



Royal College of Paediatrics and Child Health
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The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).

Section A to be answered by parent/carer

Please give us your views of the health service that your child has been attending for their epilepsy care. This should only take you five minutes to complete.

1. What is your child's year of birth? ____ ____ ____ ____
2. Is your child Female? Male?
3. **On average** over the past 6 months, how often has your child had epileptic seizures? (*tick one option only*)

Less than 1 per month

1 or more a month but not every week

1 or more a week but not every day

1 or more per day

Blank spells only

Other.....

4. Has your child been diagnosed with any of the following conditions? (*Tick all that apply*)

Learning difficulties/developmental delay

Cerebral palsy

Autism or autistic spectrum disorder

Attention Deficit Hyperactivity Disorder (ADHD)

None of the above

Other

5. When was your child's first assessment by a paediatrician for their epilepsy? (tick one option only)

- Less than 1 year ago
- Between 1 and 2 years ago
- 2 years ago or more

6. What was the age of your child at their first assessment (years and months)

7. What clinics or services has your child attended for their epilepsy and how often have they attended in the last 12 months? (Tick all that apply)

Type of service	Number of visits in last 12 months
Hospital general paediatric clinic <input type="checkbox"/>
Community paediatric clinic <input type="checkbox"/>
Teenage epilepsy clinic <input type="checkbox"/>
Specific epilepsy clinic <input type="checkbox"/>
Paediatric neurology clinic <input type="checkbox"/>
A&E <input type="checkbox"/>
GP <input type="checkbox"/>
Other..... <input type="checkbox"/>

8. What drug(s) is your child currently prescribed for their epilepsy? (Tick all that apply)

- Sodium Valproate (Epilim)
- Carbamazepine (Tegretol)
- Lamotrigine (Lamictal)
- Levetiracetam (Keppra)
- Other

If other, state drug(s).....

17. What would you like more information on? (Tick all that apply)

- Guidance on what I can or can't do
- Contact with other young people with epilepsy
- What to tell other people about my epilepsy
- Possible side effects of medication
- Support groups
- Cause of my epilepsy
- Reasons for changing medication
- Reasons for, and results of, tests
- I do not require any more information

18. Overall, are you satisfied with the care you receive from the epilepsy service?

- Yes
- No
- Unsure

Now please put your completed questionnaire in the envelope provided, seal it and return it to the clinic staff. If you prefer, you can post the envelope directly to the Epilepsy12 Audit team. It is Freepost so does not require a stamp.

Thank you very much for taking the time to complete this questionnaire



Thanks to Chetna, Lisa, Catherine, Ravi, Sohail, Jane, Katie and Philip from the RCPCH Youth Advisory Panel, for their feedback when making this questionnaire

- Staff **tell me** if my appointment is going to be late
- The waiting area **does not have activities** for my age
- Overall, the length of time spent with staff at the clinic is **about right**
- Staff are **not good at working together** with others e.g. GP School or nursery, when looking after me
- Overall, staff are friendly and polite
 - In the ward as inpatient
 - When going for tests e.g. EEG or MRI (if applicable)

If you would like to explain an answer or tell us about other concerns, please do so in this space:

9. In the last 12 months, have you found it easy to contact the health service looking after your child's epilepsy?

- Yes
- No
- Unsure

10. In the last 12 months have you been satisfied with the care your child receives for their epilepsy from the service?

- Yes
- No
- Unsure

11. Over the last 12 months, what are the **three** best things about the epilepsy service?

1.
2.
3.

12. Over the last 12 months, what **three** things about the epilepsy service could be improved?

1.
2.
3.

Section B to be answered by child or young person, or if this is not possible, by parent/carer.

If possible please now give this questionnaire **to your child** to complete. If your child does not or cannot answer the questionnaire themselves, **please answer the rest of the questionnaire yourself.**

13. Who is completing this section (questions 13-16)?

I am the child/young person

I am the parent or carer

14. If you are a parent or carer completing this section, why is this? (Tick all that apply)

My child is too young

The questions are too difficult

My child is too unwell

Other:

15. This questionnaire is being completed...

before the appointment today

after the appointment today

before and after the appointment today

16. Please let us know how strongly you agree or disagree with the statements given in this section. We are interested in your **overall impressions over the last year.**

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
• Overall, I received enough information about epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff listened to what I had to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The information I was given was hard to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff did not take time to get to know me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff did not explain things in a way I could follow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff took my thoughts into account when making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I felt the staff respected my need for privacy during clinic visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Overall, staff seemed to know what they were doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• At times I felt I was not allowed to ask questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• It is easy to contact someone in the epilepsy team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff make sure it is easy to attend the clinic e.g. when making appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I am not seen by the service often enough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>