

Epilepsy12 Information Sheet

What is the survey about?

The Epilepsy12 survey is taking place across the United Kingdom and is organised by the Royal College of Paediatrics and Child Health (RCPCH). As well as measuring how good health care is for children and young people with epilepsy, we want to know what parents, carers and patients think about the local care they have received. We hope to use this information to help improve the quality of your services.

Why have I received this letter?

Your child has been identified by your health service as having care for possible seizures in the past and prescribed medication for this.

Do I have to take part?

No. It is up to you to decide whether to take part. You are free to opt out at any time without giving a reason. This will not affect the care and treatment that you or your child receives.

How do I take part?

We would like to find out about your experience of the care received for your child's seizures in the last year. If your child is able to share their views then, with your permission, they are also invited to take part. Part A is for you and Part B for your child.

To take part, complete either the **web-based** or **paper** questionnaire. Both contain the same questions:

- a) Either use the **website** at: <https://epilepsy12.rcpch.ac.uk/patient/login/>

To login you will be asked for the reference number and passcode shown in the letter that came with this document. Follow the instructions on the website to complete the questionnaire.

- b) Or complete the enclosed **paper** questionnaire.

Please post it back in the enclosed pre-paid envelope.

Will taking part in this study be kept confidential?

Yes. Your responses will be sent to the RCPCH project team. They will be able to tell which area in the UK each questionnaire has come from but not who has sent it. Your local health service will

see all the different responses from those completing the questionnaires. However, they will not be able to tell who has provided which response.

What are the benefits of taking part?

Your experience will be used to help to improve these services. We want to learn how you felt about your care. If you liked what happened, it will encourage health services to do that more. If you don't like what happened, we can learn from you and try to make improvements.

What are the possible disadvantages of taking part?

If you find it difficult and upsetting to tell us about your experiences you can stop at any time.

What will happen to the information I provide?

Each service will receive a summary of all responses for their service. At the end of the project, the information from all UK health services will be put into a report which will be made available on our website (www.rcpch.ac.uk/epilepsy12) in 2012.

Where can I find out more?

More information about this national audit can be found on the project website www.rcpch.ac.uk/epilepsy12 or by contacting the project team (details below). Contact Epilepsy Action (0808 800 5050) or Epilepsy Scotland (0808 800 2200) if you need any further information about seizures or epilepsy.

For further information, please contact the Epilepsy12 project team:

Contacts: Zaki Kramer, Project Support or Rita Ranmal, Project Manager
Address: Clinical Standards, Royal College of Paediatrics and Child Health,
5-11 Theobalds Road, London. WC1X 8SH
Telephone: 020 7092 6167
Email: epilepsy12@rcpch.ac.uk.
Website: www.rcpch.ac.uk/epilepsy12

PART A: Parent/Carer Questionnaire: [Audit Unit Name:.....]

In this questionnaire, we ask you about your views of the health service that you and your child have been to for the care of seizures. Please answer the questions below by writing on the dotted lines or by putting a tick in the appropriate box(es). Please return it in the envelope as soon as you can.

A1. What is your child's year of birth? _ _ _ _

A2. Is your child: Male? Female?

A3. On average over the past year, how often does your child have seizures?

- Less than one per month
- 1 or more a month but less than 1 a week
- 1 or more a week but less than one a day
- 1 or more per day
- Unsure

Other, please specify.....

A4. Has your child ever been diagnosed with any of the following conditions:

- Learning difficulties/developmental delay
- Cerebral palsy
- Autism or autistic spectrum disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- None of the above

Other, please specify.....

A5. What type of clinic does your child attend for their seizures or epilepsy? Tick all that apply

- General paediatric clinic
- Community paediatric clinic
- Teenage epilepsy clinic
- Specific epilepsy clinic
- Paediatric Neurology clinic
- Don't know

Other, please specify.....

A6a. Have you found it easy to contact the health service looking after your child's seizures or epilepsy?

- Yes
- No
- Unsure

A6b. Over the past year, including planned appointments, how many times have you been in contact with this health service (either by visiting the clinic, by telephone or by email)?

- None
- 1 to 5 times
- 6 to 10 times
- More than 10 times

A7. Which areas, if any, would you like more information on? Tick all that apply

- Guidance on what my child can or can't do
- The cause of my child's epilepsy or seizures
- Possible side effects of medication
- Reasons for changing medication
- Reasons for, and results of, tests
- Support groups
- Contacting other families living with epilepsy
- What to tell other people about my child's seizures or epilepsy

Other, please specify.....

A8. What is the levels of education that you (not your child) have completed? Tick any that apply

- Secondary school
- College/apprenticeship
- Undergraduate university
- Postgraduate university

Other, please specify.....

For questions 9-25, please indicate how strongly you agree or disagree with the statements given. We are interested in your **overall** impressions so please base your answers on your experiences over all of the last year.

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
A9. Overall, I received enough information on seizures or epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A10. 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"/>
A11. 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"/>
A12. Staff did not take time to get to know me and my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A13. 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"/>
A14. Staff took my views into account in making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A15. I felt the staff respected our need for privacy during clinic visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A16. 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"/>
A17. 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"/>
A18. 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"/>
A19. 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"/>
A20. My child is 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"/>
A21. When attending the clinic staff tell me if the appointment is going to be delayed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A22. The waiting area does not have activities for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A23. Overall, the length of time spent with staff at the clinic is just about right	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A24. Staff are not good at working together with others e.g. the G.P., when looking after my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A25. Staff are good at working together with school or nursery?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A26. Overall, staff are friendly and polite?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Outpatient Clinic staff</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>In-patient ward staff</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>When going for tests staff e.g. EEG or MRI (if applicable)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A27. What are the 3 best things about the epilepsy service?	A28. What are the 3 worst things about the epilepsy service?					
1	1					
2	2					
3	3					

A29. Overall, are you satisfied with the care your child receives from the epilepsy service?

Yes No Unsure

PART B: This section is for the *Child or Young Person*

In this questionnaire, we ask you about your views of the epilepsy service that you go to. Please answer the questions below by putting a tick in the appropriate box(es).

For questions 1-17, please indicate how strongly you agree or disagree with the statements given. We are interested in your **overall** impressions so please base your answers on your experiences over all of the last year.

Strongly Agree Agree Unsure Disagree Strongly Disagree Not Applicable

B1. Overall, I received enough information on seizures or epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B2. 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"/>
B3. 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"/>
B4. 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"/>
B5. 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"/>
B6. Staff took my views into account in making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B7. 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"/>
B8. 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"/>
B9. 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"/>
B10. 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"/>
B11. 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"/>
B12. 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"/>
B13. When attending the clinic staff tell me if my appointment is delayed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B14. The waiting area does not have activities for my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B15. Overall, the length of time spent with staff at the clinic is just about right	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B16. Staff are not good at working together with others e.g. the GP, when looking after me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B17. Staff are good at working with school or nursery?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B18. Overall, staff are friendly and polite ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Outpatient Clinic staff</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Ward as inpatient staff</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>When going for tests staff e.g. EEG or MRI (if applicable)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B19. Which areas, if any, would you like more information on? *Tick all that apply*

Guidance on what I can or can't do <input type="checkbox"/>	Support groups <input type="checkbox"/>
Contact with other young people with epilepsy <input type="checkbox"/>	Cause of my epilepsy <input type="checkbox"/>
What to tell other people about my epilepsy <input type="checkbox"/>	Reasons for changing medication <input type="checkbox"/>
Possible side effects of medication <input type="checkbox"/>	Reasons for, and results of, tests <input type="checkbox"/>

B20. What are the 3 best things about the epilepsy service?	B21. What are the 3 worst things about the epilepsy service?
1.	1.
2.	2.
3.	3.

B22. Overall, are you satisfied with the care you receive from the epilepsy service?.

Yes No Unsure

Your comments:

If you would like to let us know about anything else to do with your experiences of your health services please use this box.

Parent

Child/Young Person

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