peter's Hospitals NHS Trust
Stafford Hospital - Mid Staffordshire NHS Foundation Trust
Stepping Hill Hospital - Stockport NHS Foundation Trust
Sunderland Royal Hospital - City Hospitals Sunderland NHS Foundation Trust
Tameside General Hospital - Tameside Hospital NHS Foundation Trust
The County Hospital, Wye Valley NHS Trust - Wye Valley NHS Trust
The Hillingdon Hospital - The Hillingdon Hospitals NHS Foundation Trust
Torbay District General Hospital - South Devon Healthcare NHS Foundation Trust
Trafford General Hospital - Central Manchester University Hospitals NHS Foundation Trust
Tunbridge Wells Hospital - Maidstone and Tunbridge Wells NHS Trust
Ulster Hospital - South Eastern Health and Social Care Trust
University College London Hospital - University College London Hospitals NHS Foundation Trust
University Hospital Aintree - Aintree University Hospitals NHS Foundation Trust
University Hospital Coventry - University Hospitals Coventry and Warwickshire NHS Trust
University Hospital Lewisham - The Lewisham Healthcare NHS Trust
University Hospital of North Durham - County Durham and Darlington NHS Foundation Trust
University Hospital of North Staffordshire - University Hospital Of North Staffordshire NHS Trust
University Hospital of Wales - Cardiff and Vale University Health Board (Bwrdd Iechyd Prifysgol Caerdydd a’r Fro)
Victoria Hospital, Kirkcaldy - NHS Fife
Victoria Infirmary - NHS Greater Glasgow and Clyde
Warwick Hospital - South Warwickshire NHS Foundation Trust
West Cumberland Hospital - North Cumbria University Hospitals NHS Trust
West Suffolk Hospital - West Suffolk NHS Foundation Trust
Weston General Hospital - Weston Area Health NHS Trust

Wexham Park Hospital - Heatherwood and Wexham Park Hospitals NHS Foundation Trust
Whipps Cross Hospital - Barts Health NHS Trust
Whiston Hospital - St Helens and Knowsley Hospitals NHS Trust
William Harvey Hospital, Ashford - East Kent Hospitals University NHS Foundation Trust
Withybush General Hospital - Hywle Dda Health Board (Bwrdd Iechyd Hywel Dda)
Worcestershire Royal Hospital - Worcestershire Acute Hospitals NHS Trust
Worthing Hospital - Western Sussex Hospitals NHS Trust
Wrexham Maelor Hospital - Betsi Cadwaladr University Health Board (Bwrdd Iechyd Prifysgol Betsi Cadwaladr)
Wythenshawe Hospital - University Hospital of South Manchester NHS Foundation Trust
York Hospital - York Teaching Hospital NHS Foundation Trust
Ysbyty Gwynedd - Betsi Cadwaladr University Health Board (Bwrdd Iechyd Prifysgol Betsi Cadwaladr)

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

Q3.3c 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 sezirue 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
Topirimate/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 paediatrician within the previous 12 months?
Options:
Yes
No
Not documented

Q3.6f Is it documented that the patient has seen a paediatric neurologist within the previous 12 months?
Options:
Yes
No
Not documented

Q3.6g Is it documented that the patient has seen a neurosurgeon within the previous 12 months?
Options:
Yes
No
Not documented

Q3.7 Is the patient recorded as having a learning disability?
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 lorazapam
IV phenobarbitol
IV phenytoin
IV thiamine / pabrinex
IV valproate
Rectal or intramuscular paraldehyde

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

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

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

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

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

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

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

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

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

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

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

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

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

Q6.4b For 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:

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

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

Q6.5a If no to the above, is there a statement that an attempt was made to conatact 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 a plantar examination being undertaken at any time during attendance at the Emergency Department?
Options:
Yes
No

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

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

Q8.1a Were antiepileptic drug level investigations undertaken following attendance in the Emergency Department?
Options:
Yes
No
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 advice about driving to the patient given?
Options:
Yes
No
Don't know
Not applicable (patient does not drive)

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

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

Q9.4 Was the management of future seizures discussed with the patients or carers?
Options:
Yes
No
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

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

Institutional Proforma Questions

Q1.1a Does your Trust have a written policy for management of patients with first seizures?
Options:
Yes
No
Under development/intended

Q1.1b Does your Trust have a written policy for management of status epilepticus?
Options:
Yes
No
Under development/intended

Q1.1c Does your Trust have a written policy for the pathway for onward referral of patients presenting with seizures?
Options:
Yes
No
Under development/intended

Q1.2 If a patient's seizure has stopped but the patient needs to be observed or admitted - where would they go to from the ED?
Options:
Observation ward
Medial admissions/assessment unit
General ward
Neurology ward
ITU
Other - please specify

Q2.1 Does your trust have a neurosurgeon on the staff?
Options:
Yes
No

Q2.2 Do you have a neurology ward?
Options:
Yes
No

Q2.2a If Yes - Does it take admissions from ED?
Options:
Yes
No

Q2.3 How many general neurology clinics are conducted per week?
Options:
None
1
2
3
4
More

Q2.4 How many dedicated epilepsy clinics (i.e. a clinic that only sees epilepsy-related problems) are conducted per week?
Options:
None
1
2
3
4
More

Q2.5 Do you have a neurology consultancy service available on the wards?
Options:
Yes
No

Q2.5a If yes; for how many days is that available?
Options:
1-2
3-5

Q2.6 Does your Trust have access to an Epilepsy Specialist Nurse?
Options:
Yes
No

Q2.6a If Yes - How many full time Epilepsy Specialist Nurses are there?
Options:
Free text

Q2.6b If Yes - How many part time Epilepsy Specialist Nurses are there?
Options:
Free text

Q2.6c What is their availability, i.e. how soon can an appointment be arranged?
Options:
0-2 weeks
3-4 weeks
5-6 weeks
7+ weeks

Q2.6d Who employs the Epilepsy Specialist Nurse(s)?
Options:
The Trust
The CCG
Don't know

Q2.7 Does your Trust have access to a Neurology Specialist Nurse (i.e. nurses who cover neurological conditions but are not disease-specific)?
Options:
Yes
No

Q2.7a how many full time Neurology Specialist Nurses are there?
Options:
Free text

Q2.7b how many part time Neurology Specialist Nurses are there?
Options:
Free text

Q2.8 Are you able to refer epilepsy to a psychology service?
Options:
Yes
No

Q2.9 Is it standard practice to provide patients who have experienced a seizure with a leaflet that gives advice on issues such as seizure management and driving?
Options:
Yes
No

Q3.1 Do you have access to an MRI scanner?
Options:
Yes
No

Q3.1a If yes, what is the waiting time for a routine MRI scan?
Options:
0-2 weeks
3-4 weeks
5-6 weeks
7+ weeks

Q3.2a Do you have access to routine EEGs; - From this Site?
Options:
Yes
No

Q3.2b Do you have access to routine EEGs; - From another Site?
Options:
Yes
No

Q4.3 Do you consider yourself a tertiary neurology centre??
Options:
Yes
No

Q3.3a If no, what is the name of your nearest tertiary neurology centre?
Options:
Free text

Q3.3b How far away is it?
Options:
0-20 miles
20-50 miles
More

APPENDIX FOUR

ICD10 Codes

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