

Disordered Activity?

A review of the quality of epilepsy care provided to adult patients presenting to hospital with a seizure



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Foreword

Epilepsy has been recognised for millennia, yet the basis of current diagnosis and treatment in the UK really only started its development in the 1950s following establishment of the NHS. Since then, organisations such as SUDEP Action, Epilepsy Action and the Epilepsy Society, have raised public understanding of epilepsy and its associated risks.

As a locum houseman in the 1980s, the task of running epilepsy clinics and having to monitor and juggle dosage of drugs with a very narrow therapeutic index was delegated to me without any supervision. On-call care was provided by a general medical firm, with no out of hours access to specialist neurology advice. Since the 1980s, there has unquestionably been improvement in pharmacology, and the introduction of epilepsy specialist nurses has been a great advantage. However, as this study highlights, specialist epilepsy care remains patchy, and predominantly directed to the outpatient environment. More input from neurology specialists in the urgent inpatient setting, and in the co-ordination of the care pathway would help drive some of the changes needed as identified in this report.

In other areas of specialised medicine, similar issues have been addressed by excellent communication, and good collaborative pathway design, there are some exemplars cited in this report. Despite numerous previous reports and NICE guidance, communication between specialists, generalists, patients, carers, and primary care was all too frequently lacking. Why this should be so in an era in which I, (or any NHS patient), can access my own list of medication and recent test results on an App on my phone is frankly astonishing.

When first seizure clinics were available, there were often unacceptably long delays before patients were seen. Furthermore, patients and their carers were often not given basic advice following discharge, including critical safety information regarding, for example, swimming or driving. This was of particular note for those patients in

the study who had a learning disability, with some of the case studies showing the need for clear communication for this vulnerable group who have been shown in the LeDer programme to have an increased risk of mortality. Surely this begs the question, 'Is this service fit for purpose in the 21st century?'

I do hope that this report will stimulate those responsible for the provision of epilepsy care to examine their own service, reflect on some of the examples of best practice, and implement the report's recommendations, many of which can be achieved by better planning and communication without massive financial investment, which in the current economic climate is unlikely to be available.

As ever I pay tribute to all those who have given so generously of their time, particularly during the last couple of years when it has been so difficult to maintain any sense of normality. In particular the members of the Study Advisory Group and the case reviewers. I would also like to thank the NCEPOD staff and co-ordinators who have managed throughout to keep the show on the road, by their ingenuity and perseverance.



Ian C Martin, NCEPOD Chair

EXECUTIVE SUMMARY

Data from 610 clinical questionnaires, 264 sets of case notes and 158 organisational questionnaires were used to assess the quality of care provided to adult patients with a pre-existing epilepsy disorder or who were subsequently diagnosed with epilepsy and presented to hospital following a seizure, between 1st January and 31st December 2020.

CONCLUSION

It was identified that action could be taken at all points of the patient pathway to improve the quality of care. Beginning with telling the patient's usual epilepsy team if they had been admitted, making sure anti-seizure medications were checked and ensuring the correct investigations were done. Continuing through to more input from the neurology team, as needed, particularly utilising the role of the epilepsy specialist nurse. Finally, planning and communication at discharge to make sure patients and their families/carers understand the risks associated with seizures and epilepsy so that they know what to do if they have a further seizure.

1. ALERT A PATIENT'S 'USUAL' EPILEPSY TEAM, WHEREVER BASED, WHEN A PATIENT PRESENTS WITH A SEIZURE



This provides an opportunity to discuss the patient's needs and undertake an inpatient review if appropriate.

133/315 (42.2%) patients with epilepsy did not have their admission discussed with their usual secondary care team.

45/143 (31.5%) hospitals reported that there was a policy for the emergency department to contact the epilepsy team when patients with known epilepsy were seen.

2. DOCUMENT ANTI-SEIZURE MEDICATIONS AND ACTION A CLEAR PLAN FOR ANY INVESTIGATIONS NEEDED



This ensures the information is clear in the notes, acted upon and flows through to discharge and follow-up.

47/180 (26.1%) patients did not have their anti-seizure medication (ASM) written in their notes.

119/158 (75.3%) hospitals had the facility to perform an ASM blood screen on-site.

58/252 (23.0%) patients should have had additional investigations in the emergency department.

3. MAKE NEUROLOGY ADVICE AVAILABLE WHEN NEEDED FOR PATIENTS PRESENTING WITH A SEIZURE



This supports the admitting team and therefore the patient, when seizures are hard to control.

175/503 (34.8%) patients were reviewed by a neurologist during their admission and a further 109/503 (21.7%) had their epilepsy management discussed with a neurologist, leaving 219/503 (43.5%) patients without input.

Neurology input was inadequate for 61/217 (28.1%) patients.

Only 36/494 (7.3%) patients were reviewed by an epilepsy specialist nurse.

4. EXPLAIN THE RISKS ASSOCIATED WITH SEIZURES AND EPILEPSY TO PATIENTS AND THEIR FAMILY/CARERS



Gently making people aware of risks associated with seizures will help keep them safe.

In 52/135 (38.5%) hospitals, specific information or education regarding epilepsy was not routinely provided to patients until their first clinic appointment, which may be many weeks after discharge.

Only 40/317 (12.6%) patients had any evidence in their notes that the risk of SUDEP had been considered and discussed with them.

5. COMMUNICATE DISCHARGE/FOLLOW-UP PLANS TO THE PATIENT, THEIR FAMILY/CARERS & HEALTHCARE TEAMS



This would help patients, their families/carers and healthcare team manage their epilepsy together.

Only 23/85 (27.1%) hospitals reported the waiting time for first seizure clinics to be within two-weeks following a first seizure.

42/212 (19.8%) discharge letters were poor.

Follow-up was less likely to be arranged prior to discharge if the ongoing epilepsy care was led solely by a GP (18/93; 19.4%) compared to secondary care teams (36/47; 76.6%).

Recommendations

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation.	
1	<p>Have a system in place which enables emergency medicine/admitting clinicians to communicate with the patient's usual epilepsy clinical team (wherever the team is based) when the patient presents to hospital with a seizure (see also recommendations 3 and 13)</p> <p><i>NB: Use an existing electronic alert system if available or check the patient's contact card if they are carrying one to identify the clinical team.</i></p> <p>Target audience: <i>Neurology teams, epilepsy specialist nurses with support from emergency medicine, and Integrated Care Systems</i></p>
2	<p>Document pre-existing anti-seizure medication in the case notes of patients presenting with a seizure.</p> <p><i>NB: This information should be accessed via current national systems if the patient is not able to provide their current anti-seizure medication regimen</i></p> <p>Target audience: <i>Emergency medicine, acute medicine, epilepsy specialist nurses, consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology, pharmacists</i></p>
3	<p>Measure anti-seizure medication (ASM) levels in patients with epilepsy who arrive at hospital with a seizure if there is any concern about adherence to, absorption of, or dose of their ASM.* Notify the patient's usual epilepsy clinical team (wherever the team is based) or GP if there is no usual team, to follow-up on the results or to discuss any changes to medication or dosage.</p> <p><i>*Note that blood levels may not be a good indicator for all ASMs, and careful consideration should be given before they are measured.</i></p> <p><i>NB: Use an electronic alert system if available, or the patient's contact card if they are carrying one to identify the clinical team.</i></p> <p>Target audience: <i>Emergency medicine, acute medicine, epilepsy specialist nurses, consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology</i></p>

RECOMMENDATIONS

4	<p>Prescribers should be aware of, and follow, current Medicines and Healthcare products Regulatory Agency (MHRA) guidance regarding the use of valproate medicines* in any woman or girl with child-bearing potential.</p> <p>Associated links:</p> <ul style="list-style-type: none"> • <i>*Medicines and Healthcare products Regulatory Agency (MHRA) guidance – current guidance at the time of this report release in 2022: Valproate must not be used in any woman or girl able to have children unless there is a pregnancy prevention programme (PPP) in place. This is designed to make sure patients are fully aware of the risks and the need to avoid becoming pregnant</i> • <i>Risk acknowledgement form</i> • <i>Information on the risks of valproate use in girls (of any age) and women of childbearing potential</i> • <i>Royal College of Paediatrics and Child Health. Epilepsy12</i> <p>Target audience: Prescribers of valproate medicines, medication safety officers, neurologists, obstetricians</p>
5	<p>Develop a core set of investigations for all patients who present to the emergency department with a seizure.</p> <p>Target audience: Royal College of Emergency Medicine and the Association of British Neurologists with support from the Royal College of Physicians and the Royal College of General Practitioners</p>
6	<p>Develop a protocol that sets out the requirements for undertaking a CT scan of head in patients with known epilepsy.</p> <p>Target audience: The Royal College of Radiologists, the Royal College of Emergency Medicine and the Association of British Neurologists with support from the Royal College of Physicians and the Royal College of General Practitioners</p>
7	<p>Ensure patients with suspected or treated status epilepticus have emergency access to an electroencephalogram (EEG) to confirm diagnosis and monitor the effects of treatment.</p> <p><i>NB: This aligns with SIGN 143: Diagnosis and management of epilepsy in adults (revised 2018)</i></p> <p>Target audience: Clinical directors in neurology, medical directors</p>
8	<p>Commence and maintain a seizure chart for all patients admitted to hospital following a seizure.</p> <p>Target audience: Consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology, epilepsy specialist nurses, emergency medicine and acute medicine</p>
9	<p>Ensure there is specialist neurology advice available 24/7, either in person or by telephone, for patients admitted with epilepsy.</p> <p>Target audience: Clinical directors in neurology, medical directors</p>

RECOMMENDATIONS

10	<p>Provide dedicated sessions* for epilepsy specialist nurses to act as a point of contact and co-ordinate the pathway of care for patients who present to hospital with a seizure.</p> <p><i>NB: This aligns with the Adult Epilepsy Specialist Nurse (ESN) Competency Framework</i></p> <p><i>*The number of sessions needed should be assessed locally by determining how many patients are seen annually and the sessions could be shared across different sites as needed</i></p> <p>Target audience: Directors of nursing, clinical directors in neurology, medical directors supported by executive boards</p>
11	<p>For patients presenting to hospital with a first seizure:</p> <p>Refer to a first seizure clinic appointment either in person or virtual, within two weeks of a patient having their first seizure*</p> <ol style="list-style-type: none"> Explain to the patient and their family members or carers the potential causes of, and risks associated with seizures Document the discussion in the case notes and discharge letter <i>(see recommendation 14)</i> Provide resources to support these discussions for example, patient information leaflets and details of useful websites (USEFUL LINKS) <p><i>*This aligns with NICE guideline NG217: Epilepsies in children, young people and adults (2022)</i></p> <p>Target audience: Emergency medicine, acute medicine, epilepsy specialist nurses, consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology</p>
12	<p>For patients presenting to hospital with known epilepsy:</p> <ol style="list-style-type: none"> Explain to the patient and their family members or carers the risks associated with epilepsy, including sudden unexpected death in epilepsy (SUDEP) Make a personalised risk reduction assessment, directly relevant to each patient Use all hospital presentations as an opportunity to reiterate the risks associated with epilepsy to the patient and their family members or carers Document the discussion in the case notes and discharge letter <i>(see recommendation 14)</i> Provide resources to support these discussions for example, patient information leaflets and details of useful websites (USEFUL LINKS) <p>Target audience: Emergency medicine, acute medicine, epilepsy specialist nurses, consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology</p>

RECOMMENDATIONS

13	<p>Arrange follow-up plans before the patient is discharged from a hospital admission following a seizure to include:</p> <ol style="list-style-type: none">A first seizure clinic appointment either in person or virtual, within two weeks of a patient having their first seizure*Any investigations booked and reviewed by the patient's usual epilepsy team or neurology service and results sent to the GP (<i>see also recommendations 3 and 14</i>)Information for patients and their family or carers with details about local advice services and what action to take if a further seizure occurs (USEFUL LINKS) <p><i>*This aligns with NICE guideline NG217: Epilepsies in children, young people and adults (2022)</i></p> <p>Target audience: <i>Epilepsy specialist nurses, consultant neurologists, physicians with an interest in epilepsy, specialist registrar in neurology, emergency medicine, acute medicine and third sector organisations who can provide ongoing support and guidance</i></p>
14	<p>Include the following in discharge letters to the patient and their usual epilepsy clinical team and/or GP for patients who have presented to hospital with a seizure:</p> <ol style="list-style-type: none">DiagnosisMedicationCause of the seizureRisks associated with recurrent seizuresSpecific safety advice given to the patient and their family or carersFollow-up arrangements in place (<i>see also recommendations 3, 11, 12 and 13</i>) <p>Target audience: <i>Consultant neurologists, physicians with an interest in epilepsy, specialist registrars in neurology, epilepsy specialist nurses, emergency medicine and acute medicine</i></p>

Introduction

Epilepsy is defined as the tendency to have recurrent seizures and is one of the most common long-term neurological conditions in the UK, affecting 0.8% of the population.¹ Epilepsy is more commonly diagnosed in childhood or in older age, as well as in people who are socially deprived, have a learning disability, or in those who have had a stroke or brain injury.²⁻⁵ The condition can be life-threatening; deaths in pregnant women with epilepsy have doubled since 2016.⁶ People with epilepsy also have an increased risk of suicide and unintentional injury,^{7,8} with sudden unexpected death in epilepsy (SUDEP) affecting 1.3 in 1000 patients per year, and increasing annually by 3%.⁹

Robust epilepsy care requires a multidisciplinary team led by a specialist to support diagnosis and ongoing management of the condition. This service should include a community hub as recommended by NHS RightCare.¹⁰ However, as for any medical emergency, patients experiencing a sudden increase in seizures or during a crisis, are more likely to see healthcare professionals in the ambulance service, and emergency, acute or general medical departments rather than their usual specialist team. Acute seizure care in the 12-24 hours following the seizure should involve clear communication with the patient, their family, GP and specialist team including neurology/epilepsy specialist nurses to facilitate discharge planning and follow-up appointments.

Specialist review is crucial to the management of epileptic seizure conditions. However, reports show that there is marked variation in the length of time to specialist review and whether this specialist input occurs at all. The National Audit of Seizure Management in Hospitals audit (NASH) reported that for patients with a suspected first seizure, 32% of those under 60 years of age and 75% of those over 80 were not referred to a neurologist following presentation to an acute setting.¹¹ Furthermore, 63% of patients with known epilepsy who were seen in the emergency department following a seizure had no contact with an epilepsy specialist.

Despite the national guidelines and standards on the care of patients with epilepsy^{10,12-14} this variation in care leads to delays in appropriate diagnosis, unnecessary readmissions and presentations to hospital and increased risk to the patient, as well as missed opportunities to review anti-seizure medication prescriptions, educate patients about the condition and underline the importance of adherence to medication.

This NCEPOD study was developed with wide multidisciplinary input. It identifies a number of areas affecting the care and outcome of adult patients with epilepsy that require improvement. As the Royal College of Paediatrics and Child Health run a [national audit on epilepsy in children and young people](#),¹⁵ that cohort was not included in this study, but parallels in improvements can be seen. In this NCEPOD study, particular focus was given to communication and co-ordination of care after emergency presentation with a seizure, neurology input in the emergency setting, the role of epilepsy specialist nurses and patient education regarding the risks associated with epilepsy.

WHAT PATIENTS SAID...

Data were collected using a survey to seek the experiences of patients and carers on the quality of care received and what they thought should and should not happen when patients present to hospital with a seizure.

What should happen

"Listen to whoever is supporting the person as they can advise the medical staff."

"Listen to what is normal for the patient post-seizure."

"The person's view of what they want should be taken seriously. As long as they have mental capacity, they should not have to argue with medical professionals about their own diagnosis or care."

"They should be carefully monitored and given information about what it might mean, I was quite confused about what my first seizure might mean."

"They should be admitted to a ward and have things clearly explained to them"

"They should be told everything that has happened to them at a time when they're able to take it in and ideally this should be in writing."

"They shouldn't be treated like a drug addict. We are people with an illness. Just because you can't see it and we don't always look sick it doesn't mean it's not there."

What should not happen

"Disregard the carers knowledge and experience."

"Make generalised assumptions that the patient is used to the consequences of a seizure."

"Be sent home after a few hours, especially if it's their first seizure."

"Repeated tests if person is a known epileptic and seizure is typical for them. Ignore wishes of a person that has mental capacity to decide their own care."

"Don't leave them strapped on to an ambulance board for several hours in a corridor whilst the crew wait to hand over to the nursing team."

"Do not allow them to leave alone or be left alone, do not assume they are able to retain information."

"Shouldn't ignore more serious wounds if the patient was injured during their seizure. They should be treated too"

"Do not assume its alcohol or drug related."

Method and data returns

Study Advisory Group

A multidisciplinary group of clinicians was convened to define the objectives of the study and advise on the key questions. The Study Advisory Group (SAG) comprised healthcare professionals in neurology, emergency medicine, acute medicine, general medicine, general practice, epilepsy specialist nursing, neuropsychiatry, lay and patient representatives. This group steered the study from design to completion.

Study aim

To identify variation and remediable factors in the processes of care of patients presenting to hospital following an epileptic seizure.

Objectives

The SAG identified several objectives that would address the primary aim of the study. These included:

- To identify patients seen in hospital with suspected seizure and to review their care from presentation to resolution
- To evaluate the quality of assessment of physical, psychological and social contributors to their illness
- To assess the availability of care and identify avoidable delay, obstacles to care, and harmful intervention
- To assess how the ongoing care of patients with epilepsy is managed
- To assess organisational aspects of care, including education, local and national guidelines, and delivery of ongoing care
- To produce recommendations for improvement

Study population and case ascertainment

Inclusion criteria

- All patients aged 18 or over who presented to hospital following a seizure between 1st January 2020 and 31st December 2020 and who had a pre-existing epilepsy disorder or were subsequently diagnosed with epilepsy. Patients discharged from the emergency department and those admitted to hospital were included.
- Up to six patients per hospital were selected for questionnaire completion and case note review. To avoid the effects of the COVID-19 pandemic on hospital admissions, these patients were selected from January and February 2020.

Exclusion criteria

- Patients with dissociative seizure disorders and acute symptomatic seizures.
- First seizure/undiagnosed patients who were not subsequently diagnosed with epilepsy.

Hospital participation

Data were included from hospitals in England, Wales, Northern Ireland and Jersey.

Data collection

Spreadsheet

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined time period. From this initial cohort, the sampling for inclusion into the study took place.

Questionnaires

Two questionnaires were used to collect data for this study: a clinician questionnaire for each patient and an organisational questionnaire for each participating hospital.

Clinician questionnaire

This questionnaire was sent electronically to the consultant responsible for the care of the patient at the time of their admission to hospital/emergency department, with a seizure. Information was requested on the patient's medical history, presenting features, anti-seizure medication, initial management in the emergency department and response to therapy, management as an inpatient, inpatient neurology/specialist input, discharge, follow-up and ongoing care.

Organisational questionnaire

The data requested in this questionnaire included information on the services provided for patients with seizures, guidelines and policies relevant to the care of patients presenting to hospital with a seizure disorder and the availability of specific investigations and interventions.

Case notes

Copies of the case notes were requested for peer review. These included:

- Ambulance notes/patient report form (PRF)
- Emergency department clerking proforma/records
- All inpatient annotations/medical notes/nursing notes
- Critical care notes/charts
- Computed tomography (CT)/magnetic resonance imaging (MRI) scans/electrocardiogram (ECG) and electroencephalogram (EEG) reports
- Anaesthetic charts
- Observation, fluid balance and drug charts
- Haematology/biochemistry/microbiology results
- Blood gas reports
- Consent forms
- Datix or other serious incident reports
- Discharge letter/summary
- Outpatient follow-up clinic notes and letters

Peer review of the case notes and questionnaire data

A multidisciplinary group of case reviewers comprising consultants, trainees and clinical nurse specialists from: neurology, acute medicine, emergency medicine, general medicine and specialist nursing were recruited to peer review the case notes and associated clinician questionnaires.

Questionnaires and case notes had all patient identifiers removed by the non-clinical staff at NCEPOD before being presented to the group. Each set of case notes was reviewed by at least one reviewer within a small multidisciplinary meeting using a semi-structured electronic questionnaire. At regular intervals throughout the meeting the Chair allowed a period of discussion for each reviewer to summarise their cases and ask for opinions from other reviewers or raise aspects of the case for discussion.

Information governance

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (PIAG 4-08(b))/2003, App No 007), and the Code of Practice on Confidential Information.

Each patient was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered. Any fields that contained data that could not be validated were removed.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced.

Qualitative data collected from the case reviewers' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis.

As the methodology provides a snapshot of care over a set point in time, with data collected from a number of sources to build a national picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and case studies have been used throughout this report to illustrate particular themes. None directly relate to any individual.

The findings of the report were reviewed by the SAG, case reviewers and the NCEPOD Steering Group which included clinical co-ordinators, trustees and lay representatives prior to publication.

Data returns

In total 20,161 patients were identified as meeting the study inclusion criteria (Figure 1.1) for the first 3 months of the study data collection period. This number may be an overestimate as it could not be ascertained from coding whether every patient presenting to hospital with seizure

had already been diagnosed with epilepsy or went on to be diagnosed. Up to six patients per hospital were selected in accordance with the sampling protocol. This resulted in 967 patients being included in the initial sample. A total of 120 patients were excluded as they did not meet the study inclusion criteria when the case notes were reviewed locally. The most common reason for exclusion was that the patient did not have a diagnosis of epilepsy. Of the remaining sample, 610 completed clinician questionnaires were included in the analysis and 264 sets of notes were peer reviewed by the case reviewers. In addition, organisational questionnaires were received from 158 hospitals.

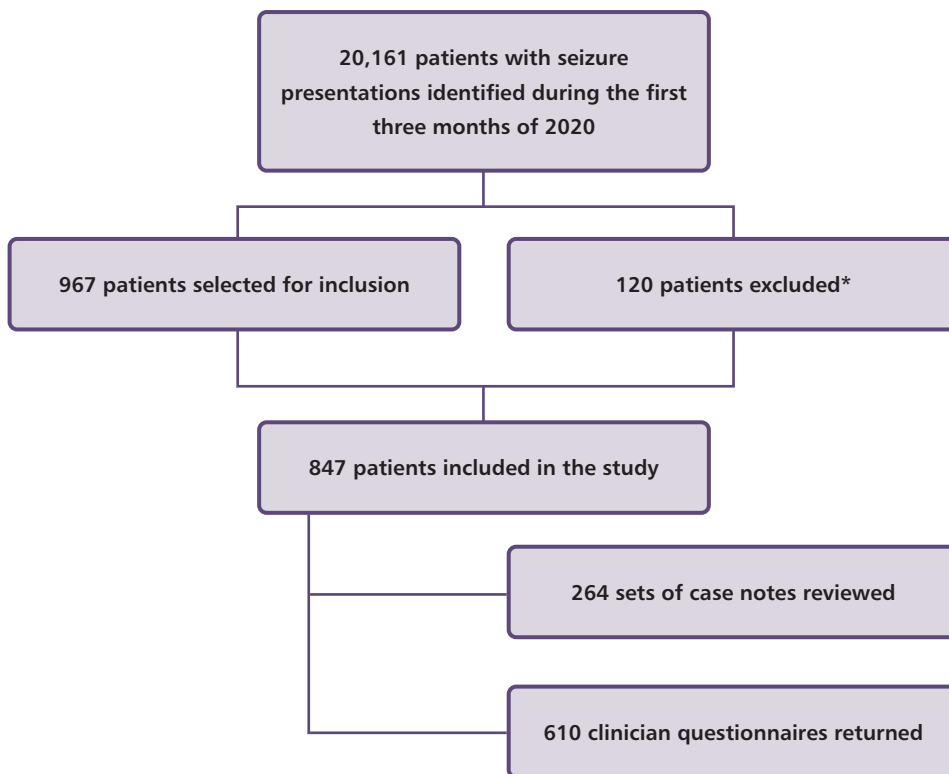


Figure 1.1 Data returned
**patients did not meet the study inclusion criteria*

Patient demographics and epilepsy history

Patient demographics

Age and sex

The age and sex of the study sample are shown in Figure 2.1. All patients were aged 18 or over as defined by the inclusion criteria. The mean age of the study sample was 46.6 years (male 46.3, female 46.9). There were 354/610 (58.0%) men and 256/610 (42.0%) women in the sample. These demographics are comparable with data from the National Audit of Seizure management in Hospitals (NASH) even though the inclusion criteria for both studies varied slightly.¹¹

Place of residence

Table 2.1 shows where patients in the study lived at the time of their presentation to hospital. Of the 464 people living in a private residence co-habitation status was unknown for 58, but 79 (19.5%) people lived alone. This may have had implications for safety-netting advice (information given to the patient about action to take if their condition fails to improve or if they have further concerns about their health in the future).

Table 2.1 Where patients in the study lived at the time of their presentation to hospital

	Number of patients	%
Private residence	464	78.8
Care home	90	15.3
Sheltered accommodation	15	2.5
Homeless	5	< 1.0
Hostel	5	< 1.0
Other hospital	4	< 1.0
University accommodation	3	< 1.0
Prison	3	< 1.0
Subtotal	589	
Unknown	21	
Total	610	

Clinician questionnaire data

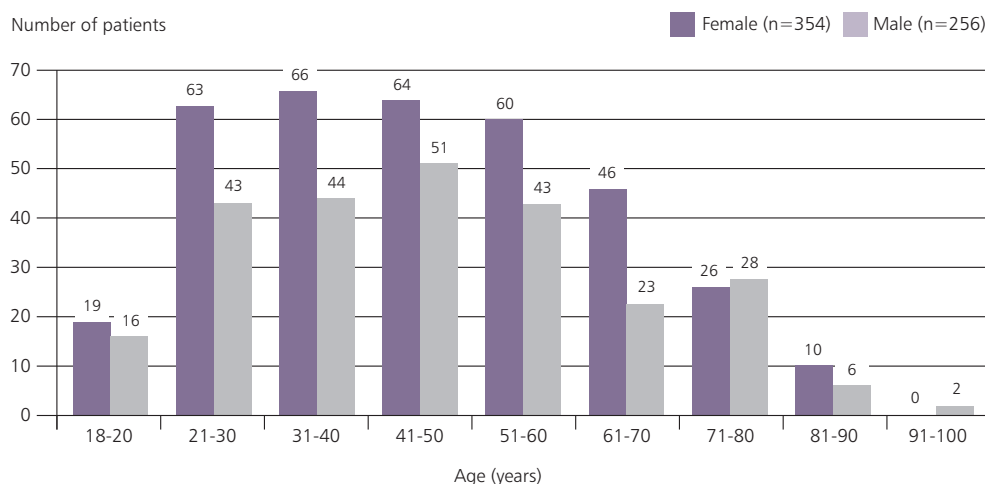


Figure 2.1 Age and sex of the study population

Clinician questionnaire data

Epilepsy history

Epilepsy had been previously diagnosed in 528/599 (88.1%) patients (Table 2.2), and of these 238/485 (49.1%) had presented to hospital (for any reason, not just seizure) within the previous six-months (Table 2.3). Of the 71 patients who had not been previously diagnosed with epilepsy the index admission was the first recorded seizure for 38 patients.

Comorbidities

There were 472/601 (78.5%) patients who had existing comorbidities relevant to their epilepsy. The comorbidities were divided into conditions that may have caused the epilepsy and those that are either associated with epilepsy or caused by the epilepsy (Table 2.4). Additional age-related health conditions experienced by some of the older patients in the study have not been included, as they were neither the cause of the epilepsy nor associated with it.

Table 2.2 The patient had been diagnosed with epilepsy prior to this presentation

	Number of patients	%
Yes	528	88.1
No	71	11.9
Subtotal	599	
Unknown	11	
Total	610	

Clinician questionnaire data

Table 2.3 The patient had presented to hospital in the six-months prior to this presentation

	Number of patients	%
Yes	238	49.1
No	247	50.9
Subtotal	485	
Unknown	43	
Total	528	

Clinician questionnaire data

Table 2.4 Existing comorbidities

May have caused the epilepsy	Number of patients	%
Stroke	70	11.6
Alcohol addiction	69	11.5
History of traumatic brain injury	35	5.8
Diabetes	30	5.0
Recreational drug habits	29	4.8
Childhood onset neurodevelopment disorders (e.g. autism)	24	4.0
Brain tumour	19	3.2
Associated with, or caused, by the epilepsy		
Learning disability	104	17.3
Mood disorders (e.g. depression/anxiety)	74	12.3
Acquired cognitive impairment	42	7.0
Mental illness (e.g. schizophrenia/psychosis)	38	6.3
NEAD (non-epileptic attack disorder)	23	3.8
Personality disorder	21	3.5

Clinician questionnaire data

Answers may be multiple; n=472

Time since diagnosis of epilepsy

There were 35/367 (9.5%) patients who had been diagnosed with epilepsy within the last 12 months (Table 2.5), while 176/367 (48.0%) patients were diagnosed over 10 years prior to this presentation. It should be noted that the clinician completing the questionnaire was unable to answer this question for 161/528 (30.5%) patients.

Table 2.5 Time since the patient was diagnosed with epilepsy

	Number of patients	%
< 1 month	2	<1
1-6 months	23	6.3
7-12 months	10	2.7
> 1 year < 2 years	33	9.0
>2 years < 5 years	64	17.4
>5 years < 10 years	59	16.1
>10 years < 20 years	73	19.9
> 20 years	103	28.1
Total	367	
Unknown	161	
Total	528	

Clinician questionnaire data

Anti-seizure medication

Case reviewers found that most patients diagnosed with epilepsy had a current prescription for anti-seizure medication (ASM) (232/236; 98.3%), and this was not known for two patients. Table 2.6 shows the types of ASM commonly used and Table 2.7 shows the number of different ASMs that were prescribed to each patient. There were 23/76 (30.3%) patients who were prescribed valproate medicines who were female, and 10 were under the age of 50 years and seven under the age of 40. It was not clear from the records whether these patients had been given appropriate counselling on the potential effects of valproate medicines, and where appropriate, the risks of taking it during pregnancy, and whether they had been offered effective contraception.

Table 2.6 Anti-seizure medication used

	Number of patients	%
Levetiracetam/Keppra	102	43.9
Valproate medicines/Epilim chrono/Orlept	76	32.8
Lamotrigine/Lamictal	72	31.0
Clobazam/Frisium	33	14.2
Carbamazepine/Tegretol/Tegretol Retard	32	13.8
Phenytoin/Epanutin	17	7.2
Topiramate/Topamax	11	4.7
Pregabalin/Lyrica	10	4.3
Other	49	21.1

Case reviewer data

Answers may be multiple; n=232

Table 2.7 Number of anti-seizure medications prescribed

	Number of patients	%
1	116	50.0
2	67	28.9
3	33	14.2
4	9	3.9
5	6	2.6
6	1	<1.0
Total	232	

Case reviewer data

It was of note that 47/180 (26.1%) patients presenting to hospital with a seizure did not have clear documentation of their ASM in their hospital records, either due to the patient not knowing or not being able to tell the staff, or due to a failure to record the information.

In the opinion of the case reviewers the choice of ASM and doses were appropriate in 141/155 (91.0%) cases reviewed (Table 2.8 overleaf). The case reviewers reported inappropriate ASM regimens due to sub-therapeutic doses in six patients, no change in ASM despite recent admissions for a seizure in five patients and wrong choice of ASM in three patients.

CASE STUDY 1

A young patient with known epilepsy and a learning disability presented to a hospital outside of their usual area with a tonic-clonic seizure. The patient had presented to the emergency department ten times in the previous 12 months. The patient was unable to report on medication history or usual epilepsy management, and no attempt was made to obtain this information from external records. No assessment of mental capacity was carried out. The patient was discharged with an appointment for a ‘first fit’ clinic and no updates were sent to the usual treating team, primary care team or family.

Reviewers were of the opinion that this case study illustrated the necessity for a system that allowed treating teams to communicate information about previous and ongoing care to relevant parties, to ensure continuity of care and appropriate preventative treatment and follow-up. The General Medical Council’s Good Medical Practice highlights the importance of communication with primary care and colleagues.

Table 2.8 Appropriate doses of anti-seizure medication

	Number of patients	%
Yes	141	91.0
No	14	9.0
Subtotal	155	
Unable to tell	25	
Total	180	

Case reviewer data

There were 24/227 (10.6%) patients who were reported to have had diarrhoea and/or vomiting and/or constipation and may not have been absorbing their medication properly even though they were taking their ASM as prescribed (recorded for 20 patients).

However, there were 44/184 (23.9%) patients who were not taking their medication as prescribed. The reasons for this were documented for 29 patients and included: side effects of ASM, denial of epilepsy, forgetting to take the medication or running out of medication, alcohol and/or drug use.

Sub-optimal ASM levels may have been expected for 68/227 (30.0%) patients either due to non-adherence or reduced ASM absorption. Measurement of ASM levels was only performed for 33/229 (14.4%) patients (Table 2.9). The use of ASM screening was no better in the patients who were not taking their medication (7/44; 15.9%) or in those where ASM absorption may have been affected 6/24 (25.0%). The availability of ASM screening is discussed further in Chapter 4.

Table 2.9 Serum anti-seizure medication levels undertaken during this hospital presentation

	Number of patients	%
Yes	33	14.4
No	196	85.6
Subtotal	229	
Unknown	6	
Total	235	

Case reviewer data

CASE STUDY 2

A middle-aged patient with known epilepsy presented to hospital with a tonic-clonic seizure, having been free from seizures for 10 years. The patient had been unwell for 48 hours prior to admission with vomiting and diarrhoea. The seizure was managed in the emergency department (ED) and included measurement of anti-seizure medication (ASM) levels. Discharge home with follow-up was arranged with the specialist epilepsy team. The ED team communicated the patient’s admission to the primary care and specialist teams, including the fact an ASM level had been taken.

Reviewers were of the opinion that the care given in ED was appropriate and that the measurement of ASM levels was exemplary with excellent communication with all appropriate parties on discharge.

Pre-hospital care

People with epilepsy are often sent to hospital by members of the public who have witnessed the person having a seizure. Many people have self-limiting seizures which do not need medication to control and families and carers of people with epilepsy are often able to manage seizure episodes at home. People experiencing a prolonged tonic-clonic seizure will need to be given benzodiazepines to control the seizure. This initial care often falls to ambulance teams, but the public and primary care teams may also be involved in protecting the patient's airway to prevent death.

In this study most patients came to hospital by ambulance 511/595 (85.9%) with a further 55/595 (9.2%) patients who self-referred and 13/595 (2.2%) who were referred by a GP (Table 3.1).

Table 3.1 Mode of presentation

	Number of patients	%
Ambulance	511	85.9
Self	55	9.2
GP	13	2.2
Other	16	2.7
Subtotal	595	
Unknown	15	
Total	610	

Clinician questionnaire data

Of the patients who arrived by ambulance or were referred by a GP, 143/455 (31.4%) had received pre-hospital anti-seizure medication (ASM) (Table 3.2). The types of ASM used in the pre-hospital settings are shown in Table 3.3. The most common ASM given in the pre-hospital setting was diazepam with 90/143 (62.9%) patients receiving it alone or in combination with another ASM. A small number

of patients (4) received clobazam as a rescue medicine at their usual place of residence, prior to the arrival of the ambulance crew. In all but four patients the clinician completing the questionnaire considered that the dose of ASM was appropriate: three were considered excessive, and one patient was not given enough.

Table 3.2 The patient was given anti-seizure medication in the pre-hospital setting

	Number of patients	%
Yes	143	31.4
No	312	68.6
Subtotal	455	
Unknown	69	
Total	524	

Clinician questionnaire data (patients brought in by ambulance (511) and those referred by a GP (13))

Table 3.3 Type of anti-seizure medications given in the pre-hospital setting

	Number of patients	%
Diazepam	84	58.7
Midazolam	34	23.8
Lorazepam	11	7.7
Midazolam, diazepam	4	2.8
Clobazam	4	2.8
Midazolam, other	3	2.1
Diazepam, lorazepam	2	1.4
Midazolam, lorazepam	1	<1.0
Total	143	

Clinician questionnaire data

A relatively large number of patients did not require an intervention in the pre-hospital setting (161/433; 37.2%). For those who did, 215/433 (49.7%) had an intravenous cannula inserted, 148/433 (34.2%) had an ECG, and a small number had cardiopulmonary resuscitation or were intubated (Table 3.4).

Table 3.4 Procedures that were performed in the pre-hospital setting

	Number of patients	%
Cannula insertion	215	49.7
Electrocardiogram	148	34.2
Other	53	12.2
Intubation	5	1.2
Cardiopulmonary resuscitation	4	<1.0
None	161	37.2

Clinician questionnaire data

Answers may be multiple; n=433 (unknown for 91)

Where the case reviewers were able to rate the pre-hospital care, they determined that it was good or adequate in most cases reviewed (154/158; 97%), with only a small minority of patients receiving what was considered to be poor care (4/158; 2.5%), in all instances this was due to issues with ASM (Table 3.5).

Table 3.5 Quality of pre-hospital care

	Number of patients	%
Good	103	65.2
Adequate	51	32.3
Poor	4	2.5
Subtotal	158	
Unable to rate	80	
Total	238	

Case reviewer data

CASE STUDY 3

An ambulance team was called to see a young patient who had been found having a tonic-clonic seizure while watching a local club rugby game. The patient was known to have epilepsy and some onlookers had taken video of the episode. When the ambulance crew arrived, the patient's seizure had passed. The crew obtained a full history of the seizure and reviewed the video of the event. A history of the patient's epilepsy and medication was obtained from a family member as the patient was still drowsy. The patient was taken to the emergency department where a typed handover sheet including a comprehensive history, medication details and seizure description was handed to staff.

Reviewers agreed that the ambulance care, history taking, and handover were excellent, in particular the typed handover sheet and seizure history.

Presentation to hospital

People with epilepsy who present to hospital will most commonly have had some form of generalised tonic-clonic seizure. At the start of the seizure the person becomes unconscious, their body goes stiff, and they may fall backwards. They jerk and shake as their muscles relax and tighten rhythmically. After the seizure they may be tired and confused. Patients may develop status epilepticus, which is when seizures last too long or are repeated. This is defined as a seizure lasting five minutes or more, or one tonic-clonic seizure following another without the patient regaining consciousness.¹⁶

For patients with tonic-clonic seizures first-line treatment with buccal, rectal or intravenous benzodiazepines may be needed to control seizures on admission to hospital or in the community. Second-line treatment with levetiracetam, phenytoin or valproate medicines may be needed if patients do not respond to first-line treatment.¹⁴

People often present to the emergency department (ED) but may also be cared for in medical admission units or critical care depending on their condition. Investigations for patients presenting with seizures includes baseline bloods, imaging such as CT and MRI (not always), EEG and anti-seizure medication (ASM) blood levels. Patients who are admitted should be monitored for further seizures – this can be done using a seizure chart. People who are admitted to hospital are a subset of those who have seizures as shorter seizures may be managed at home with family or carers.

Type of seizure

Overall, case reviewers found 183/229 (79.9%) patients had had a tonic-clonic seizure and 19/229 (8.3%) had status epilepticus (Table 4.1). A relatively small number of patients were having an active seizure on arrival to the ED (39/264; 14.8%). Of the 39 patients who were actively convulsing on admission to the ED, 18 responded to initial therapy.

Table 4.1 Type of seizure the patient had prior to presentation to hospital

	Number of patients	%
Tonic-clonic	183	79.9
Focal	17	7.4
Status epilepticus	19	8.3
Other	10	4.4
Subtotal	229	
Unknown	35	
Total	264	

Case reviewer data

Just under half of the patients had a further seizure in hospital (116/259; 44.8%) (Table 4.2) and the case reviewers stated that for 13/103 (12.6%) patients the seizure could have been managed better (Table 4.3), by earlier treatment with first-line therapy and/or escalation to second line therapy.

Table 4.2 The patient had a further seizure in hospital

	Number of patients	%
Yes	116	44.8
No	143	55.2
Subtotal	259	
Unknown	5	
Total	264	

Case reviewer data

Table 4.3 The further seizure could have been managed better

	Number of patients	%
Yes	13	12.6
No	90	87.4
Subtotal	103	
Unknown	13	
Total	116	

Case reviewer data

CASE STUDY 4

An older patient with known epilepsy and dementia was brought to hospital by ambulance having had a tonic-clonic seizure. On arrival the patient was no longer having a seizure but was kept on a trolley in the corridor due to capacity issues in the emergency department (ED). The patient had several further seizures while in the corridor and was finally taken to a setting where these could be controlled. There was a delay in assessment of the patient. The patient was given a loading dose of phenytoin rather than benzodiazepines and was subsequently admitted to the medical admissions unit. ED documentation, including the reason for giving phenytoin, was unclear and the seizure history was incomplete.

Reviewers were of the opinion that the care provided could be improved, particularly the need for early assessment and control of seizures. They were of the opinion that first-line treatment with benzodiazepines should have occurred and that phenytoin loading was inappropriate.

Investigations**Investigations available**

A completed organisational questionnaire was returned from 158 hospitals to which patients were admitted or assessed after presenting with seizures due to epilepsy. Most had a 24/7 ED (150/158; 94.9%), 101/158 (63.9%) hospitals had a neurology department on-site and 25/158 (15.8%) had neurosurgery on-site (Figure 4.1).

Access to cross-sectional imaging techniques such as CT (154/158 97.5%) and MRI (151/158; 95.6%) were available in most hospitals (Table 4.4 overleaf), while 93/158 (58.9%) had EEG. It was reported from only 119/158 (75.3%) hospitals that the facility to perform an ASM blood screen on-site was available, which may have given rise to some of the deficiencies seen in ASM screening detailed in Chapter 2. The Study Advisory Group and case reviewers were of the opinion that access to ASM levels should be available in all hospitals admitting patients with seizures and that while it was the responsibility of the ED clinician or admitting clinician to order the relevant ASM screen, responsibility for actioning the findings should lie with the team managing the patient's epilepsy.

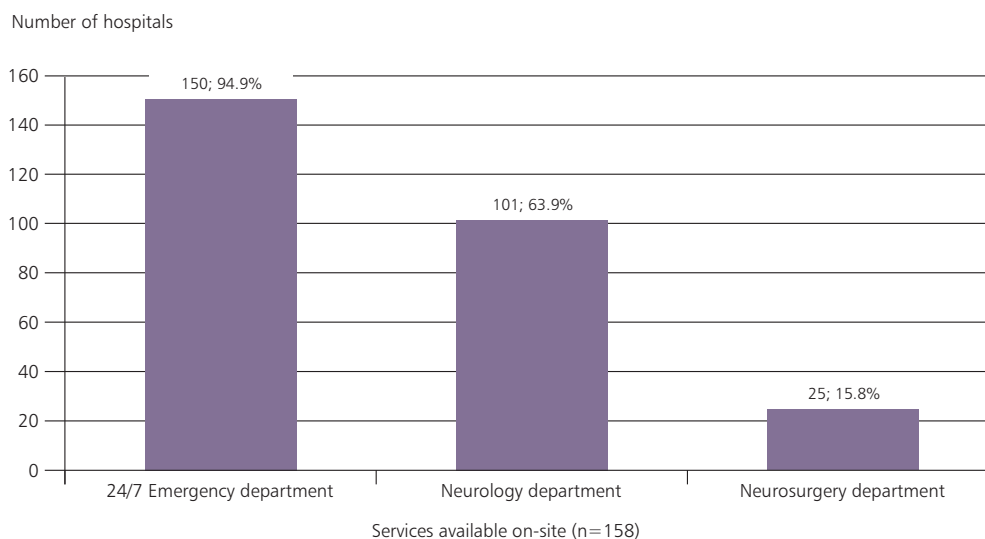


Figure 4.1 Availability of emergency and neurology/neurosurgery services on-site
Organisational questionnaire data

Table 4.4 Investigations available on-site

	Number of hospitals	%
CT scan of head	154	97.5
12-lead electrocardiogram (ECG)	153	96.8
Magnetic resonance imaging (MRI)	151	95.6
Anti-seizure medication blood screen	119	75.3
3-lead electrocardiogram (ECG)	113	71.5
Electroencephalogram (EEG)	93	58.9
Outpatient/ambulatory video EEG	65	41.1
Inpatient video telemetry	35	22.2

Organisational questionnaire data
Answers may be multiple; n=158

There was greater capacity to perform an ASM screening in hospitals with a neurology department on-site (Table 4.5) than in those with no neurology department on-site (87/101; 86.1% vs 32/57; 56.1%) but this did not account for the low levels of screening reported by the clinicians and case reviewers. Hospitals without a neurology department on-site were also less likely to have availability of electroencephalograms (EEG) (20/57; 35.1%) than those with a neurology department on-site (73/101; 72.3%).

MRI was available seven days a week during extended hours in 64/151 (42.4%) hospitals while in 38/151 (25.2%) it was only available during normal working hours Monday to Friday (Table 4.6). EEG was mainly available (75/93; 80.6%) during normal working hours Monday to Friday. It was very rare for hospitals to offer extended hours for EEG (7/93; 7.5%) (Table 4.7).

Table 4.5 Investigations available on-site with and without an on-site neurology department

Investigations	Neurology department on-site			
	Yes		No	
	Number of hospitals	%	Number of hospitals	%
MRI	101	100.0	50	87.7
CT scan of head	101	100.0	53	93.0
12-lead electrocardiogram	99	98.0	54	94.7
Anti-seizure medication blood screen	87	86.1	32	56.1
Electroencephalogram (EEG)	73	72.3	20	35.1
3-lead electrocardiogram	67	66.3	46	80.7
Outpatient/ambulatory video EEG	55	54.5	10	17.5
Inpatient video telemetry	30	29.7	5	8.8

Organisational questionnaire data

Answers may be multiple; n=101

Answers may be multiple; n=57

Table 4.6 Availability of magnetic resonance imaging (MRI)

	Number of hospitals	%
Monday - Friday (normal working hours)	38	25.2
Monday - Friday (extended hours)	8	5.3
Seven days a week (normal working hours)	33	21.9
Seven days a week (extended hours)	64	42.4
Other	8	5.3
Total	151	

Organisational questionnaire data

Table 4.7 Availability of electroencephalography (EEG)

	Number of hospitals	%
Monday - Friday (normal working hours)	75	80.6
Monday - Friday (extended hours)	1	1.1
Seven days a week (normal working hours)	7	7.5
Seven days a week (extended hours)	6	6.5
Other	4	4.3
Total	93	

Organisational questionnaire data

Investigations undertaken in the ED

The investigations carried out in the ED are shown in Table 4.8. Most patients had urea and electrolytes, full blood count, and liver function tests. In addition, 133/264 (50.4%) patients had a CT scan of head. An ASM screen was documented for 26/264 (9.8%) patients.

Table 4.8 Investigations that were undertaken

	Number of patients	%
Renal function	253	95.8
Full blood count	247	93.6
Liver function tests	223	84.5
Blood glucose test	201	76.1
Electrocardiogram	157	59.5
Calcium	137	51.9
CT scan of head	133	50.4
Magnesium	113	42.8
Anti-seizure medication level screen	26	9.8
Alcohol screen	8	3.0
Drugs screen	5	1.9

Case reviewer data
Answers may be multiple: n=264

The case reviewers thought that these investigations undertaken in the ED were appropriate for 194/252 (77.0%) patients (Table 4.9) but for 58/252 (23.0%) they reported that other investigations should have been performed (Table 4.10).

Table 4.9 Appropriate investigations were undertaken in the emergency department

	Number of patients	%
Yes	194	77.0
No	58	23.0
Subtotal	252	
Unknown	12	
Total	264	

Case reviewer data

Table 4.10 Investigations that should have been undertaken

	Number of patients	%
Anti-seizure medication level screen	29	50.0
Blood glucose test	15	25.9
Calcium	13	22.4
Magnesium	12	20.7
Electrocardiogram	10	17.2
Alcohol screen	8	13.8
CT scan of head	8	13.8
Full blood count	6	10.3
Drugs screen	6	10.3
Liver function tests	5	8.6
Other	5	8.6
Renal function	3	5.2

Case reviewer data
Answers may be multiple: n=58

Although a formal assessment of over-investigation was not undertaken, there were several discussions in the case reviewer meetings regarding the large number of patients who received a CT scan of head. There were eight unprompted examples highlighted in the comments of where it had been an unnecessary investigation.

CASE STUDY 5

A young patient with cerebral palsy, learning difficulties, and known epilepsy experienced a seizure at home. The patient's breathing had been a little laboured prior to admission along with a raised temperature. The patient was admitted to the emergency department and had a CT scan of head as part of his work up. Subsequently, the patient was found to have aspiration pneumonia. Good input was received from the learning disability team and gastroenterologists in relation to aspiration.

Reviewers could find no reason for the patient having a CT scan of head. The presenting symptoms should have triggered an early chest X-ray. Reviewers were of the opinion that this case highlighted how CT scans are sometimes over-utilised in people with epilepsy.

Admission

There were 533/610 (87.4%) patients who were admitted to hospital for further investigation/treatment/observation. Most (382/529; 72.2%) were admitted to an acute admissions unit but 53/529 (10.0%) were admitted directly to a high dependency setting. Only 15/529 (2.8%) were admitted to a neurology ward (Table 4.11).

Table 4.11 Type of ward to which the patient was first admitted

	Number of patients	%
Acute admissions unit	382	72.2
General ward	52	9.8
Intensive care unit (level 3)	46	8.7
Neurology ward	15	2.8
High dependency unit (level 2)	7	1.3
Other	27	5.1
Subtotal	529	
Unknown	4	
Total	533	

Clinician questionnaire data

NB: The number of patients admitted to hospital in the current study was greater than that seen in the three NASH audits which reflects the differences in the inclusion criteria (all seizures in the NASH audit compared to seizures caused by epilepsy in the current study).

Investigations undertaken as an inpatient

In addition to the investigations carried out in the ED, clinicians completing a questionnaire were asked about the investigations patients received as an inpatient. Table 4.12 shows that 353/503 (70.2%) patients received an ECG and 15/503 (3.0%) had an EEG. Quite a large proportion of patients (286/503; 56.9%) received a CT scan of head while in hospital. Overall, the case reviewers were of the opinion that patients had received all the appropriate inpatient investigations, with only seven examples of when a patient would have benefited from further investigations while in hospital (data not shown).

Seizure charts

Clinicians reported that 210/503 (41.7%) patients had a seizure chart for their inpatient stay (Table 4.13). The case reviewers believed the use of a seizure chart would have benefited a further 25/243 (10.3%) patients as 11/25 of these patients were documented as having further seizures in hospital.

Table 4.12 Investigations received by the patient while admitted

	Number of patients	%
ECG	353	70.2
EEG	15	3.0
CT scan of head	286	56.9
MRI	47	9.3

Clinician questionnaire data

Answers may be multiple; n=503 (30 unknown responses)

Table 4.13 Use of a seizure chart for the patient while admitted

	Number of patients	%
Yes	210	41.7
No	293	58.3
Subtotal	503	
Unknown	30	
Total	533	

Case reviewer data

CASE STUDY 6

A middle-aged patient with known stable epilepsy and a learning disability was admitted with seizures and unexplained headache. There was no documentation of mental capacity to consent to undergo treatment. The patient was given a lumbar puncture without documented consent or capacity documentation.

Reviewers were of the opinion that an assessment and documentation of mental capacity should have occurred, especially prior to an invasive procedure.

Mental capacity

Only a minority (62/200; 31.0%) of patients had documentation of an assessment of mental capacity (Table 4.14). The case reviewers concluded that the assessment and subsequent plan was appropriate in 142/179 (79.3%) patients, despite many not being documented as having an assessment of mental capacity (Table 4.15). This might have been due to patients who were functioning normally by clinical assessment not needing to be referred for a formal review.

Table 4.14 Documentation of an assessment of mental capacity

	Number of patients	%
Yes	62	31.0
No	138	69.0
Subtotal	200	
Unknown	34	
Total	234	

Case reviewer data

Table 4.15 Assessment and subsequent plan was appropriate

	Number of patients	%
Yes	142	79.3
No	37	20.7
Subtotal	179	
Unknown	21	
Total	200	

Case reviewer data

Specialist input

As discussed in previous chapters, patients with epilepsy may present to several specialties including emergency medicine and critical care but are rarely, as inpatients, under the care of a specialist epilepsy neurology team. Teams looking after patients presenting to the emergency department (ED) or admitted to hospital often need specialist epilepsy team advice from a neurologist or epilepsy specialist nurse (ESN). This can be difficult as neurology services are often concentrated in the outpatient setting and most emergency care is not provided by the neurology team. Acute teams may need advice and review regarding diagnosis, medication changes, adherence issues and counselling regarding the risks associated with epilepsy. Different neurology team members may be needed depending on the advice required. A particularly difficult area that was identified by the Study Advisory Group was continuity of care during and after admission. Communication with the patient's usual epilepsy team (which may be at another hospital) and the patient's GP is essential to ensure good epilepsy control, adherence to medication and ongoing counselling.

Organisational data

Availability of neurologists

A total of 96/158 (60.8%) hospitals reported that consultant neurologists were based on-site, of these, 47/94 (50.0%) reported six or more consultant neurologists, while 47/94 (50.0%) had five or fewer. A further 43/158 (27.2%) hospitals reported that there were visiting consultant neurologists with dedicated sessions. Only a small number of hospitals had ad hoc or no access to neurologists on-site (Table 5.1). Of the 96 hospitals from which it was reported that a consultant neurologist was on-site, 59/96 (61.5%) had one or more neurologists with a specialist interest in epilepsy.

Table 5.1 Availability of consultant neurologists on-site

	Number of hospitals	%
Consultant neurologists based on-site	96	60.8
Visiting consultant neurologists with dedicated sessions	43	27.2
Visiting consultant neurologists on ad hoc basis (no dedicated sessions)	5	3.2
Not available on-site	9	5.7
Other	5	3.2
Total	158	

Organisational questionnaire data

Many neurologists work mainly as outpatient-based specialists with some inpatient sessions that are more likely to be based in a hub/central hospital rather than spoke/district general hospitals.^{17,18} Access to urgent neurology advice is important for patients presenting to hospital with seizures especially after a period of good control. This includes access to medical and epilepsy specialist nurses (ESNs) who provide complementary skills.^{10,14,19}

Figure 5.1 overleaf shows the different access to urgent neurology cover that was reported for hospitals during normal working hours and out of hours. In total, 66/158 (41.8%) hospitals reported an on-call neurology consultant or registrar during normal working hours, while only 37/158 (23.4%) reported this out of hours. Only 19/158 (12.0%) hospitals reported an on-site neurology consultant or registrar during normal working hours and 5/158 (3.2%) out of hours. Telephone advice only, was available in 37/158 (23.4%) hospitals during normal working hours and in 62/158 (39.2%) out of hours. Three hospitals reported that there was no arrangement for urgent neurology cover during normal working hours and 12 had no arrangement out of hours.

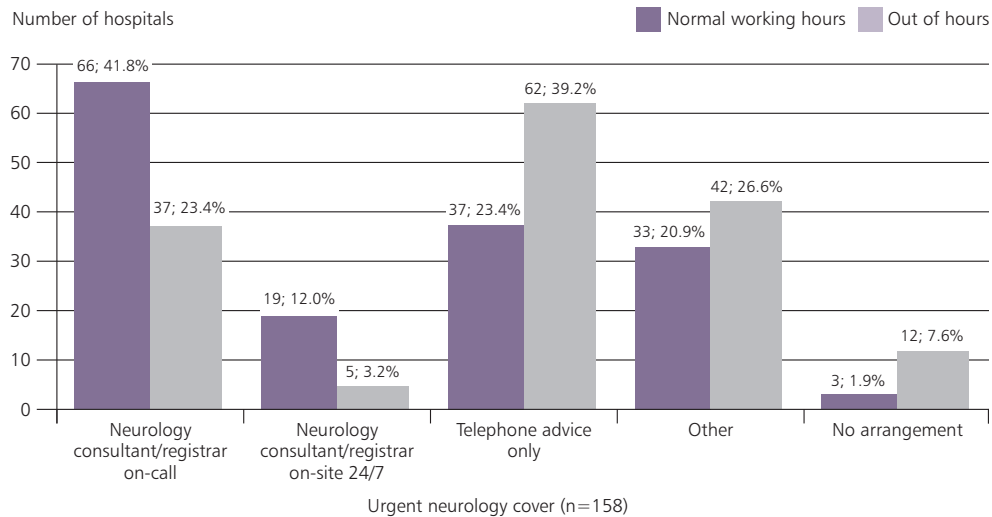


Figure 5.1 How urgent neurology cover was obtained
Organisational questionnaire data

Availability of epilepsy specialist nurses

In 2015 the Royal College of Nursing published a consensus document on the role of the ESN which included the provision of a holistic, collaborative and co-ordinated approach to the care of patients with epilepsy.¹⁹ This means that ESNs should be involved in the care and follow-up of patients who are admitted to hospital with epilepsy, especially if they have developed increased seizure frequency after a period of remission. They are a very useful point of contact for patients who need to clarify their management plan after admission or if they experience an increased frequency of seizures. In addition, ESNs should be involved in counselling patients with a new diagnosis of epilepsy within 30 days of diagnosis^{14,20} and NICE recommends ESN review within three months of diagnosis and access to an ESN advice line between appointments.¹⁴

In total, 73/158 (46.2%) hospitals reported they had ESNs on-site and ESNs were not available on-site in 55/158 (34.8%). Furthermore, there were 34/73 (46.6%) hospitals with on-site ESNs with one or fewer whole time equivalent (WTE) posts and 55/73 (75.3%) hospitals had two or fewer WTE posts (Table 5.2).

Table 5.2 Availability of epilepsy specialist nurses (ESNs) on-site

	Number of hospitals	%
ESNs based on-site	73	46.2
Visiting ESNs with dedicated sessions	14	8.9
Visiting ESNs on ad hoc basis (no dedicated sessions)	16	10.1
Not available on-site	55	34.8
Total	158	

Organisational questionnaire data

CASE STUDY 7

A middle-aged patient with known epilepsy and alcohol abuse was admitted with an increased number of seizures in the preceding week after a period of abstinence. Adherence to medication had been adequate but the patient had been struggling at times with control of their drinking. Having been admitted to the medical admissions unit the patient was discharged within 48 hours, during which time they were not referred to or seen by the neurology team or alcohol cessation service. On discharge no follow-up was arranged and no contact was made with the patient's neurology team.

Reviewers considered that this case highlighted the need for greater specialist neurology input into the care of people presenting with deterioration in their seizure status. They were also of the opinion that the post-discharge care of the patient could have been co-ordinated better if members of the neurology and alcohol team had been contacted.

Clinical data

The clinicians completing a questionnaire on the patients they treated reported that only 175/503 (34.8%) patients were reviewed by a neurologist during their admission and a further 109/503 (21.7%) had their epilepsy management discussed with a neurologist, leaving 219/503 (43.5%) patients with no neurology input (Table 5.3). Furthermore, only 36/494 (7.3%) patients were reviewed by an ESN during their admission (Table 5.4). The low number of patients reviewed by an ESN may be because their job plans are for outpatient liaison (key worker) roles rather than for inpatient care. If this is the case, it should be standard practice to contact the ESN pre-discharge so that the treating team are aware of the admission and the discharge. However, this was rarely hospital policy.

Table 5.3 Neurology input during the admission

	Number of patients	%
Reviewed	175	34.8
Discussed	109	21.7
None	219	43.5
Subtotal	503	
Unknown	30	
Total	533	

Clinician questionnaire data

Table 5.4 Epilepsy specialist nurse input during the admission

	Number of patients	%
Yes	36	7.3
No	458	92.7
Subtotal	494	
Unknown	39	
Total	533	

Clinician questionnaire data

Table 5.5 shows that 133/315 (42.2%) patients diagnosed with epilepsy and admitted to hospital, did not have their admission discussed with the secondary care team managing their epilepsy.

Table 5.5 Patient was discussed with a member of the team managing their epilepsy

	Number of patients	%
Yes	182	57.8
No	133	42.2
Subtotal	315	
Epilepsy managed by GP	96	
Unknown	58	
Total	469	

Clinician questionnaire data

In the opinion of the case reviewers the overall neurology input was adequate for the care of 156/217 (71.9%) patients. This implied that not every patient who was admitted to hospital with a seizure needed specialist neurology input. However, it was of note that for 61/217 (28.1%) patients the neurology input received was reported to be inadequate. The reasons included patients with complex epilepsy not being reviewed when their pattern of seizures had changed, input regarding medicine reconciliation and educating patients about the importance of taking their medication correctly.

There was little difference in the adequacy of neurology input if patients were treated in hospitals with neurology on-site (87/120; 72.5% adequate) or not (47/68; 69.1% adequate) (Table 5.6). This may reflect how urgent neurology care for patients following a seizure was organised rather than the absence or presence of neurologists on-site.

During the hospital admission 124/220 (56.4%) patients had changes made to the type or dose of their anti-seizure medication (ASM). The case reviewers were asked to give their opinion on whether the changes or lack of changes to the patient's medication were appropriate. The case reviewers stated that the changes/lack of changes were inappropriate for 37/209 (17.7%) cases reviewed. There was an even split between cases where there should have been changes made (18/37) and those where the changes made were inappropriate.

The importance of neurology input is demonstrated by the case reviewers' opinion on the appropriateness of the ASM changes that were made. A total of 126/137 (92.0%) patients with adequate neurology input had appropriate ASM changes compared to 24/46 (52.2%) who did not receive adequate neurology input (Table 5.7).

Table 5.6 Adequate neurology input by availability of a neurology department on-site

	Neurology department on-site			
	Yes		No	
Adequate	Number of patients	%	Number of patients	%
Yes	87	72.5	47	69.1
No	33	27.5	21	30.9
Subtotal	120		68	
Unknown	15		5	
Total	135		73	

Case reviewer data

Table 5.7 Adequate neurology input and appropriateness of anti-seizure medication changes

Adequate neurology input	Appropriate ASM changes				Subtotal	Unknown	Total
	Yes	%	No				
Yes	126	92.0	11	137	4	141	
No	24	52.2	22	46	4	50	
Subtotal	150		33	183	8	191	
Unknown	24		22	46	4	50	
Total	174		55	229	12	241	

Case reviewer data

Information for patients

Providing information for patients and carers on the diagnosis of epilepsy and its implications is important to ensure they understand the possible causes of seizures and are able to optimise their treatment for the condition. National guidelines recommend that information is provided at each patient contact to ensure a clear management plan, risk assessment and mitigation to ensure patients can contribute effectively to the self-management of their epilepsy and avoid risks. These risks include sudden unexpected death in epilepsy (SUDEP), effects of drugs and alcohol on seizure control, use of anti-seizure medication (ASM) in pregnancy, adherence to medication, and limitations on activities such as driving²¹ and swimming. Doctors have a duty to ensure that patients are aware of the risks of a diagnosis of epilepsy and its treatment,²² although this information could be delivered by an epilepsy specialist nurse (ESN). Tools such as the 'SUDEP Action Checklist'²³ and 'EpSMon app'²⁴ exist to help clinicians assess and communicate risks to patients but these have not been widely adopted to date.

Organisational data

It was reported from 135/142 (95.1%) hospitals that patients were provided with specific information or education regarding their epilepsy, it was unknown for 16. In 67/135 (49.6%) hospitals patient information or education was provided before discharge from hospital, with 52/135 (38.5%) not providing specific information or education regarding epilepsy until the patient's first clinic appointment, which may be many weeks after discharge (Table 6.1). If delivery of this information is delayed then patients could be at risk of death when driving or swimming, for example. All hospitals should provide information to patients at each patient contact. Previous work has cited that the majority of patients wanted more information and felt they had received little advice about the causes of epilepsy, effects and interactions of drugs and avoidance of potentially dangerous situations.^{25,26}

Table 6.1 When the patient information was provided

	Number of hospitals	%
Before discharge from hospital	18	13.3
First clinic appointment	52	38.5
Before discharge and at first clinic appointment	49	36.3
Other	16	11.9

*Organisational questionnaire data
Answers may be multiple; n=135*

There was variation in the information and education that patients were given during their hospital admission (Table 6.2). Although timing of the delivery of patient information is important, particularly in relation to SUDEP,^{27,28} it should be discussed with all patients at an appropriate time and place. In this study 110/135 (81.5%) hospitals reported information on SUDEP was given to patients. Furthermore, 65/135 (48.1%) hospitals reported that a written self-management plan was included in patient information.

Table 6.2 Information given to patients

	Number of hospitals	%
Driving	124	91.9
Management of epilepsy related risks (e.g. alcohol, drugs, medication non-adherence)	120	88.9
Need to assess risk factors	117	86.7
Sudden unexpected death in epilepsy (SUDEP)	110	81.5
First point of contact	108	80
Complications of epilepsy	105	77.8
Impact on life	105	77.8
Written self-management plan	65	48.1

*Organisational questionnaire data
Answers may be multiple; n=135*

Clinical data

An inpatient admission provides an opportunity to ensure that safety advice is given to patients, including on SUDEP. However, only 40/317 (12.6%) patients had any evidence in their notes that the risk of SUDEP had been considered and only 38/347 (11.0%) cases had evidence that it had been discussed (Tables 6.3 and 6.4). It should be noted that clinicians were unable to comment on whether SUDEP had been considered and/or discussed in many cases (271/588 and 241/588 respectively). It may be that in patients who have recurrent seizures it is not appropriate to discuss SUDEP during every admission.

Table 6.3 Risk of SUDEP was considered

	Number of patients	%
Yes	40	12.6
No	277	87.4
Subtotal	317	
Unknown	271	
Total	588	

Clinician questionnaire data

Table 6.4 Evidence that risk of SUDEP/other risks had been discussed with the patient

	Number of patients	%
Yes	38	11.0
No	309	89.0
Subtotal	347	
Unknown	241	
Total	588	

Clinician questionnaire data

CASE STUDY 8

A middle-aged patient presented for the first time with seizures. The patient had experienced two seizures in 24 hours with the second requiring intravenous benzodiazepines administered by ambulance staff. The patient was discharged after a short inpatient stay of less than 24 hours. There was no documentation of safety advice being given to the patient (driving, unsupervised swimming) or SUDEP risk. Referral was made to neurology outpatient services, but the patient was not seen until eight weeks after discharge.

Reviewers were of the opinion that the patient should have received information on safety risks, what to do in case of further seizures, safety netting and SUDEP risk as a minimum standard during the admission. The patient should not have waited eight weeks to receive this information at an outpatient clinic.

Follow-up and re-attendance

First seizure clinics are essential points of referral for patients presenting with seizures for the first time. They should be accessed easily and quickly, and national guidance recommends that this should be within two-weeks of first seizure presentation.^{13,14} First seizure clinics are important to allow for the rapid diagnosis and treatment of epilepsy or other causes of seizure.

Follow-up

Outpatient clinics

First seizure clinics were available on-site in 100/154 (64.9%) hospitals (Table 7.1). In hospitals where first seizure clinics were not offered, 13/54 (24.1%) referred patients elsewhere within the trust/health board, 23/54 (42.6%) referred to another trust or health board and 18/54 (33.3%) referred patients to a general neurology/epilepsy clinic (Table 7.2).

Only 23/85 (27.1%) hospitals reported that the waiting time for first seizure clinics was within the recommended guidance of two-weeks following a first seizure, with 31/85 (36.5%) saying it was two to four weeks and 31/85 (36.5%) more than four weeks (Figure 7.1).

Table 7.1 First seizure clinics available on-site

	Number of hospitals	%
Yes	100	64.9
No	54	35.1
Subtotal	154	
Unknown	4	
Total	158	

Organisational questionnaire data

Table 7.2 Where patients were referred when on-site first seizure clinic was not on-site

	Number of hospitals	%
First seizure clinic elsewhere within the trust/health board	13	24.1
First seizure clinic at another trust/health board	23	42.6
General neurology/epilepsy clinic	18	33.3
Total	54	

Organisational questionnaire data

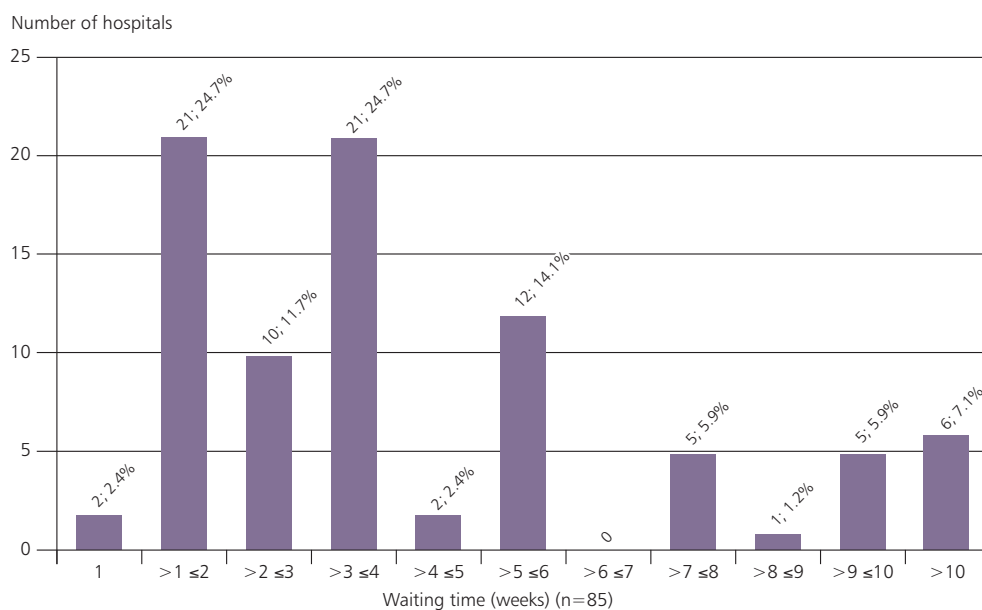


Figure 7.1 Waiting time for a first seizure clinic appointment

Organisational questionnaire data

It is recommended that all patients with a first seizure are referred from the emergency department (ED) to a first seizure clinic.¹⁴ Most hospitals (133/149; 89.3%) reported that it was routine protocol to refer patients who attend the ED with a suspected first seizure to the first seizure clinic (Table 7.3).

Table 7.3 Routine protocol to refer patients who attend the emergency department with a suspected first seizure to the first seizure clinic

	Number of hospitals	%
Yes	133	89.3
No	16	10.7
Subtotal	149	
Unknown	9	
Total	158	

Organisational questionnaire data

CASE STUDY 9

An older patient with dementia had a first seizure in a care home. The patient had a good performance status otherwise. The ambulance crew notes were incomplete. The patient was admitted and immediately commenced on levetiracetam by the acute medical team. The patient was discharged to their care home with no follow-up arranged.

Reviewers were of the opinion that the patient should have had a neurology review to ensure that treatment was optimal and manageable and should have been followed up. This would also have allowed the patient's family to meet the neurology team and understand the illness, care and response needed.

A total of 129/152 (84.9%) hospitals reported that outpatient clinics for patients with epilepsy were available. If outpatient clinics were not run at the hospital patients with epilepsy were referred to another hospital within the same or a neighbouring trust/health board.

NICE recommends that patients presenting with seizure recurrence after a period of readmission should be reviewed within two weeks for an assessment by an

epilepsy specialist.¹⁴ Routine outpatient appointments were offered to patients presenting with recurrent seizures in the majority of hospitals (135/146; 92.5%) (unknown for 12). However, only 45/143 (31.5%) hospitals reported that there was a policy for the ED to contact the epilepsy team when patients with known epilepsy were seen (this was unknown in 15).

Some hospitals have developed rapid advice services to help patients with epilepsy obtain advice when they have problems with epilepsy control. In this study, 79/152 (52.0%) hospitals reported that a rapid advice service was available. Table 7.4 details the services which were provided. The large majority operated a rapid telephone support service (74/79; 93.7%).

Table 7.4 Rapid advice services available

	Number of hospitals	%
Telephone support	74	93.7
Email response service	44	55.7
Text message service	6	7.6
Walk-in clinic	2	2.5
Other	8	10.1

Organisational questionnaire data
Answers may be multiple; n=79

Access to other services

Additional services sometimes required in the treatment of epilepsy include neurophysiology, neuropsychiatry and neuropsychology. These are often located in hospitals which treat patients with more complex epilepsy, although all hospitals should have access to these services. Figure 7.2 overleaf shows the distribution of these services and the access hospitals had to them. Most (155/158; 98.1%) had access to neurophysiology, with 75/158 (47.5%) hospitals having on-site access and the remainder (73/158; 46.2%) having off-site access at either the same or a different trust/health board. Neuropsychiatry and neuropsychology services were less accessible with 41/158 (25.9%) hospitals reporting they had no access to neuropsychiatry while 31/158 (19.6%) had no access to neuropsychology. The remaining hospitals had some access to these services, although this was more likely to be off-site at a different trust or health board.

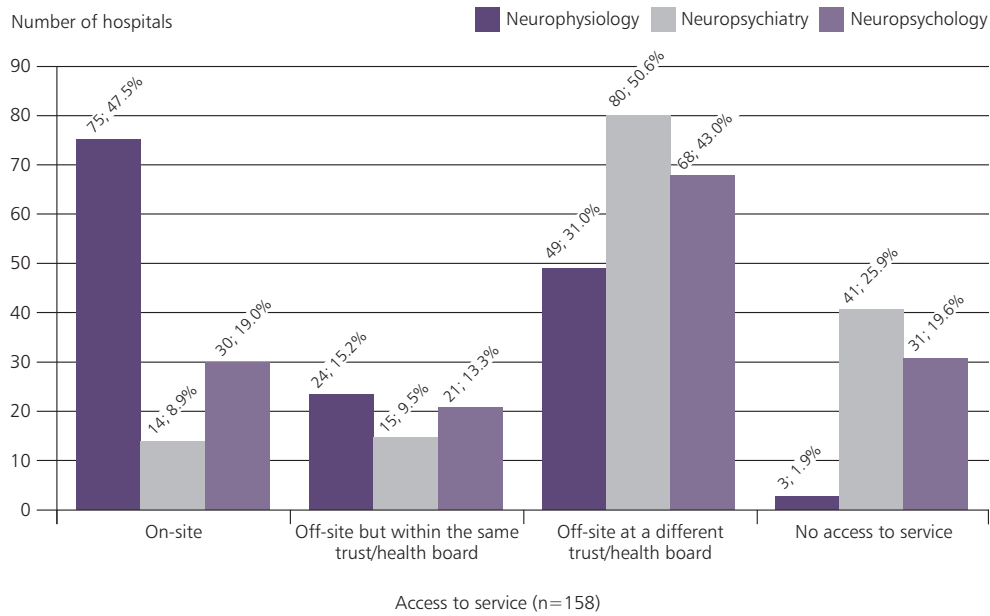


Figure 7.2 Other services
Organisational questionnaire data

Alcohol and drug support

Patients presenting with epilepsy who use drugs or alcohol often have poor adherence to medication as well as an increased risk of seizures. This in turn puts them at an increased risk of sudden unexpected death in epilepsy (SUDEP), accident, injury, and mental health crises. Services to help patients abstain from drugs and alcohol are essential to improve their self-management of their epilepsy.

A total of 94/129 (72.9%) hospitals reported that there was a drug and alcohol service on-site, 10/129 (7.8%) were off-site and 16/129 (12.4%) were based in the community (Figure 7.3 overleaf). These data show that there is still room for improvement following the 2013 and 2016 NCEPOD reports recommending that every hospital should have a seven-day alcohol specialist service and access to services within 24 hours of admission.^{29,30} Reviewers were of the opinion that changes in commissioning of drug and alcohol services may explain the lack of progress in this area.

CASE STUDY 10

A middle-aged patient presented to the emergency department with seizures presumed to be due to alcohol withdrawal. There was no documentation of usual alcohol intake, time of last drink or symptoms of withdrawal, and no treatment plan for alcohol withdrawal. A mental capacity assessment was not undertaken before the patient’s self-discharge despite concerns about a recent head injury.

Reviewers reported that patients with chaotic lifestyles pose challenges, but these can be mitigated by thorough assessment and planning and including relevant drug and alcohol services.

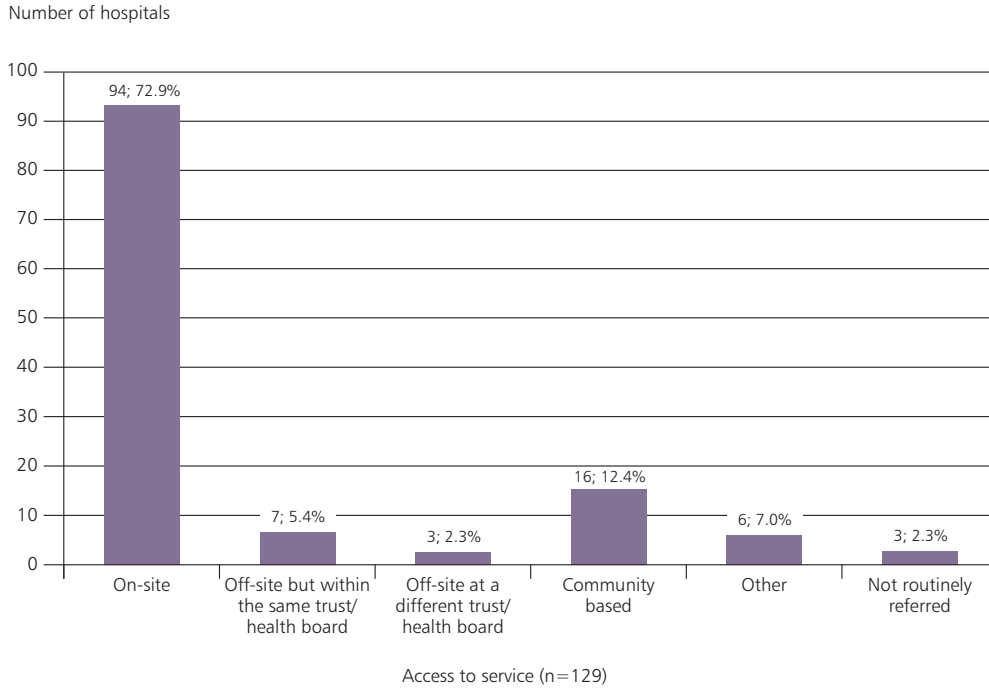


Figure 7.3 Drug and alcohol liaison services
Organisational questionnaire data

Follow-up

Discharge location

Most patients were discharged to their usual residence (573/591; 97.0%) (Table 7.5). The clinicians completing questionnaires reported that nine patients died while in hospital, but the cause of death was not explored nor linked with the quality of care due to the small sample size.

Table 7.5 Discharge location

	Number of patients	%
Usual residence	573	97.0
Other hospital	9	1.5
Died	9	1.5
Subtotal	591	
Unknown	19	
Total	610	

Organisational questionnaire data

Clinical follow-up

Table 7.6 overleaf shows which teams were responsible for the patient’s ongoing epilepsy care. In only 132/472 (28.0%) patients was it exclusively the secondary care team from the hospital at which the patient presented for this admission. In a further 51/472 (10.8%) the care was shared by that hospital and the patient’s GP. The patient’s GP was solely responsible for ongoing epilepsy care for 108/472 (22.9%) patients. This means that for 271/472 (57.4%) patients, the ongoing care was not with a team from the hospital treating the acute admission, and communication about the episode and ensuring that ongoing reviews had been arranged would have been of paramount importance.

The case reviewers considered that patients were more likely to have appropriate follow-up if they had adequate neurology input (108/134; 80.6%); this compared with 22/49 (44.9%) patients who had inadequate neurology input.

Table 7.6 Who was responsible for the patient's ongoing epilepsy care

	Number of patients	%
Secondary care team at the admitting hospital	132	28.0
Secondary care team at another hospital	109	23.1
GP	108	22.9
GP/secondary care team at the admitting hospital	51	10.8
GP/secondary care team at another hospital	34	7.2
Secondary care/secondary care at another hospital	18	3.8
Other	20	4.2
Subtotal	472	
Unknown	38	
Total	510	

Clinician questionnaire data

Table 7.7 shows that patients were much less likely to have follow-up arranged prior to discharge from hospital if their ongoing epilepsy care was led solely by their GP (18/93; 19.4%) compared to when their ongoing care included secondary care teams, 36/47 (76.6%). While this may not be surprising, it does demonstrate the importance of the GP discharge letter to ensure that appropriate management/follow-up occurs in the community.

Table 7.7 Follow-up and who was managing the ongoing care

Who was managing the patient's ongoing epilepsy care	Follow-up appointment was arranged			Subtotal	Unknown	Total
	Yes	No	%			
Secondary care at the admitting hospital	94	30	75.8	124	8	132
Secondary care at another hospital	61	42	59.2	103	6	109
GP	18	75	19.4	93	15	108
GP/secondary care at the admitting hospital	36	11	76.6	47	4	51
GP/secondary care at another hospital	22	8	73.3	30	4	34

Clinician questionnaire data

Discharge letter

The diagnosis was mentioned in the discharge letter of 491/538 (91.3%) patients and the medication in 442/538 (82.2%) but explicit guidance on follow-up was only present in 288/538 (53.6%) of the letters and safety advice was only included in a small minority (111/538; 20.6%) (Table 7.8).

Table 7.8 Information contained in the discharge letter

	Number of patients	%
Diagnosis	491	91.3
Medication	442	82.2
Explicit guidance on follow-up	288	53.5
Cause/provocation	224	41.6
Safety advice	111	20.6
Driving advice	61	11.3
Risk assessment	33	6.1
Other	64	11.9

Clinician questionnaire data

Answers may be multiple; n=538

This meant case reviewers decided that the discharge letter could only be classified as good for 66/212 (31.1%) patients, and it was classified as poor for 42/212 (19.8%) (Table 7.9).

Table 7.9 Quality of the discharge summary

	Number of patients	%
Good	66	31.1
Adequate	104	49.1
Poor	42	19.8
Total	212	

Case reviewer data

Investigations

Follow-up was arranged for 135/219 (61.6%) patients and not known for 40, with follow-up investigations only organised for 34/223 (15.2%) patients (Table 7.10).

Table 7.10 Follow-up investigations were arranged

	Number of patients	%
Yes	34	15.2
No	189	84.8
Subtotal	223	
Unknown	36	
Total	259	

Case reviewer data

Of these 34 patients, 18 had been discussed with a neurologist. The case reviewers believed that follow-up was adequate for 160/221 (72.4%) patients which meant that 61/221 (27.6%) had suboptimal follow-up (Table 7.11).

Table 7.11 Follow-up investigations were adequate

	Number of patients	%
Yes	160	72.4
No	61	27.6
Subtotal	221	
Unknown	38	
Total	259	

Case reviewer data

Similar to the lack of follow-up, 54/225 (24.0%) patients were not referred where appropriate to services such as social services or drug and alcohol clinics (Table 7.12).

Table 7.12 Patient was referred to all the appropriate services

	Number of patients	%
Yes	171	76.0
No	54	24.0
Subtotal	225	
Unknown	34	
Total	259	

Case reviewer data

Re-attendance

There were 227/538 (42.2%) patients who re-attended the ED in the six-months following their discharge (it was unknown for 50) and in 169/227 (74.4%) cases this was due to another seizure. The frequency of re-attendance for epilepsy is shown in Figure 7.4 with 97/166 (58.4%) patients attending more than once and 24/166 (14.5%) patients having five or more attendances during the six months. This may in part have been due to the patients finding it difficult to control their epilepsy but it underscores the importance of good communication and follow-up.

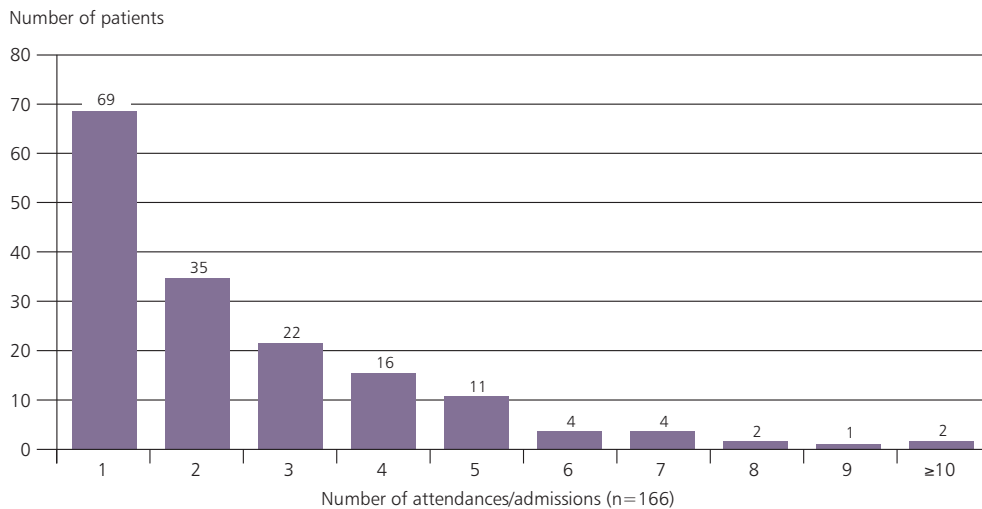


Figure 7.4 Frequency of re-attendance for epilepsy
Clinician questionnaire data

Overall quality of care

The grading system below was used by the case reviewers to grade the overall care each patient received:

- Good practice: A standard that you would accept from yourself, your trainees and your institution
- Room for improvement: Aspects of clinical care that could have been better
- Room for improvement: Aspects of organisational care that could have been better
- Room for improvement: Aspects of both clinical and organisational care that could have been better
- Less than satisfactory: Several aspects of clinical and/or organisational care that were well below the standard that you would accept from yourself, your trainees and your institution
- Insufficient data: Insufficient information submitted to NCEPOD to assess the quality of care

The case reviewers considered that the overall quality of care was good for 111/261 (42.5%) of patients whose cases were reviewed (Figure 8.1). Where there was room for improvement, of note is the finding issues with clinical care alone (108/261; 41.4%) or in combination with organisational issues (25/261; 9.6%) were the main reason for this, while that organisational issues on their own accounted for 12/261 (5%) patients who received suboptimal care. It was often difficult to determine what was poor clinical care and what was poor organisation of the clinical care.

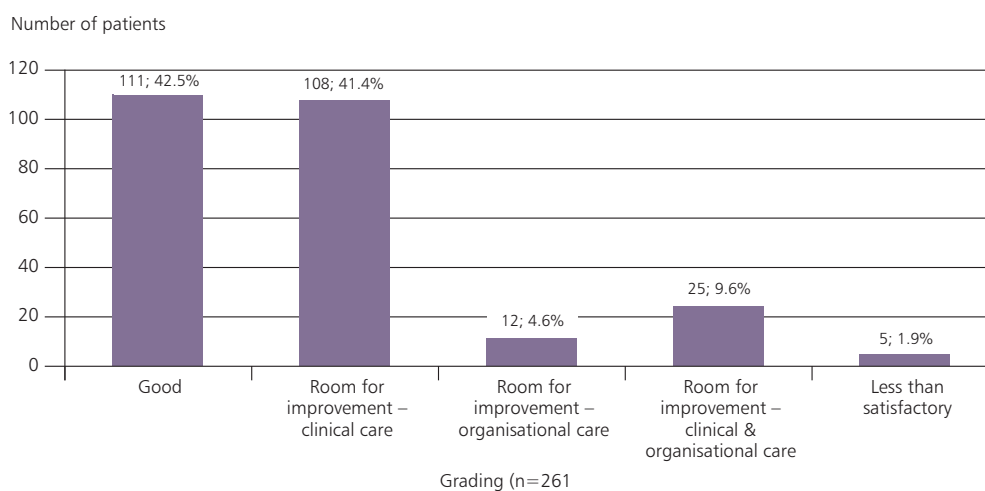


Figure 8.1 Overall quality of care

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Glossary

Term	Abbreviation	Definition
Anti-seizure medication	ASM	These are the most commonly used treatment for epilepsy. They help control seizures in around 7 out of 10 of people. They work by changing the levels of chemicals in the brain.
Aspiration pneumonia		This occurs when food or liquid is breathed into the airways or lungs, instead of being swallowed.
Electroencephalogram	EEG	This is a test that measures electrical activity in the brain using small, metal discs (electrodes) attached to the scalp.
Epilepsy		This is a common condition that affects the brain and causes frequent seizures. Seizures are bursts of electrical activity in the brain that temporarily affect how it works. They can cause a wide range of symptoms. Epilepsy can start at any age, but usually starts either in childhood or in people over 60.
Epilepsy specialist nurse	ESN	Specialist nurses play a key role in supporting continuity of care between settings for people with epilepsy.
Sudden unexpected death in epilepsy https://sudep.org/sudden-unexpected-death-epilepsy-sudep	SUDEP	This is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. SUDEP deaths are often unwitnessed with many of the deaths occurring overnight. There may be obvious signs a seizure has happened, though this isn't always the case. The cause of SUDEP is not yet known. Researchers are investigating a range of possibilities such as the effect of seizures on breathing and the heart. SUDEP occurs in approximately 1 per 1000 people with epilepsy (1 in 4,500 children) each year.
Tonic-clonic seizure		At the start of the seizure the person becomes unconscious, their body goes stiff, and they may fall backwards. They jerk and shake as their muscles relax and tighten rhythmically. After the seizure they may be tired and confused. Patients may develop status epilepticus, which is when seizures last too long or are repeated. This is defined as a seizure which lasts five minutes or more, or one tonic-clonic seizure follows another without the patient regaining consciousness.
Valproate medicines		An anti-seizure medication.

Useful links

 <p>SUDEP Action  <i>Making every epilepsy death count</i></p>	<p>www.sudep.org/i-want-information</p>
	<p>www.epilepsy.org.uk/</p>
	<p>www.epilepsysociety.org.uk/</p>
	<p>www.nhs.uk/conditions/epilepsy/</p>
	<p>www.nice.org.uk/guidance/ng217</p>
	<p>www.theabn.org/</p>
	<p>www.nash-audit.com</p>
	<p>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1084397/assessing-fitness-to-drive-may-2022.pdf Page 18</p>

Key findings

CHAPTER 2

1. The mean age of the study sample was 46.6 years (male 46.3, female 46.9)
2. There were 354/610 (58.0%) men and 256/610 (42.0%) women in the sample
3. Epilepsy had been previously diagnosed in 528/599 (88.1%) patients
4. 238/485 (49.1%) patients had presented to hospital (for any reason, not just seizure) within the previous six-months
5. 472/601 (78.5%) patients had existing comorbidities
6. 104/601 (17.3%) patients had a learning disability
7. 69/601 (11.5%) patients had reported alcohol addiction
8. 232/236 (98.3%) patients diagnosed with epilepsy had a current prescription for anti-seizure medication
9. 47/180 (20.7%) patients presenting to hospital with a seizure did not have clear documentation of their ASM in their hospital records
10. 44/184 (23.9%) patients were not taking their medication as prescribed
11. 23/76 (30.3%) patients who were prescribed sodium valproate were female, and 10 were under the age of 50 years and seven under the age of 40

CHAPTER 3

12. 511/595 (85.9%) patients came to hospital by ambulance with a further 55/595 (9.2%) patients who self-referred
13. 143/455 (31.4%) patients received pre-hospital anti-seizure medication
14. The case reviewers rated the pre-hospital care as good or adequate for 154/158 (97.5%) patients

CHAPTER 4

15. 183/229 (79.9%) patients had had a tonic-clonic seizure and 19/229 (8.3%) had status epilepticus
16. A relatively small number of patients were having an active seizure on arrival to the ED (39/264; 14.8%)
17. Just under half of the patients had a further seizure in hospital (116/259; 44.8%)

18. 101/158 (63.9%) hospitals had a neurology department on-site
19. It was reported from only 119/158 (75.3%) hospitals that the facility to perform an ASM blood screen on-site was available
20. Electroencephalogram (EEG) was available in 93/158 (58.9%) hospitals
21. EEG was mainly available (75/93; 80.6%) during normal working hours Monday to Friday. It was very rare for hospitals to offer extended hours for EEG (7/93; 7.5%)
22. 133/264 (50.4%) patients had a CT scan of head
23. An anti-seizure medication screen was documented for 26/264 (9.8%) patients
24. The case reviewers thought that these investigations were appropriate for 194/252 (77.0%) patients but for 58/252 (23.0%) they reported that other investigations should have been performed
25. 533/610 (87.4%) patients were admitted to hospital for further investigation/treatment/observation
26. 382/529 (72.2%) patients were admitted to an acute admissions ward
27. 53/529 (10.0%) were admitted directly to a high dependency setting
28. 15/503 (3.0%) had an EEG
29. 210/503 (41.7%) patients had a seizure chart for their inpatient stay
30. The case reviewers believed the use of a seizure chart would have benefited a further 25/243 (10.3%) patients as 11/25 of these patients were documented as having further seizures in hospital

CHAPTER 5

31. 96/158 (60.8%) hospitals reported that consultant neurologists were based on-site
32. 43/158 (27.2%) hospitals reported that there were visiting consultant neurologists with dedicated sessions
33. 47/94 (50.0%) hospitals that had neurologists on-site had six or more consultant neurologists, while 47/94 (50.0%) had five or fewer

KEY FINDINGS

34. A smaller number (26/94; 27.7%) of hospitals reported that they had three or fewer consultant neurologists on-site
 35. Of the 96 hospitals from which it was reported that a consultant neurologist was on-site, 59/96 (61.5%) had one or more neurologists with a specialist interest in epilepsy
 36. Telephone advice only, was available in 37/158 (23.4%) hospitals during normal working hours and in 62/158 (39.2%) out of hours
 37. 73/158 (46.2%) hospitals reported they had ESNs on-site and ESNs were not available on-site in 55/158 (34.8%)
 38. 34/73 (46.6%) hospitals with on-site ESNs with one or fewer whole time equivalent (WTE) posts and 55/73 (75.3%) hospitals had two or fewer WTE posts
 39. Only 175/503 (34.8%;) patients were reviewed by a neurologist during their admission and a further 109/503 (21.7%) had their epilepsy management discussed with a neurologist, leaving 219/503 (43.5%) patients with no neurology input
 40. Furthermore, only 36/494 (7.3%) patients were reviewed by an ESN during their admission
 41. For patients diagnosed with epilepsy and admitted to hospital, 133/315 (42.2%) did not have their admission discussed with the secondary care team managing their epilepsy
 42. For 61/217 (28.1%) patients the neurology input received was reported to be inadequate 124/220 (56.4%) patients had changes made to the type or dose of ASM. The case reviewers stated that the changes/lack of changes were inappropriate for 37/209 (17.7%) cases reviewed
 43. 126/137 (92.0%) patients with adequate neurology input had appropriate ASM changes compared to 24/46 (52.2%) who did not receive adequate neurology input
- CHAPTER 6**
44. It was reported from 135/142 (95.1%) hospitals that patients were provided with specific information or education regarding their epilepsy
45. In 67/135 (49.6%) hospitals patient information or education was provided before discharge from hospital, with 52/135 (38.5%) not providing specific information or education regarding epilepsy until the patient's first clinic appointment, which may be many weeks after discharge
 46. 110/135 (81.5%) hospitals reported information on SUDEP was given to patients
 47. Only 40/317 (12.6%) patients had any evidence in their notes that the risk of SUDEP had been considered and only 38/347 (11.0%) cases had evidence that it had been discussed
 48. 65/135 (48.1%) hospitals reported that a written self-management plan was included in patient information
 49. Clinicians were unable to comment on whether SUDEP had been considered and/or discussed in many cases (271/588 and 241/588 respectively). It may be that in patients who have recurrent seizures it is not appropriate to discuss SUDEP during every admission
- CHAPTER 7**
50. First seizure clinics were available on-site in 100/154 (64.9%) hospitals
 51. Only 23/85 (27.1%) hospitals reported that the waiting time for first seizure clinics was within the recommended guidance of two-weeks following a first seizure, with 31/85 (36.5%) saying it was two to four weeks and 31/85 (36.5%) more than four weeks
 52. Most hospitals (133/149; 89.3%) reported that it was routine protocol to refer patients who attend the ED with a suspected first seizure to the first seizure clinic
 53. 129/152 (84.9%) hospitals reported that outpatient clinics for patients with epilepsy were available. If outpatient clinics were not run at the hospital patients with epilepsy were referred to another hospital within the same or a neighbouring trust/health board
 54. only 45/143 (31.5%) hospitals reported that there was a policy for the ED to contact the epilepsy team when patients with known epilepsy were seen
 55. 79/152 (52.0%) hospitals reported that a rapid advice service was available

KEY FINDINGS

56. The patient's GP was solely responsible for ongoing epilepsy care for 108/472 (22.9%) patients. This means that for 271/472 (57.4%) patients, the ongoing care was not with a team from the hospital treating the acute admission, and communication about the episode and ensuring that ongoing reviews had been arranged would have been of paramount importance
57. The case reviewers believed that follow-up was adequate for 160/221 (72.4%) patients which meant that 61/221 (27.6%) had suboptimal follow-up
58. The case reviewers considered that patients were more likely to have appropriate follow-up if they had adequate neurology input (108/134; 80.6%); this compared with 22/49 (44.9%) patients who had inadequate neurology input
59. 54/225 (24.0%) patients were not referred where appropriate to services such as social services or drug and alcohol clinics
60. The diagnosis was mentioned in the discharge letter of 491/538 (91.3%) patients and the medication in 442/538 (82.2%) but explicit guidance on follow-up was only present in 288/538 (53.6%) of the letters and safety advice was only included in a small minority (111/538; 20.6%)
61. Case reviewers decided that the discharge letter could only be classified as good for 66/212 (31.1%) patients, and it was classified as poor for 42/212 (19.8%)
62. Patients were much less likely to have follow-up arranged prior to discharge from hospital if their ongoing epilepsy care was led solely by their GP (18/93; 19.4%) compared to when their ongoing care included secondary care teams, 36/47 (76.6%)
63. 227/538 (42.2%) patients re-attended the ED in the six-months following their discharge (it was unknown for 50) and in 169/227 (74.4%) cases this was due to another seizure

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