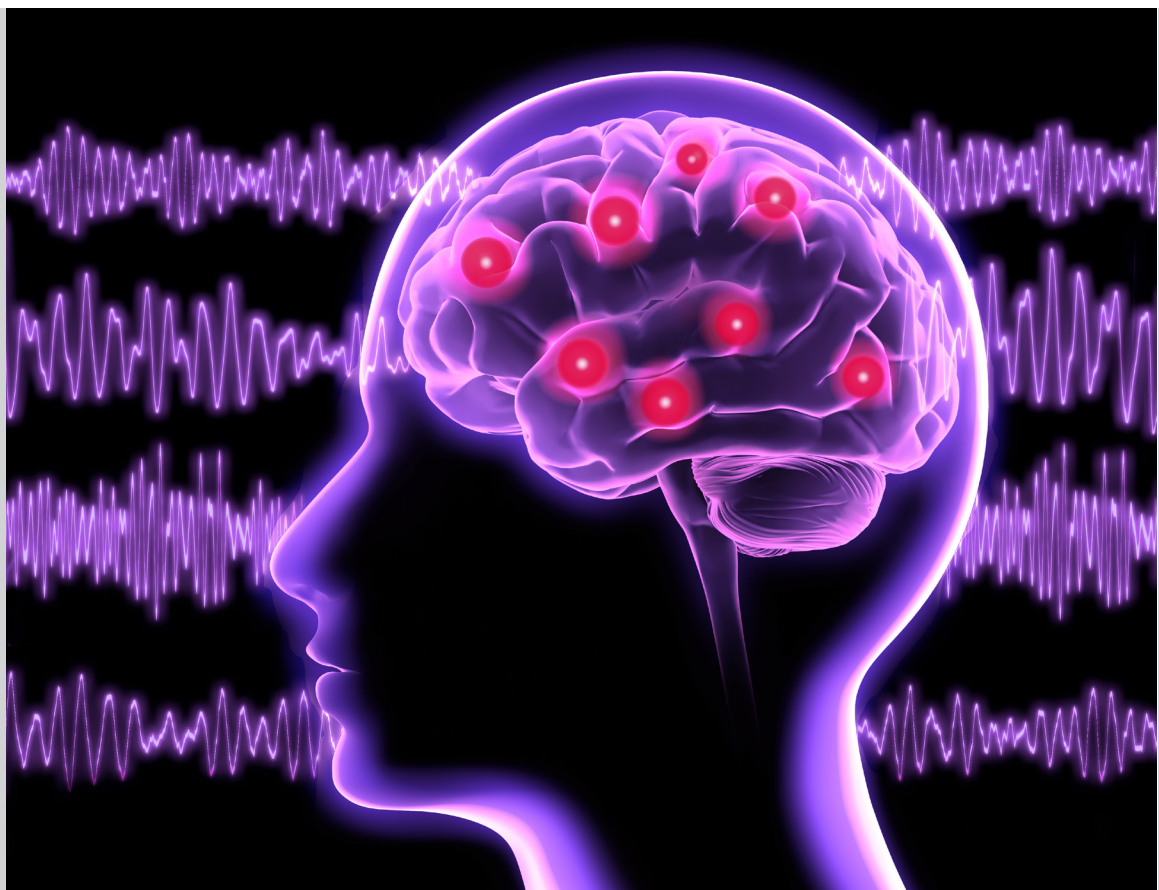


Disordered Activity?

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

SUMMARY



Disordered Activity?

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

A report published by the National Confidential Enquiry into Patient Outcome and Death (2022)

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The Medical and Surgical Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn

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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 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.

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: <i>Prescribers of valproate medicines, medication safety officers, neurologists, obstetricians</i></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: <i>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</i></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: <i>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</i></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: <i>Clinical directors in neurology, medical directors</i></p>
8	<p>Commence and maintain a seizure chart for all patients admitted to hospital following a seizure.</p> <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>
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: <i>Clinical directors in neurology, medical directors</i></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 <i>(USEFUL LINKS)</i> <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 <i>(USEFUL LINKS)</i> <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 (<i>USEFUL LINKS</i>) <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>

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.

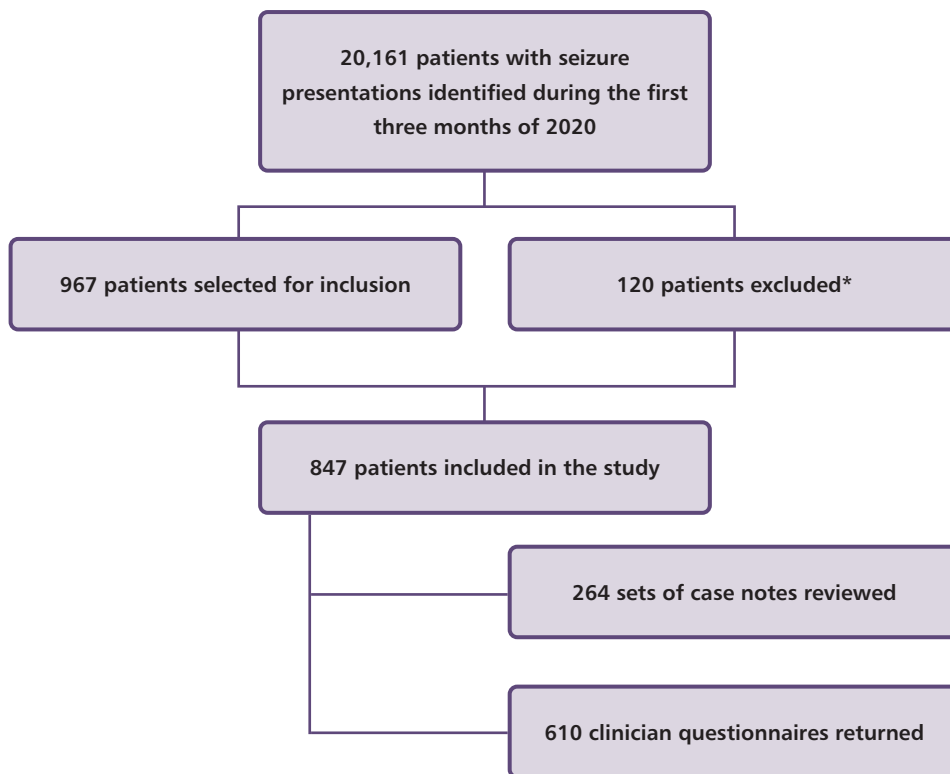


Figure 1.1 Data returned
**patients did not meet the study inclusion criteria*

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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