

Epilepsy: Hospital attendance

A. Introduction

What is this study about:

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

Inclusions

All patients aged 18 or over who presented to hospital following a seizure between 1st January 2020 - 31st December 2020 and had a pre-existing epilepsy disorder or were subsequently diagnosed with epilepsy. Patients discharged from the emergency department and those admitted to hospital are included.

Who should complete the questionnaire?

The questionnaire should be completed by the consultant responsible for the patient at the time of admission (or in the emergency department if the patient was not admitted).

Please do not include any patient identifiers in the free text boxes.

Questions or help:

Further information regarding this study can be found here: <https://www.ncepod.org.uk/epilepsy.html>
If you have any queries about this study or this questionnaire, please contact: epilepsy@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation:

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

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Recommendations from NCEPOD reports have had an impact on many areas of healthcare including:

Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) – following publication of the 2005 NCEPOD 'An Acute Problem' report.

Appointment of a National Clinical Director for Trauma Care – following publication of 'Trauma: Who Cares?' 2007.

Development of NICE Clinical Guidelines for Acute Kidney Injury, published 2013 – 'Adding Insult to Injury' 2009.

Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 – 'On the right trach?' 2014.

Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 – 'Time to Get Control' 2015.

Development of the British Thoracic Society's Quality Standards for NIV, published 2018 – 'Inspiring Change' 2017.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

5f. If answered "No" to [5a] then:

What was the grade of the person who made the diagnosis?

- Consultant
- Staff grade/Associate specialist
- Trainee with CCT
- Senior specialist trainee (ST3+ or equivalent)
- Junior specialist trainee (ST1& ST2 or CT equivalent)
- Specialist nurse (Nurse consultant, Nurse practitioner, Clinical nurse specialist)
- Senior staff nurse, enrolled nurse
- Unknown

If not listed above, please specify here...

5g. If answered "No" to [5a] then:

What was the specialty of the person who made the diagnosis?

- Neurology
- Geriatric medicine
- General medicine
- Unknown
- Learning disability medicine

If not listed above, please specify here...

All patients

6a. Was the seizure precipitated by alcohol excess or withdrawal?

- Yes - excess
- Yes - withdrawal
- No
- Unknown

6b. Was the seizure precipitated by illicit substances?

- Yes
- No
- Unknown

6c. Was the seizure precipitated by a head injury?

- Yes
- No
- Unknown

7a. Did the patient have any comorbidities?

- Yes
- No
- Unknown

7b. If answered "Yes" to [7a] then:

Please indicate which comorbidities the patient had

- Brain tumour
- History of traumatic brain injury
- Stroke
- Childhood onset neurodevelopment disorders (e.g. autism)
- Diabetes
- Alcohol addiction
- Recreation drug habits
- Intellectual disability/Learning disability
- Mental Illness (e.g. schizophrenia/psychosis)
- Mood disorders (e.g. depression/anxiety)
- Personality disorder
- NEAD (Non-Epileptic Attack Disorder)
- Acquired cognitive impairment

Please specify any additional options here...

**7c. If answered "Childhood onset neurodevelopment disorders (e.g. autism)" to [7b] then:
Please provide details**

childhood onset neurodevelopment disorders

**7d. If answered "Mental Illness (e.g. schizophrenia/psychosis)", "Mood disorders (e.g. depression/anxiety)" or "Personality disorder" to [7b] then:
Please provide details**

mental health condition

8a. What was the patients employment status?

- Employed Self employed Unemployed Unknown

If not listed above, please specify here...

**8b. If answered "Employed" or "Self employed" to [8a] then:
What was the patient's job at the time of presentation?**

9a. Where did the patient live?

- Private Residence Care Home Homeless Unknown

If not listed above, please specify here...

**9b. If answered "Private Residence" to [9a] then:
Did the patient live alone?**

- Yes No Unknown

Patients diagnosed with epilepsy prior to this presentation

**10a. If answered "Yes" to [5a] then:
When was the patient diagnosed with epilepsy?**

- < 1 month 1-6 months 7-12 months
 > 1 year < 2 years > 2 years < 5 years >5 years < 10 years
 > 10 years < 20 years > 20 years Unknown

If not listed above, please specify here...

**10b. If answered "Yes" to [5a] then:
What was the date of the patient's last seizure prior to this one?**

Unknown

**10c. If answered "Yes" to [5a] then:
How frequently had the patient experienced seizures in the 12 months prior to this seizure?**

- Never Daily Weekly Monthly
 Yearly Unknown

If not listed above, please specify here...

**10d. If answered "Yes" to [5a] then:
Had the frequency of seizures increased in the last 6 months?**

- Yes No Unknown

10e.If answered "Yes" to [5a] then:

Did any of the seizures fulfil the definition of status epilepticus?

- Yes No Unknown

10f. If answered "Yes" to [5a] then:

Did the patient present to hospital in the 6 months prior to this presentation?

- Yes No Unknown

10g.If answered "Yes" to [5a] and "Yes" to [10f] then:

How many times did the patient present to the Emergency Department in the 6 months prior to this hospital presentation?

- 1 2-5 6-10 >10
 Unknown

If not listed above, please specify here...

Anti-epileptic drugs

11a.Had the patient been previously prescribed anti-epileptic drugs (AEDs)?

- Yes No Unknown

11b.If answered "Yes" to [11a] then:

What AEDs had been prescribed? (please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Acetazolamide/Diamox | <input type="checkbox"/> Brivaracetam/Briviact |
| <input type="checkbox"/> Carbamazepine/Tegretol/ Tegretol Retard | <input type="checkbox"/> Clobazam/Frisium |
| <input type="checkbox"/> Clonazepam/Rivotril/ Rivatril | <input type="checkbox"/> Diazepam/Valium |
| <input type="checkbox"/> Eslicarbazepine Acetate/ Zebinix | <input type="checkbox"/> Ethosuximide/Emeside/ Zarontin |
| <input type="checkbox"/> Gabapentin/Neurontin | <input type="checkbox"/> Lacosamide/Vimpat |
| <input type="checkbox"/> Lamotrigine/Lamictal | <input type="checkbox"/> Levetiracetam/Keppra |
| <input type="checkbox"/> Oxazepam/Serax | <input type="checkbox"/> Oxcarbazepine/Trileptal |
| <input type="checkbox"/> Perampanel/Fycompa | <input type="checkbox"/> Phenobarbital |
| <input type="checkbox"/> Phenytoin/Epanutin | <input type="checkbox"/> Pregabalin/Lyrica |
| <input type="checkbox"/> Primidone/Mysoline | <input type="checkbox"/> Retigabine/Trobalt |
| <input type="checkbox"/> Rufinamide/Inovelon | <input type="checkbox"/> Stiripentol/Diacomit |
| <input type="checkbox"/> Sulthiame/Ospolot | <input type="checkbox"/> Tiagabine/Gabatril |
| <input type="checkbox"/> Topiramate/Topamax | <input type="checkbox"/> Valproic acid/Epilim/Epilim Chrono/Orlept |
| <input type="checkbox"/> Vigabatrin/Sabril | <input type="checkbox"/> Zonisamide/Zonegran |

Please specify any additional options here...

11c.If answered "Yes" to [11a] then:

Was the patient taking the medication as prescribed / recommended by the specialist?

- Yes No Unknown

11d.If answered "Yes" to [11a] and "No" to [11c] then:

Were reasons for the non-compliance documented?

- Yes No Unknown

11e.If answered "Yes" to [11a] and "No" to [11c] and "Yes" to [11d] then:

What were they?

11f. If answered "Yes" to [11a] then:

Was there evidence that the patient had missed a dose?

- Yes No Unknown

11g.If answered "Yes" to [11a] then:

Was there evidence that the patient had diarrhoea and/or vomiting and/or constipation (i.e. that may have prevented drug absorption)?

- Yes No Unknown

11h.If answered "Yes" to [11a] then:

Was the patient on vitamin supplementation?

- Yes No Unknown

11i. If answered "Yes" to [11a] then:

Was a plasma antiepileptic drug screen undertaken during this hospital presentation?

- Yes No Unknown

12. Was the patient taking any of the following at the time of their presentation to ED/admission?

- Opiate analgesic Antibiotics Anti-depressants None

Please specify any additional options here...

Patients diagnosed with epilepsy prior to this presentation

13a.If answered "Yes" to [5a] then:

What was the date of the patient's last epilepsy review prior to this hospital presentation?

- Unknown

13b.If answered "Yes" to [5a] then:

Who was the review with?

- | | |
|--|--|
| <input type="radio"/> GP | <input type="radio"/> Specialist epilepsy nurse |
| <input type="radio"/> Neurologist | <input type="radio"/> Neurosurgeon |
| <input type="radio"/> Intellectual disability psychiatrist | <input type="radio"/> Drug and alcohol liaison service |
| <input type="radio"/> Community nurse | <input type="radio"/> Care of the elderly |
| <input type="radio"/> Unknown | |

If not listed above, please specify here...

13c. If answered "Yes" to [5a] then:

What was the outcome of the review?

- Change in medication type Change in medication dose No medication changes
 Unknown

Please specify any additional options here...

C. Emergency department

1. Mode of presentation?

- Self referral GP referral Ambulance Unknown

If not listed above, please specify here...

**2a. If answered "GP referral" or "Ambulance" to [1] then:
Was the patient given any drugs prehospital?**

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
What drugs were given pre-hospital?**

- Midazolam Diazepam Lorazepam

Please specify any additional options here...

**2c. If answered "Yes" to [2a] then:
Were the doses of pre-hospital drugs appropriate?**

- Yes No Unknown

**2d. If answered "Yes" to [2a] and "No" to [2c] then:
Please expand on your answer (pre-hosp drugs)**

**2e. If answered "GP referral" or "Ambulance" to [1] then:
What procedures were performed prehospital?**

- CPR ECG Intubation Cannula insertion
 None Unknown

Please specify any additional options here...

3a. Date of arrival to Emergency Department

- Unknown

3b. Time of arrival to the Emergency Department

- Unknown

4a. Date of first assessment by medical staff

- Unknown

4b. Time of first assessment by medical staff

- Unknown

5a. Was the patient having an active seizure on arrival to the Emergency Department?

- Yes No Unknown

**5b. If answered "Yes" to [5a] then:
Did the seizure respond to first line therapy?**

- Yes No Unknown

6a. Was the patient conscious on arrival to the Emergency Department?

- Yes No Unknown

6b. What was the patient's GCS on arrival to the Emergency Department?

- 3 4 5 6
 7 8 9 10
 11 12 13 14
 15 Not recorded

6c. What was the patient's AVPU on arrival to the Emergency Department?

- Alert Voice Pain Unresponsive
 Not recorded

What were the patients first documented vital signs

7a. Heart rate

bpm Unknown
Value should be no more than 999

7b. Temperature

°C Unknown
Value should be between 20 and 50

7c. Systolic BP

 Unknown
Value should be no more than 999

7d. Diastolic BP

 Unknown
Value should be no more than 999

7e. Respiratory rate

 Unknown
Value should be no more than 999

7f. Oxygen saturation

% Unknown
Value should be no more than 100

8. Which of the following investigations were undertaken?

- | | | |
|---|---|---------------------------------------|
| <input type="checkbox"/> Blood glucose test | <input type="checkbox"/> Urea and electrolytes | <input type="checkbox"/> LFTs |
| <input type="checkbox"/> FBC | <input type="checkbox"/> Anticonvulsant serum level | <input type="checkbox"/> Drugs screen |
| <input type="checkbox"/> Alcohol screen | <input type="checkbox"/> CT head scan | <input type="checkbox"/> Calcium |
| <input type="checkbox"/> Magnesium | <input type="checkbox"/> Zinc | <input type="checkbox"/> ECG |
| <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

9a. Was the patient an undiagnosed/first seizure patient at the time of this presentation?

- Yes No Unknown

Undiagnosed/first seizure patients

9b. If answered "Yes" to [9a] then:

Does your hospital have a local guideline for the management of first seizure patients in the emergency department?

- Yes No Unknown

9c. If answered "Yes" to [9a] and "Yes" to [9b] then:

Was the local guideline followed?

- Yes No Unknown

9d. If answered "Yes" to [9a] then:

Was an eyewitness account of the seizure available?

- Yes No Unknown

9e. If answered "Yes" to [9a] and "Yes" to [9d] then:

Was video evidence of the seizure recorded?

- Yes No Unknown
-

Patients with known epilepsy

10. If answered "No" to [9a] then:

Did the patient have an agreed comprehensive written epilepsy care plan?

- Yes No Unknown
-

All patients

11. What was the outcome from the ED attendance?

- Discharged home Admitted to hospital
 Transferred to another hospital Died in ED
 Unknown

If not listed above, please specify here...

--

1a. Was the patient admitted to hospital?

- Yes No

**1b. If answered "Yes" to [1a] then:
Reason for admission**

**1c. If answered "Yes" to [1a] then:
What type of ward was the patient first admitted?**

- Acute admissions unit General ward Neurology ward
 HDU (level 2) ITU (level 3) Unknown

If not listed above, please specify here...

**2. If answered "Yes" to [1a] then:
Was the patient discussed with a member of the team managing their epilepsy?**

- Yes
 No
 Not applicable - patient's epilepsy managed by GP
 Not applicable - patient hadn't been diagnosed with epilepsy
 Unknown

If not listed above, please specify here...

**3a. If answered "Yes" to [1a] then:
Was the patient discussed with a neurologist during this admission?**

- Yes No Unknown

**3b. If answered "Yes" to [1a] then:
Was the patient reviewed by a neurologist during this admission?**

- Yes No Unknown

**4. If answered "Yes" to [1a] then:
Was the patient reviewed by a specialist epilepsy nurse during this admission?**

- Yes No Unknown

**5. If answered "Yes" to [1a] then:
What investigations, monitoring and assessments did the patient receive as an inpatient?**

- | | |
|---|--|
| <input type="checkbox"/> ECG | <input type="checkbox"/> EEG |
| <input type="checkbox"/> CT | <input type="checkbox"/> MRI |
| <input type="checkbox"/> Seizure chart | <input type="checkbox"/> Anticonvulsant levels |
| <input type="checkbox"/> Mental health assessment | <input type="checkbox"/> Suicide risk |
| <input type="checkbox"/> SUDEP risk | <input type="checkbox"/> Social services |
| <input type="checkbox"/> Specialist assessment/referral | <input type="checkbox"/> Unknown |

Please specify any additional options here...

6a. If answered "Yes" to [1a] then:

Was the patient admitted to critical care (level 2/3 care) at any point during this admission?

Yes

No

Unknown

6b. If answered "Yes" to [1a] and "Yes" to [6a] then:

What support did the patient receive in critical care?

Respiratory

Cardiovascular

Renal Replacement Therapy

Cardiac output monitoring

Anaesthesia to control seizure

Unknown

Please specify any additional options here...

Please complete this section for all patients (those discharged from ED as well as those admitted to hospital)

1a. What was the date of discharge or death?

Unknown

1b. What was the discharge location

- Usual residence Other hospital NA died in hospital Unknown

If not listed above, please specify here...

1c. If answered "Usual residence" to [1b] then:
Was this

- Private residence Care home Unknown

If not listed above, please specify here...

1d. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Was the patient discharged with medication?

- Yes No Unknown

1e. If answered "Yes" to [1d] then:
What medications were prescribed?

- | | |
|--|--|
| <input type="checkbox"/> Acetazolamide/Diamox | <input type="checkbox"/> Brivaracetam/Briviact |
| <input type="checkbox"/> Carbamazepine/Tegretol/ Tegretol Retard | <input type="checkbox"/> Clobazam/Frisium |
| <input type="checkbox"/> Clonazepam/Rivotril/ Rivatril | <input type="checkbox"/> Diazepam/Valium |
| <input type="checkbox"/> Eslicarbazepine Acetate/ Zebinix | <input type="checkbox"/> Ethosuximide/Emeside/ Zarontin |
| <input type="checkbox"/> Gabapentin/Neurontin | <input type="checkbox"/> Lacosamide/Vimpat |
| <input type="checkbox"/> Lamotrigine/Lamictal | <input type="checkbox"/> Levetiracetam/Keppra |
| <input type="checkbox"/> Oxazepam/Serax | <input type="checkbox"/> Oxcarbazepine/Trileptal |
| <input type="checkbox"/> Perampanel/Fycompa | <input type="checkbox"/> Phenobarbital |
| <input type="checkbox"/> Phenytoin/Epanutin | <input type="checkbox"/> Pregabalin/Lyrica |
| <input type="checkbox"/> Primidone/Mysoline | <input type="checkbox"/> Retigabine/Trobalt |
| <input type="checkbox"/> Rufinamide/Inovelon | <input type="checkbox"/> Stiripentol/Diacomit |
| <input type="checkbox"/> Sulthiame/Ospolot | <input type="checkbox"/> Tiagabine/Gabatril |
| <input type="checkbox"/> Topiramate/Topamax | <input type="checkbox"/> Valproic acid/Epilim/Epilim Chrono/Orlept |
| <input type="checkbox"/> Vigabatrin/Sabril | <input type="checkbox"/> Zonisamide/Zonegran |

Please specify any additional options here...

1f. If answered "Yes" to [1d] then:
Was the medication dispensed by the hospital pharmacy?

- Yes No Unknown

1g. If answered "Yes" to [1d] then:
Was the patient given advice regarding pregnancy and associated risks with medication?

- Yes No Not applicable Unknown

1h. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
On discharge, was the patient given written advice regarding driving?

- Yes No Unknown

1i. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
On discharge, was the patient given written advice on emergency contacts?

- Yes No Unknown

**1j. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Did the patient have a named family member/friend/carer with them to aid information sharing and discharge?**

- Yes No Unknown

**2a. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Was a discharge letter sent to the GP?**

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
What did it include?**

- | | |
|---|--|
| <input type="checkbox"/> Explicit guidance on follow up | <input type="checkbox"/> Diagnosis |
| <input type="checkbox"/> Cause/provocation | <input type="checkbox"/> Medication |
| <input type="checkbox"/> Driving advice | <input type="checkbox"/> Safety advice |
| <input type="checkbox"/> Risk assessment | |

Please specify any additional options here...

**2c. If answered "Explicit guidance on follow up" to [2b] then:
What guidance on follow up was given?**

**2d. If answered "Yes" to [2a] then:
Was a copy of the discharge letter given to the patient?**

- Yes No Unknown

**3a. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Was a follow up appointment arranged for the patient?**

- Yes No Unknown

**3b. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Were follow up investigations arranged?**

- Yes No Unknown

**3c. If answered "Yes" to [3b] then:
What follow up investigations were arranged?**

- | | | |
|---|---|--------------------------------------|
| <input type="checkbox"/> CT scan | <input type="checkbox"/> MRI scan | <input type="checkbox"/> EEG |
| <input type="checkbox"/> Anti-convulsant blood test | <input type="checkbox"/> Electrolyte test | <input type="checkbox"/> LFT changes |
| <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

**3d. If answered "Yes" to [3a] then:
Did the patient attend the follow up appointment?**

- Yes No Unknown

**3e. If answered "No" to [3d] then:
Was the failure to attend the appointment followed up?**

- Yes No Unknown

**4a. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Did the patient have/know a First Point Of Contact?**

- Yes No Unknown

**4b. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Was the patient put in contact with any support charities?**

- Yes No Not applicable Unknown

**4c. If answered "Yes" to [4b] then:
Which charities?**

- | | |
|---|---|
| <input type="checkbox"/> Epilepsy action . | <input type="checkbox"/> SUDEP action |
| <input type="checkbox"/> Epilepsy Society | <input type="checkbox"/> Epilepsy Wales |
| <input type="checkbox"/> Epilepsy action Northern Ireland | <input type="checkbox"/> Unknown |

Please specify any additional options here...

**5a. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Was SUDEP (Sudden Unexpected Death in Epilepsy) risk considered?**

- Yes No Unknown

**5b. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Is there evidence that SUDEP (Sudden Unexpected Death in Epilepsy) risk and other risks
had been discussed with the patient?**

- Yes No Unknown

**5c. If answered "Yes" or "No" to [5b] then:
Please expand on your answer (risks)**

**6. If answered "Care home" to [1c] then:
Did the care home have a care plan for the patient?**

- Yes No Unknown

Readmissions

**7a. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:
Did the patient re-attend the Emergency Department in the 6 months post discharge?**

- Yes No Unknown

**7b. If answered "Yes" to [7a] then:
How many attendances?**

Unknown

**7c. If answered "Yes" to [7a] then:
Were the reasons for reattendance/readmission related to the patients seizures/epilepsy?**

- Yes No Unknown

**7d. If answered "Yes" to [7a] and "Yes" or "No" to [7c] then:
Please expand on this (readmission)**

Ongoing care

8a. Who was the patient's ongoing epilepsy care managed by?

- | | |
|--|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Secondary care at this hospital |
| <input type="checkbox"/> Secondary care other hospital | |
| <input type="checkbox"/> Not applicable, first seizure/undiagnosed patient | |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

8b. If answered "NA died in hospital" to [1b] then:

Was the Team/Person responsible for the patients ongoing care informed of their death?

- Yes No Unknown

8c. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:

Was the patient referred to any specialist services?

- Yes No Unknown

8d. If answered "Yes" to [8c] then:

Which services?

- Psychiatric services Social services Drugs and alcohol services

Please specify any additional options here...

9. If answered "Usual residence", "Other hospital" or "Unknown" to [1b] then:

Outcome 6 months post discharge

- Alive Died Unknown

If not listed above, please specify here...

10. If you would like to add anything else regarding this patients presentation or ongoing care please do so here

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE By doing so you have contributed to the dataset that will form the report and recommendations due for release in the autumn of 2022