

## Adult Patient / Carer 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](https://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 of the questionnaire according to age – this version is for any carer of someone with CAH, or patients 20 years or over)**

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 is the patient who attended the most recent appointment for CAH?**

- ☐ Less than 12 months
- ☐ 1- 5 years
- ☐ 6-9 years
- ☐ 10-14 years
- ☐ 15-19 years
- ☐ 20 years or older

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### 3. How old are you?

- ☐ Less than 20 years (please ensure you complete the questionnaire with the appropriate age stated at the top of the page)
- ☐ 20-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50 years or older

### 4. How would you describe the sex of the patient:

- ☐ Male
- ☐ Female
- ☐ Prefer not to say
- ☐ Other (please specify) \_\_\_\_\_

### 5. How would you describe the ethnic background of the patient:

- ☐ 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)

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

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### 7. 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

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8. In the last 12 months, how many times has your child had an appointment at this hospital for the care of CAH (please include all appointments, even if they were by phone or video link)

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

9. At these appointments in the last 12 months, have you had the opportunity to discuss the following topics in relation to CAH (Please tick):

	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					
How to increase steroid doses when unwell					
Psychological effects					
Levels of physical activity					
General wellbeing					
Fertility					
Heart disease					
Genital surgery					

10. During your last appointment for your child's 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

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

- ☐ Yes
- ☐ No, but I will get a copy of the clinic letter
- ☐ No, and I would have liked one
- ☐ No, but I did not want one

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12. Do you feel confident managing your child's CAH?

	Yes, very confident	Yes, somewhat confident	No, not confident
Day to day			
When they have another illness			
In an emergency			

13. 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: (please specify) \_\_\_\_\_

14. If a formal educational course teaching about CAH was available, would you attend?

- ☐ Yes
- ☐ No
- ☐ Unsure

15. 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

16. Have people you have spoken to from other families of children 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 families of children with CAH

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17. Has your child had the following things checked in the last 12 months in relation to their CAH (please tick):

	Yes	No	Unsure
Weight			
Height			
Blood pressure			
Examined without clothes to check on the progression of puberty			
X-ray to assess bone age			
A blood test at the hospital checking the 17OH Progesterone hormone			
A blood test at the hospital checking the Androstenedione hormone			
A blood test at the hospital checking Renin to assess the need for treatment with fludrocortisone			
A blood spot test at home (blood dripped onto a card) to check their hormones			
A urine test to check for hormones			

18. What do you think about how closely your child's CAH is monitored?

- ☐ We come to more appointments than is necessary
- ☐ We have the right number of appointments
- ☐ It is okay, but they could be reviewed more frequently
- ☐ They are not seen often enough
- ☐ Don't know / not sure

19. Do you think you know enough about the medications that your child is prescribed to manage their CAH?

- ☐ Yes
- ☐ Yes, but I would like to know more
- ☐ No, I think I should know a lot more
- ☐ My child doesn't take any medications for their CAH
- ☐ Don't know / not sure

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20. Do you think that a doctor at a different hospital might treat your child's CAH differently?

- ☐ Yes
- ☐ No
- ☐ Not sure

21. Overall, are you satisfied with the service provided to care for your child with CAH?

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

22. Do you have any other comments about the management of CAH that you would like to share with us?

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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.