

Epilepsy Study Organisational Questionnaire

A. Introduction

Please complete one organisational questionnaire for each hospital in your Trust/Health Board that treats patients that have had an epileptic seizure

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.

Who should complete this questionnaire:

This questionnaire has been designed to collect data on the organisational structures surrounding the care provided to patients that have a seizure and ongoing epilepsy management.

It should be completed by or with input from, clinicians(s) that provide care to this group of patients. This is likely to include, but not limited to, Neurology, Specialist Epilepsy clinicians, Emergency medicine, Acute medicine and Intensive care medicine.

Questions or help:

Further information regarding the study can be found here: <https://www.ncepod.org.uk/epilepsy.html>

If you have any queries about the study or this questionnaire, please contact: epilepsy@ncepod.org.uk or telephone 020 7251 9060.

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

B. The Hospital

1. How many inpatient beds does this hospital have?

beds

2a. Does this hospital have an Emergency Department?

Yes

No

2b. If answered "Yes" to [2a] then: Is the Emergency Department open 24/7?

Yes

No

3. Does the hospital have a Neurology Department on-site?

Yes

No

4. Does the hospital have a Neurosurgery Department on-site?

Yes

No

1a. What is the availability of consultant neurologists on-site?

- Consultant neurologists based on-site
 Visiting consultant neurologists with dedicated sessions
 Visiting consultant neurologists on adhoc basis (no dedicated sessions)
 Not available on-site

If not listed above, please specify here...

**1b. If answered "Consultant neurologists based on-site" to [1a] then:
How many consultant neurologists are employed at this hospital?**

Unknown

**1c. If answered "Consultant neurologists based on-site" to [1a] then:
How many whole time equivalent consultant neurologists are employed at this hospital?**
 WTE

Unknown

**1d. If answered "Visiting consultant neurologists with dedicated sessions" to [1a] then:
How many neurology consultant sessions on-site at this hospital per week?**
 sessions

Unknown

1e. What are the arrangements for urgent in-hours neurology cover?

- Neurology consultant/registrar on-site 24/7 On-call neurology consultant/registrar
 Telephone advice only No arrangement

If not listed above, please specify here...

1f. What are the arrangements for urgent out-of-hours neurology cover?

- Neurology consultant/registrar on-site 24/7 On-call neurology consultant/registrar
 Telephone advice only No arrangement

If not listed above, please specify here...

**2a. If answered "Consultant neurologists based on-site" to [1a] then:
Does the hospital have consultant neurologists with a specialism in epilepsy on-site?**

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
How many consultant neurologists with specialism in epilepsy are employed at this hospital?**

Unknown

3a. What is the availability of epilepsy specialist nurses on-site?

- Epilepsy specialist nurses based on-site
 Visiting epilepsy specialist nurses with dedicated sessions
 Visiting epilepsy specialist nurses on adhoc basis (no dedicated sessions)
 Not available on-site

If not listed above, please specify here...

**3b. If answered "Epilepsy specialist nurses based on-site" to [3a] then:
How many epilepsy specialist nurses are employed at this hospital?**

Unknown

**3c. If answered "Epilepsy specialist nurses based on-site" to [3a] then:
How many whole time equivalent epilepsy specialist nurses are employed at this hospital?**

 WTE

Unknown

**3d. If answered "Visiting epilepsy specialist nurses with dedicated sessions" to [3a] then:
How many sessions on-site at this hospital per week?**

 sessions

Unknown

4. Which of the following does the hospital have on-site?

please tick all that apply

Liaison psychiatry nurse

Intellectual disability psychiatrist

Neuroradiologist

Neurophysiologist

Neurosurgeon

Please specify any additional options here...

D. Services

1a. Does this hospital operate a rapid advice service for patients with epilepsy to self refer to?

- Yes No Unknown

**1b. If answered "Yes" to [1a] then:
Which services are available?**

please tick all that apply

- Walk-in clinic Telephone support Email response service
 Text message service

Please specify any additional options here...

**1c. If answered "Walk-in clinic" to [1b] then:
Hours available (walk in clinic)**

- Monday - Friday (normal working hours) Monday - Friday (extended hours)
 7 days a week (normal working hours) 7 days a week (extended hours)

If not listed above, please specify here...

**1d. If answered "Telephone support" to [1b] then:
Hours available (telephone support)**

- Monday - Friday (normal working hours) Monday - Friday (extended hours)
 7 days a week (normal working hours) 7 days a week (extended hours)

If not listed above, please specify here...

**1e. If answered "Email response service" to [1b] then:
Hours available (email response service)**

- Monday - Friday (normal working hours) Monday - Friday (extended hours)
 7 days a week (normal working hours) 7 days a week (extended hours)

If not listed above, please specify here...

**1f. If answered "Text message service" to [1b] then:
Hours available (text message service)**

- Monday - Friday (normal working hours) Monday - Friday (extended hours)
 7 days a week (normal working hours) 7 days a week (extended hours)

If not listed above, please specify here...

**1g. If answered "Walk-in clinic" to [1b] then:
Hours available (other)**

- Monday - Friday (normal working hours) Monday - Friday (extended hours)
 7 days a week (normal working hours) 7 days a week (extended hours)

If not listed above, please specify here...

2a. Which of the following are available on-site (investigations)?

please tick all that apply

- | | |
|----------------------------------------------------------|---------------------------------------------------------------|
| <input type="checkbox"/> Electroencephalogram (EEG) | <input type="checkbox"/> MRI |
| <input type="checkbox"/> CT | <input type="checkbox"/> 3-lead electrocardiogram (ECG) |
| <input type="checkbox"/> 12-lead electrocardiogram (ECG) | <input type="checkbox"/> Anti-seizure medication blood screen |
| <input type="checkbox"/> Vagal Nerve Stimulation (VNS) | <input type="checkbox"/> Inpatient video telemetry |
| <input type="checkbox"/> Outpatient/ambulatory video EEG | |

Please specify any additional options here...

**2b. If answered "Electroencephalogram (EEG)" to [2a] then:
What hours is EEG available?**

- | | |
|--------------------------------------------------------------|--------------------------------------------------------|
| <input type="radio"/> Monday - Friday (normal working hours) | <input type="radio"/> Monday - Friday (extended hours) |
| <input type="radio"/> 7 days a week (normal working hours) | <input type="radio"/> 7 days a week (extended hours) |

If not listed above, please specify here...

**2c. If answered "MRI" to [2a] then:
What hours is MRI available?**

- | | |
|--------------------------------------------------------------|--------------------------------------------------------|
| <input type="radio"/> Monday - Friday (normal working hours) | <input type="radio"/> Monday - Friday (extended hours) |
| <input type="radio"/> 7 days a week (normal working hours) | <input type="radio"/> 7 days a week (extended hours) |

If not listed above, please specify here...

3a. Does this hospital have an on-site drug and alcohol liaison service?

- | | | |
|---------------------------|--------------------------|-------------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Unknown |
|---------------------------|--------------------------|-------------------------------|

**3b. If answered "Yes" to [3a] then:
What hours is the service available?**

- | | |
|--------------------------------------------------------------|--------------------------------------------------------|
| <input type="radio"/> Monday - Friday (normal working hours) | <input type="radio"/> Monday - Friday (extended hours) |
| <input type="radio"/> 7 days a week (normal working hours) | <input type="radio"/> 7 days a week (extended hours) |

If not listed above, please specify here...

**3c. If answered "No" to [3a] then:
Where are patients with known epilepsy/suspected first seizure referred to if their episode was precipitated by drugs and/or alcohol?**

- Alcohol and drug liaison service within Trust/Health Board
- Alcohol and drug liaison service within neighbouring Trust/Health Board
- Community based alcohol and drug liaison service
- Not routinely referred

If not listed above, please specify here...

Please indicate how each of the following services are accessed

4a. Neurophysiology

- | | |
|-------------------------------------------------------------|--------------------------------------------------------------|
| <input type="radio"/> On-site | <input type="radio"/> Off-site but within Trust/Health Board |
| <input type="radio"/> Off-site different Trust/Health Board | <input type="radio"/> No access to service |

If not listed above, please specify here...

4b. Neuropsychiatry

- On-site
- Off-site different Trust/Health Board
- Off-site but within Trust/Health Board
- No access to service

If not listed above, please specify here...

**4c. If answered "On-site", "Off-site but within Trust/Health Board" or "Off-site different Trust/Health Board" to [4b] then:
What is the current average waiting time (neuropsychiatry)?**

 Weeks Unknown

4d. Neuropsychology

- On-site
- Off-site different Trust/Health Board
- Off-site but within Trust/Health Board
- No access to service

If not listed above, please specify here...

**4e. If answered "On-site", "Off-site but within Trust/Health Board" or "Off-site different Trust/Health Board" to [4d] then:
What is the current average waiting time (neuropsychology)?**

 Weeks Unknown

E. Protocols and policies

1a. Does this hospital have a protocol for patients who have suffered a head injury?

- Yes No Unknown

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

Does this include guidance for patients with epilepsy?

- Yes No Unknown
-

2a. Does this hospital have a guideline for the emergency management of suspected first seizure patients?

- Yes No Unknown

2b. If a first seizure patient presents to the Emergency Department, is it hospital policy to contact the on-call neurologist?

- Yes No Unknown
-

3. Does the hospital have a protocol for treating convulsive status epilepticus?

- Yes No Unknown
-

4. Is it hospital policy for the Emergency Department to contact the epilepsy team when existing epilepsy patients are admitted?

- Yes No Unknown

1a. Does this hospital run first seizure clinics?

These may be virtual clinics

- Yes No Unknown

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

What is the current waiting time for an appointment to the first seizure clinic following a first seizure?

Weeks Unknown

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

Is it routine protocol to refer patients that attend the Emergency Department with a suspected first seizure to the first seizure clinic?

- Yes No Unknown

1d. If answered "No" to [1a] then:

Where are first seizure patients usually referred?

- First seizure clinic elsewhere within the Trust/Health Board
 First seizure clinic at another Trust/Health Board
 Community based first seizure clinic

If not listed above, please specify here...

1e. If answered "No" to [1a] then:

Is it routine protocol to refer patients that attend the Emergency Department with a suspected first seizure to a first seizure clinic?

- Yes No Unknown

2. Following a diagnosis of epilepsy what services are patients routinely referred to/provided with?

please tick all that apply

- Telephone follow-up Primary care follow-up Epilepsy clinic

Please specify any additional options here...

3a. Does this hospital run outpatient clinics for epilepsy patients?

- Yes No Unknown

3b. Are patients with epilepsy offered routine outpatient appointments?

- Yes No Unknown

3c. If answered "No" to [3a] then:

Where are epilepsy patients referred for their ongoing management?

- Epilepsy clinic elsewhere within the Trust/Health Board
 Epilepsy clinic at another Trust/Health Board
 Community based epilepsy clinic

If not listed above, please specify here...

4. Which of the following are provided for patients with epilepsy who attend this hospital?

please tick all that apply

- A named lead consultant
- A nominated key worker
- A named Epilepsy specialist nurse
- An agreed personal care plan/long-term care plan
- Escalation of treatment policy
- Shared care agreement with specialist centre
- Arrangements to provide feedback
- Emergency care plan

Please specify any additional options here...

5a. Is medication adherence routinely monitored for people with established epilepsy?

- Yes - all patients
- Yes - all patients experiencing an increase in seizures
- No

If not listed above, please specify here...

5b. If answered "Yes - all patients" or "Yes - all patients experiencing an increase in seizures" to [5a] then:

How is this done?

- Anti-seizure medication blood levels

If not listed above, please specify here...

6a. Are patients provided with specific information/education regarding epilepsy?

- Yes
- No
- Unknown

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

What does it include?

please tick all that apply

- Need to assess risk factors
- Complications of epilepsy
- Written self-management plan
- SUDEP (Sudden Unexpected Death in Epilepsy)
- Management of epilepsy related risks (eg. alcohol, drugs, medication non-adherence)
- Impact on life
- Driving
- First point of contact

Please specify any additional options here...

6c. If answered "Yes" to [6a] then:
When is patient education/information provided?

- Before discharge from hospital
- First clinic appointment
- Before discharge and at first clinic appointment

If not listed above, please specify here...

Additional Information

7. Please use this space should you wish to provide further details on any of the answers you have provided (please include the question number)

8. Please use this space to provide any details of how the COVID pandemic has affected the current service provision for epilepsy patients.

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