

Child 6-9 years version

Service Evaluation Questionnaire to evaluate services in the UK that manage Congenital Adrenal Hyperplasia in children and young people

You can access the survey at forms.office.com/r/p8ApDjx4vJ or via scanning:



Alternatively, please complete your answers on this paper copy below (**please check you are completing the correct version according to age – this version is for children between 6 and 9 years old**)

We would appreciate your opinion about the service provided to you at this hospital to manage the condition Congenital Adrenal Hyperplasia (CAH). This information will be shared with the staff at this hospital to help them improve the services provided locally. The information will also be collected from different hospitals across the country to help find out how to improve services nationally and whether there are any areas that need to be researched. The collection of anonymous results of the survey will be shared at conferences and in journal articles as well as with national research funding bodies to try to improve national services for people with CAH.

If you have any specific comments about the service you have received recently, you can enter those at the end of the survey. Your answers will remain anonymous, and will not negatively affect the care you are provided with.

1. Are you the:

- ☐ Patient the most recent appointment was for (please ensure you complete the age specific questionnaire)
- ☐ Primary carer for the patient
- ☐ Carer for the patient, but not the primary carer on a regular basis
- ☐ Other (please explain) _____

2. How old are you?

- ☐ Less than 12 months (if so, only the carer should complete the adult version of this questionnaire)
- ☐ 1- 5 years (if so, only the carer should complete the adult version of this questionnaire)
- ☐ 6-9 years (this is the correct questionnaire - please continue)
- ☐ 10-14 years (please ensure you complete the questionnaire with 'Child 10-14 years version' at the top of the page)
- ☐ 15-19 years (please ensure you complete the questionnaire with 'Adolescent 15-19 years version' at the top of the page)
- ☐ 20 years or older (please ensure you complete the questionnaire with 'Adult Patient / Carer version' at the top of the page)

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3. Are you a:

- ☐ Boy
- ☐ Girl
- ☐ Other (please tell us) _____

4. What is the name of the hospital that you go to for your CAH?

5. Do you know what medicine you take for your CAH?

- ☐ Yes
- ☐ No
- ☐ Not sure

6. Do you know what you have to do with your medicine for CAH if you feel poorly?

- ☐ Yes
- ☐ No
- ☐ Not sure

7. Sometimes, one nurse or doctor will say one thing, and another will say something different. Has this ever happened to you about CAH?

- ☐ Yes
- ☐ No

8. Have other children you have spoken to with CAH ever said they've been told different things about CAH than you have been told?

- ☐ Yes
- ☐ No
- ☐ I have not spoken to any other children with CAH

9. What do you think about how often you have to come to the hospital?

- ☐ I have to come to the hospital too much
- ☐ I come to the hospital the right number of times
- ☐ I think I should come to the hospital more often

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10. Do you think the doctors and nurses at the hospital do a good job at helping you look after your CAH?

- ☐ Yes
- ☐ No
- ☐ Not sure

11. Do you have anything else you would like to tell us about CAH?

Thank you for completing this questionnaire. The results of this will be shared with the staff at this hospital to help them improve the services provided locally. The information will also be collected from different hospitals across the country to help find out how to improve services nationally and whether there are any areas that need to be researched. The collection of anonymous results of the survey will be shared with hospitals that manage CAH patients and national research funding bodies, but no one else.