

Adolescent 15-19 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 adolescents between 15 and 19 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 (please ensure you complete the questionnaire with 'Child 6-9 years version' at the top of the page)
- 10-14 years (please ensure you complete the questionnaire with 'Child 10-14 years version' at the top of the page)
- 15-19 years (this is the correct questionnaire - please continue)
- 20 years or older (please ensure you complete the questionnaire with 'Adult Patient / Carer version' at the top of the page)

Adolescent 15-19 years version

3. Do you describe yourself as:

- Male
- Female
- Prefer not to say
- Other (please specify) _____

4. What is your ethnic background?

- White (English, Welsh, Scottish, Northern Irish or British / Irish / Gypsy or Irish Traveller / Any other White background)
- Mixed or Multiple ethnic groups (White and Black Caribbean / White and Black African / White and Asian / Any other Mixed or Multiple ethnic background)
- Asian or Asian British (Indian / Pakistani / Bangladeshi / Chinese / Any other Asian background)
- Black, African, Caribbean or Black British (African / Caribbean / Any other Black, African or Caribbean background)
- Other ethnic group (Arab /Any other ethnic group)

5. What is the name of the hospital that organised your most recent appointment for CAH (if this was a phone or video appointment, please put the name of the hospital that the clinician was calling you from)

6. How long have you been treated at this hospital for CAH?

- This was the first appointment
- Less than 12 months but more than one appointment
- 1-2 years
- 3-5 years
- 6-10 years
- Over 10 years

7. In the last 12 months, how many times have you had a hospital appointment for your CAH (please include all appointments, even if they were by phone or video link)

- Once
- Twice
- Three times
- Four times
- More than four times

Adolescent 15-19 years version

8. At these appointments in the last 12 months, have you had the opportunity to discuss the following topics in relation to CAH:

	Yes, thoroughly	Yes, to some extent, but not enough	No, but I would have liked to	No, but I did not want to	Can't remember / not sure
Ideas and goals about management					
When to increase steroid doses when unwell					
Psychological effects					
Levels of physical activity					
General wellbeing					

9. During your last appointment for CAH, did you discuss and agree on a plan of how to manage the CAH until your next appointment?

- Yes
- No
- Can't remember / not sure

10. During your last appointment for CAH, were you offered a printed or electronic copy of your care plan?

- Yes
- No, but a copy of the clinic letter will be sent home
- No, and I would have liked one
- No, but I did not want one
- Can't remember / not sure

11. Do you feel confident managing your CAH?

- Yes, definitely
- Yes, to some extent
- No

Adolescent 15-19 years version

12. In some diseases like diabetes, patients can attend a formal education course to help them manage the disease. Have you attended anything like this for CAH?

- Yes
- No
- Can't remember / not sure
- Other:

13. If an educational course teaching about CAH was available, would you attend?

- Yes
- No
- Unsure

14. Sometimes, one health professional will say one thing, and another will say something quite different. In the last 12 months, has this happened to you in relation to CAH?

- Yes, often
- Yes, sometimes
- No
- Can't remember / not sure

15. Have other people with CAH ever made you think that the advice you have received is different from the advice that they have received?

- Yes, very different advice
- Yes, somewhat different advice
- No, they have been given the same advice
- I have not spoken to any other people with CAH

16. 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

Adolescent 15-19 years version

17. Do you think you know enough about the medications that you take for your CAH?

- Yes
- Yes, but I would like to know more
- No, I think I should know a lot more
- I don't take any medications for my CAH
- Don't know / not sure

18. Do you think that a doctor at a different hospital might treat your CAH differently?

- Yes
- No
- Not sure

19. Overall, are you satisfied with the service provided to manage your CAH?

- Completely satisfied
- Somewhat satisfied
- Neutral
- Somewhat dissatisfied
- Completely dissatisfied

20. Do you have any other comments about CAH that you would like to tell us?

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 at conferences and in journal articles as well as with national research funding bodies to try to improve national services for people with CAH.