

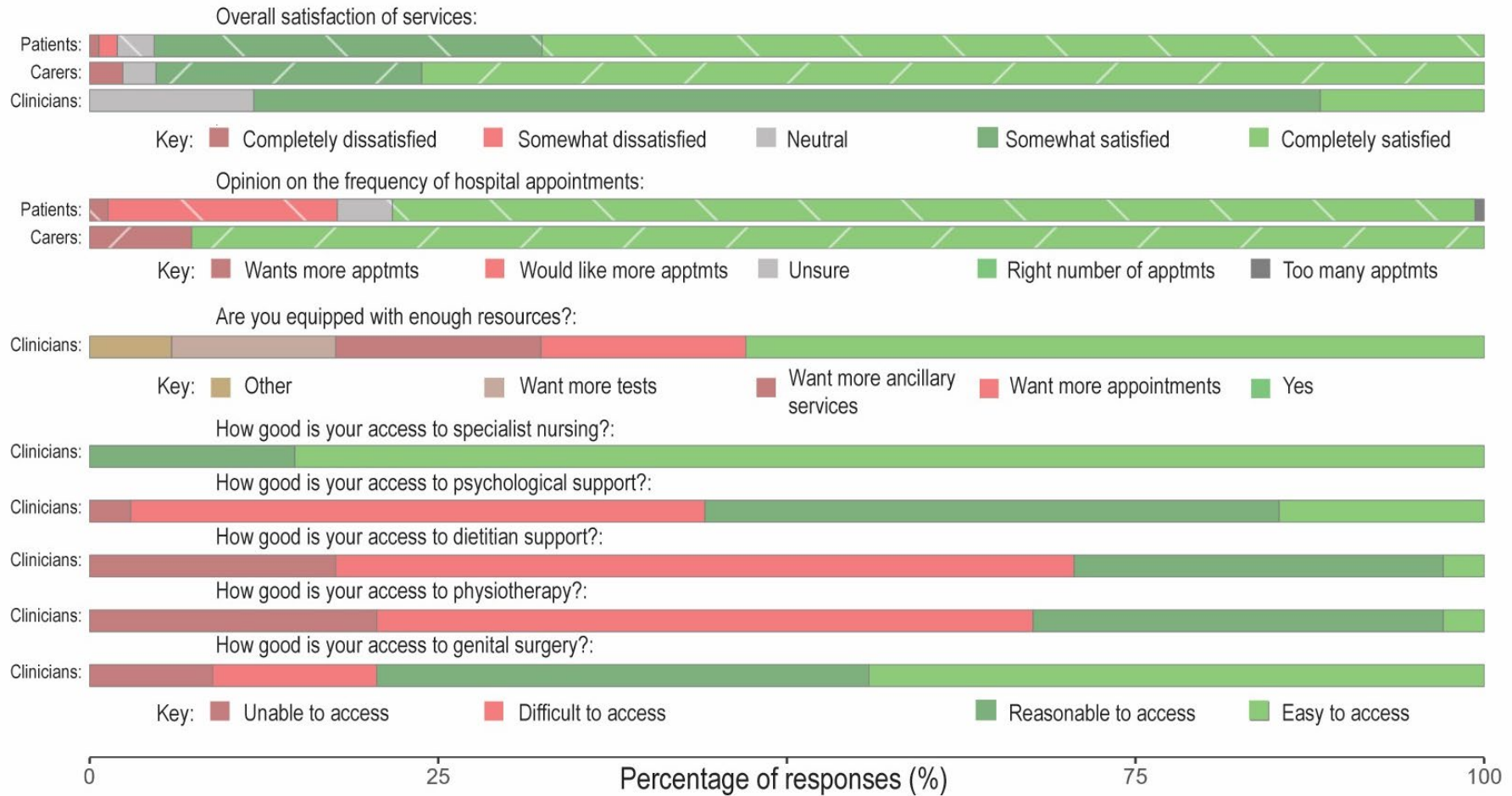
Supplementary material to accompany manuscript:

National service evaluation of the quality of care for children and young people with congenital adrenal hyperplasia in the United Kingdom: survey responses from patients and clinicians

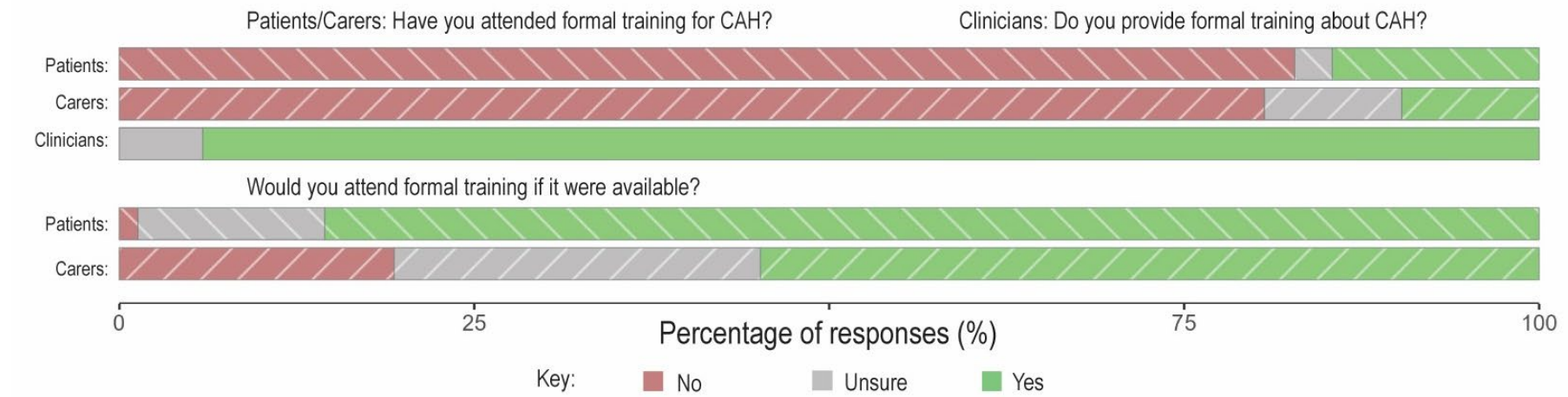
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Supplementary Figure 1

Satisfaction with services and frequency of hospital assessments, alongside clinician access to multidisciplinary resources



Supplementary Figure 2



Report of attendance at formal education, and desire to access a formal education course about CAH

Supplementary table 1

All statistical software packages used within *R: A language and environment for statistical computing*. Our thanks to all authors, who without these packages this work would have not been possible.

Name of software package	Citation
Base R	https://www.R-project.org/
dplyr	https://github.com/tidyverse/dplyr
ggplot2	https://ggplot2.tidyverse.org
ggpattern	https://coolbutuseless.github.io/package/ggpattern/
DescTools	https://cran.r-project.org/package=DescTools
summarytools	https://github.com/dcomtois/summarytools

Method of response weighting:

To account for the distribution of the number of responses per centre being unequal, a sensitivity analysis was conducted to weight responses in relation to the number of responses that would be expected for each hospital as a proportion of its catchment population. The trust catchment population was taken from the UK Office for Health Improvement & Disparities (<https://tinyurl.com/ar7saj5e>), and from the Scottish Health and Social Care Open Data website (<https://www.opendata.nhs.scot/dataset/population-estimates>). The underlying assumption was that data missing from hospitals that did not take part in the service evaluation, or did not receive any responses, was that this data was missing completely at random. The target of weighting was to prevent any hospitals with a disproportionately large number of responses from having an undue influence on any particular category of response.

Patient and carer response weighting

The weighting for each question response was calculated for each question, to account for a variable number of missing responses across different questions. The total catchment population surveyed was calculated as the sum of the catchment areas of all hospitals that featured in response to the question. The proportion of the catchment population of that hospital was multiplied by the inverse proportion of the responses from that hospital to create an individual weighting for responses pertaining to that hospital. Responses for the small number of patients or carers that did not enter a centre (1 and 2 respectively) were not included in weighted response percentages.

Example: If a hospital served 5% of the catchment population of all of the hospitals that had an answer to that particular question, and the total number of answers received pertaining to that hospital was 5% of the total number of answers, the weight for each of those answers would be $(5/100 \times 100/5) = 1$, so all answers for that hospital would be multiplied by 1 because the proportion of answers was appropriate.

If instead the total number of answers pertaining to a hospital was 20% of the total number of answers, but the hospital only served 5% of the catchment population pertaining to the answers to that question, the weight for each answer would be $(5/100 \times 100/20) = 0.25$. All answers from that hospital would be multiple by 0.25, because they effectively have four times as many answers as they would do if the proportion of answers matched the appropriate proportion of catchment population.

Clinician weighting

Clinician responses were weighted to equilibrate responses to the equivalent of 1 clinician per centre.

Example: If 3 clinicians from a centre submitted responses to the survey, their responses multiplied by 1/3.

After responses to each question were weighted, percentage of weighted responses was calculated and is reported in supplementary table 2 below, alongside the raw percentage and raw proportion of responses for each question for comparison.

Supplementary table 2

Responses to all questions across questionnaires, alongside response percentages adjusted for weighting.

	Patients Percent of all responses (n) (weighted percentage of responses)				Parents Percent of all responses (n) (weighted percentage of responses)				Clinicians Percent of all responses (n) (weighted percentage of responses)			
Demographics												
Number of respondents	43				152				34			
Number of centres	27 (1 unknown)				34 (2 unknown)				18 (0 unknown)			
How old is the patient who attended the most recent appointment for CAH?	<12 months:	0%	(0/43)	(0%)	<12 months:	9.2%	(14/152)	(8.5%)	-			
	1-5 years:	0%	(0/43)	(0%)	1-5 years:	29.6%	(45/152)	(29.5%)				
	6-9 years:	27.9%	(12/43)	(26.7%)	6-9 years:	25.6%	(39/152)	(21.5%)				
	10-14 years:	39.5%	(17/43)	(38.7%)	10-14 years:	26.3%	(40/152)	(23.0%)				
	15-19 years:	32.6%	(14/43)	(34.5%)	15-19 years:	9.2%	(14/152)	(17.5%)				
How old are you? (Clinicians: What is your job role?)	-				<20 years:	0.7%	(1/151)	(0.5%)	Consultant Endocrinologist: 70.6% (24/34) (74.1%)			
					20-29 years:	10.6%	(16/151)	(7.2%)	Consultant SPIN: 11.8% (4/34) (13.0%)			
					30-39 years:	39.1%	(59/151)	(33.0%)	Registrar: 5.9% (2/34) (6.5%)			
					40-49 years:	39.7%	(60/151)	(50.4%)	Nurse: 11.8% (4/34) (6.5%)			
					>50 years:	9.9%	(15/151)	(8.9%)				
How would you describe the sex of the patient?	Male:	44.2%	(19/43)	(41.3%)	Male:	46.7%	(71/152)	(42.0%)	-			
	Female:	55.8%	(24/43)	(58.7%)	Female:	52.6%	(80/152)	(57.8%)				
	Prefer not to say	0.0%	(0/43)	(0.0%)	Prefer not to say	0.7%	(1/152)	(0.2%)				
How would you describe the ethnic background of the patient?	Asian:	25.8%	(8/31)	(29.3%)	Asian:	13.2%	(20/152)	(11.7%)	-			
	Black:	3.2%	(1/31)	(5.9%)	Black:	1.3%	(2/152)	(0.9%)				
	Mixed:	9.7%	(3/31)	(12.3%)	Mixed:	5.3%	(8/152)	(5.4%)				
	Other:	3.2%	(1/31)	(1.6%)	Other:	2.0%	(3/152)	(4.7%)				
	White:	58.1%	(18/31)	(51.0%)	White:	78.3%	(119/152)	(77.2%)				

<i>Time treated / practicing</i>												
How long have you been treated at this hospital for CAH? (Clinicians: How long have you treating children with CAH?)	1 visit:	3.2%	(1/31)	(3.6%)	1 visit:	2.0%	(3/152)	(2.7%)				
	< 12 months:	0.0%	(0/31)	(0.0%)	< 12 months:	11.2%	(17/152)	(12.3%)	1-2 years:	5.9%	(2/34)	(3.7%)
	1-2 years:	6.5%	(2/31)	(7.4%)	1-2 years:	15.1%	(23/152)	(12.5%)	3-5 years:	14.7%	(5/34)	(11.1%)
	3-5 years:	12.9%	(4/31)	(14.8%)	3-5 years:	24.3%	(37/152)	(22.3%)	6-10 years:	23.5%	(8/34)	(14.8%)
	6-10 years:	12.9%	(4/31)	(15.0%)	6-10 years:	27.0%	(41/152)	(23.9%)	>10 years:	55.9%	(19/34)	(70.4%)
>10 years:	64.5%	(20/31)	(59.2%)	>10 years:	20.4%	(31/152)	(26.2%)					
In the last 12 months, how many appointments have you had at this hospital for CAH? (Clinicians: How many patients with CAH have you treated in the last 12 months?)	1:	16.1%	(5/31)	(15.6%)	1:	12.6%	(19/152)	(15.0%)	1:	2.9%	(1/33)	(5.6%)
	2:	38.7%	(12/31)	(33.7%)	2:	27.8%	(42/152)	(31.5%)	2-5:	17.6%	(6/33)	(8.3%)
	3:	25.8%	(8/31)	(32.0%)	3:	24.5%	(37/152)	(22.8%)	6-10:	29.4%	(10/33)	(31.5%)
	4:	6.5%	(2/31)	(7.8%)	4:	18.5%	(28/152)	(14.6%)	11-20:	26.5%	(9/33)	(24.1%)
	>4:	12.9%	(4/31)	(10.9%)	>4:	16.6%	(25/152)	(16.0%)	21-50:	11.8%	(4/33)	(15.7%)
									11.8%	(4/33)	(14.8%)	
<i>Satisfaction with services</i>												
Overall, are you satisfied with the service provided to care for your child with CAH? (Clinicians: Are you satisfied with the service you provide?)	Completely dissatisfied:	2.4%	(1/42)	(1.2%)	Completely dissatisfied:	0.7%	(1/151)	(0.0%)	Completely dissatisfied:	0.0%	(0/34)	(0.0%)
	Somewhat dissatisfied:	0.0%	(0/42)	(0.0%)	Somewhat dissatisfied:	1.3%	(2/151)	(0.8%)	Somewhat dissatisfied:	0.0%	(0/34)	(0.0%)
	Neutral:	2.4%	(1/42)	(2.3%)	Neutral:	2.6%	(4/151)	(4.6%)	Neutral:	11.8%	(4/34)	(22.2%)
	Somewhat satisfied:	19.0%	(8/42)	(19.1%)	Somewhat satisfied:	27.8%	(42/151)	(35.4%)	Somewhat satisfied:	76.5%	(26/34)	(69.4%)
	Completely satisfied:	76.2%	(32/42)	(77.4%)	Completely satisfied:	67.5%	(102/151)	(59.3%)	Completely satisfied:	11.8%	(4/34)	(8.3%)
<i>Discussions in clinic</i>												
At these appointments in the last 12 months, have you had the opportunity to discuss:						(Clinicians: How often do you discuss the following topics:)						
Ideas and goals about management	Not sure:	3.2%	(1/31)	(4.7%)	Not sure:	4.1%	(6/147)	(2.0%)	Never:	2.9%	(1/18)	(0.9%)
	No, I didn't want to:	0.0%	(0/31)	(0.0%)	No, I didn't want to:	2.0%	(3/147)	(0.7%)	Sometimes:	20.6%	(7/18)	(13.9%)
	No, I would have liked to:	9.7%	(3/31)	(12.3%)	No, I would have liked to:	3.4%	(5/147)	(1.2%)	Often:	41.2%	(14/18)	(44.4%)
	Yes, but not enough:	6.5%	(2/31)	(3.1%)	Yes, but not enough:	19.0%	(28/147)	(26.3%)	Always:	35.3%	(12/18)	(40.7%)
	Yes, thoroughly:	80.6%	(25/31)	(79.8%)	Yes, thoroughly:	71.4%	(105/147)	(69.8%)				
How to increase steroid doses when unwell	Not sure:	12.5%	(3/24)	(6.4%)	Not sure:	0.7%	(1/147)	(0.6%)	Never:	0.0%	(0/18)	(0.0%)
	No, I didn't want to:	8.3%	(2/24)	(12.3%)	No, I didn't want to:	4.1%	(6/147)	(5.5%)	Sometimes:	0.0%	(0/18)	(0.0%)
	No, I would have liked to:	0.0%	(0/24)	(0.0%)	No, I would have liked to:	0.7%	(1/147)	(0.3%)	Often:	11.8%	(4/18)	(11.1%)
	Yes, but not enough:	4.2%	(1/24)	(4.2%)	Yes, but not enough:	6.8%	(10/147)	(7.3%)	Always:	88.2%	(30/18)	(88.9%)
	Yes, thoroughly:	75.0%	(18/24)	(77.0%)	Yes, thoroughly:	87.8%	(129/147)	(86.3%)				
Psychological effects	Not sure:	16.7%	(2/12)	(19.5%)	Not sure:	5.5%	(8/146)	(2.8%)	Never:	2.9%	(1/34)	(0.9%)
	No, I didn't want to:	8.3%	(1/12)	(8.4%)	No, I didn't want to:	15.8%	(23/146)	(16.5%)	Sometimes:	70.6%	(24/34)	(71.3%)
	No, I would have liked to:	16.7%	(2/12)	(16.1%)	No, I would have liked to:	27.4%	(40/146)	(29.1%)	Often:	26.5%	(9/34)	(27.8%)
	Yes, but not enough:	41.7%	(5/12)	(38.5%)	Yes, but not enough:	20.5%	(30/146)	(30.4%)	Always:	0.0%	(0/34)	(0.0%)
	Yes, thoroughly:	16.7%	(2/12)	(17.6%)	Yes, thoroughly:	30.8%	(45/146)	(21.2%)				

Levels of physical activity	Not sure: 8.3% (1/12) (11.1%) No, I didn't want to: 8.3% (1/12) (8.4%) No, I would have liked to: 0.0% (0/12) (0.0%) Yes, but not enough: 16.7% (2/12) (8.4%) Yes, thoroughly: 66.7% (8/12) (72.2%)	Not sure: 6.1% (9/147) (7.0%) No, I didn't want to: 10.2% (15/147) (11.4%) No, I would have liked to: 20.4% (30/147) (19.6%) Yes, but not enough: 16.3% (24/147) (17.0%) Yes, thoroughly: 46.9% (69/147) (45.0%)	Never: 5.9% (2/34) (6.5%) Sometimes: 64.7% (22/34) (62.0%) Often: 17.6% (6/34) (13.9%) Always: 11.8% (4/34) (17.6%)
General wellbeing (Clinicians: Mental health)	Not sure: 8.3% (1/12) (11.1%) No, I didn't want to: 0.0% (0/12) (0.0%) No, I would have liked to: 0.0% (0/12) (0.0%) Yes, but not enough: 16.7% (2/12) (8.4%) Yes, thoroughly: 75.0% (9/12) (80.5%)	Not sure: 0.0% (0/150) (0.0%) No, I didn't want to: 1.3% (2/150) (0.5%) No, I would have liked to: 7.3% (11/150) (4.3%) Yes, but not enough: 8.7% (13/150) (14.0%) Yes, thoroughly: 82.7% (124/150) (81.2%)	Never: 6.1% (2/33) (2.8%) Rarely: 48.5% (16/33) (42.1%) Sometimes: 42.4% (14/33) (49.5%) Always: 3.0% (1/33) (5.6%)
Fertility	-	Not sure: 2.8% (4/145) (2.7%) No, I did not want to: 37.2% (54/145) (48.2%) No, I would have liked to: 21.4% (31/145) (19.7%) Yes, but not enough: 14.5% (21/145) (11.0%) Yes, thoroughly: 24.1% (35/145) (18.4%)	Never: 0.0% (0/33) (0.0%) Rarely: 27.3% (9/33) (21.5%) Sometimes: 66.7% (22/33) (70.1%) Always: 6.1% (2/33) (8.4%)
Heart disease	-	Not sure: 11.0% (16/145) (17.0%) No, I did not want to: 37.9% (55/145) (38.6%) No, I would have liked to: 33.8% (49/145) (32.2%) Yes, but not enough: 6.2% (9/145) (4.0%) Yes, thoroughly: 11.0% (16/145) (8.2%)	Never: 3.0% (1/33) (0.9%) Rarely: 45.5% (15/33) (41.1%) Sometimes: 42.4% (14/33) (49.5%) Always: 9.1% (3/33) (8.4%)
Genital surgery	-	Not sure: 6.4% (9/140) (11.6%) No, I didn't want to: 45.0% (63/140) (42.4%) No, I would have liked to: 15.7% (22/140) (15.1%) Yes, but not enough: 13.6% (19/140) (13.1%) Yes, thoroughly: 19.3% (27/140) (17.8%)	-
Genital surgery – carers of girls	-	Not sure: 1.3% (1/76) (11.1%) No, I didn't want to: 32.9% (25/76) (25.7%) No, I would have liked to: 19.7% (15/76) (19.5%) Yes, but not enough: 18.4% (14/76) (18.3%) Yes thoroughly: 27.6% (21/76) (25.5%)	-
Genital surgery – carers of girls < 5 (29)	-	Not sure: 0.0% (0/30) (0.0%) No, I didn't want to: 13.3% (4/30) (18.4%) No, I would have liked to: 20.0% (6/30) (13.4%) Yes, but not enough: 33.3% (10/30) (31.2%) Yes thoroughly: 33.3% (10/30) (36.9%)	-
Reduced adult height	-	-	Never: 0.0% (0/33) (0.0%) Rarely: 6.1% (2/33) (1.9%) Sometimes: 63.6% (21/33) (72.9%) Always: 30.3% (10/33) (25.2%)
Bone disease	-	-	Never: 9.1% (3/33) (4.7%) Rarely: 48.5% (16/33) (57.9%) Sometimes: 39.4% (13/33) (31.8%) Always: 3.0% (1/33) (5.6%)
Mental health	-	-	Never: 6.1% (2/33) (2.8%) Rarely: 48.5% (16/33) (42.1%) Sometimes: 42.4% (14/33) (49.5%) Always: 3.0% (1/33) (5.6%)
Tumours	-	-	Never: 6.1% (2/33) (1.9%) Rarely: 51.5% (17/33) (61.7%) Sometimes: 39.4% (13/33) (33.6%) Always: 3.0% (1/33) (2.8%)

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?	Not sure: 9.7% (3/31) (10.9%) No: 0.0% (0/31) (0.0%) Yes: 90.3% (28/31) (89.1%)	Not sure: 0.7% (1/150) (8.2%) No: 3.3% (5/150) (4.0%) Yes: 96.0% (144/150) (87.8%)	-
During your last appointment for your child's CAH, were you offered a printed or electronic copy of your care plan? (Clinician: Do you provide a care plan?)	Clinic Letter only: 26.3% (5/19) (30.7%) Not sure: 0.0% (0/19) (0.0%) No, I would have liked one: 36.8% (7/19) (34.2%) No, I didn't want one: 15.8% (3/19) (13.7%) Yes: 21.1% (4/19) (21.3%)	Clinic letter only: 42.8% (65/152) (45.0%) Not sure: 2.6% (4/152) (6.1%) No, I would have liked one: 22.4% (34/152) (15.6%) No, I didn't want one: 6.6% (10/152) (5.1%) Yes: 25.7% (39/152) (28.2%)	Clinic Letter only: 32.4% (11/34) (25.0%) Sometimes: 5.9% (2/34) (2.8%) Often: 20.6% (7/34) (16.7%) Always: 41.2% (14/34) (55.6%)
Advice, education, and confidence			
Do you feel confident managing your child's CAH Day to day?	No: 0.0% (0/31) (0.0%) Somewhat confident: 29.0% (9/31) (30.9%) Very confident: 71.0% (22/31) (69.1%)	No: 0.0% (0/151) (0.0%) Somewhat confident: 14.6% (22/151) (17.4%) Very confident: 85.4% (129/151) (82.6%)	-
Do you feel confident managing your child's CAH when they have another illness?	-	No: 1.5% (2/135) (4.3%) Somewhat confident: 42.2% (57/135) (39.9%) Very confident: 56.3% (76/135) (55.7%)	-
Do you feel confident managing your child's CAH in an emergency?	-	No: 10.1% (14/135) (12.8%) Somewhat confident: 49.6% (69/135) (47.6%) Very confident: 40.3% (56/135) (39.6%)	-
Do you think patients and families are confident managing CAH?	-	-	No: 0.0% (0/34) (0.0%) To some extent: 88.2% (30/34) (95.4%) Yes, definitely: 11.8% (4/34) (4.6%)
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? (Clinicians: Do you provide formal education?)	No: 80.6% (25/31) (78.2%) Unsure: 9.7% (3/31) (9.3%) Yes: 9.7% (3/31) (12.5%)	No: 82.8% (125/151) (90.1%) Unsure: 3.3% (5/151) (1.8%) Yes: 13.9% (21/151) (8.1%)	No: 0.0% (0/34) (0.0%) Not sure: 5.9% (2/34) (4.6%) Yes: 94.1% (32/34) (95.4%)
If a formal educational course teaching about CAH was available, would you attend?	Yes: 54.8% (17/31) (59.8%) No: 19.4% (6/31) (13.7%) Unsure: 25.8% (8/31) (26.5%)	Yes: 85.5% (130/152) (80.4%) No: 1.3% (2/152) (1.5%) Unsure: 13.2% (20/152) (18.1%)	-
Clinicians: What professionals provide the education: (Note: multiple selections allowed)	-	-	Doctor: 71.9% (23/32) (64.1%) Nurse: 100.0% (32/32) (100.0%) Youth worker: 3.1% (1/32) (2.9%) Pharmacist: 3.1% (1/32) (5.8%) Psychologist: 15.6% (5/32) (14.6%) Dietitian: 3.1% (1/32) (5.8%)

Clinicians: How long does formal education take:	-	-	<1 hour: 32.3% (10/31) (40.2%) 1-4 hours: 67.7% (21/31) (59.8%)
Clinicians: written guidance at education	-	-	No: 0.0% (0/30) (0.0%) Not sure: 10.0% (3/30) (13.8%) Yes: 90.0% (27/30) (86.2%)
Clinicians: do you liaise with school?	-	-	No: 5.9% (2/18) (2.8%) Not sure: 8.8% (3/18) (4.6%) Sometimes: 35.3% (12/18) (31.5%) Often: 2.9% (1/18) (0.9%) Yes: 47.1% (16/18) (60.2%)
How easy to contact endocrine in working hours	-	-	No: 3.0% (1/33) (0.9%) Not sure: 30.3% (10/33) (26.2%) Yes: 66.7% (22/33) (72.9%)
How easy outside of working hours:	-	-	Unable: 15.2% (5/33) (23.4%) Not easily: 30.3% (10/33) (17.8%) Not sure: 12.1% (4/33) (13.1%) Reasonably easy: 33.3% (11/33) (38.3%) Very easy: 9.1% (3/33) (7.5%)
How easy in an emergency:	-	-	Unable: 9.1% (3/33) (16.8%) Not easily: 21.2% (7/33) (15.0%) Not sure: 9.1% (3/33) (7.5%) Reasonably easy: 45.5% (15/33) (45.8%) Very easy: 15.2% (5/33) (15.0%)
In the last 12 months have you experienced conflicting advice from different health professionals in relation to CAH? (Clinicians: Do families get conflicting advice within the NHS?)	Yes, often: 2.4% (1/41) (1.2%) Yes, sometimes: 22.0% (9/41) (20.7%) No: 68.3% (28/41) (73.4%) Unsure: 7.3% (3/41) (4.8%)	Yes, often: 7.3% (11/151) (8.0%) Yes, sometimes: 19.9% (30/151) (26.8%) No: 72.8% (110/151) (65.2%) Unsure: 0.0% (0/151) (0.0%)	Never: 0.0% (0/18) (0.0%) Sometimes: 41.2% (14/18) (35.2%) Often: 52.9% (18/18) (58.3%) Always: 5.9% (2/18) (6.5%)
Have people you have spoken to from other families ever made you think that the advice get is different from the advice they have received? (Clinicians: Would patients be managed differently at a different hospital?)	Not spoken to anyone else: 75.6% (31/41) (74.9%) No, the same advice: 22.0% (9/41) (23.3%) Yes, somewhat different: 0.0% (0/41) (0.0%) Yes, very different advice: 2.4% (1/41) (1.8%)	Not spoken to anyone else: 54.3% (82/151) (47.8%) No, the same advice: 11.9% (18/151) (11.1%) Yes, somewhat different: 29.8% (45/151) (35.9%) Yes, very different advice: 4.0% (6/151) (5.2%)	Unlikely: 30.3% (10/33) (26.7%) Possible: 66.7% (22/33) (67.6%) Very likely: 3.0% (1/33) (5.7%)

Do you think you know enough about the medications that your child is prescribed to manage their CAH?	I don't take medication: 0.0% (0/42) (0.0%) No, I want to know more: 7.1% (3/42) (6.2%) Unsure: 11.9% (5/42) (9.5%) Yes, but want to know more: 23.8% (10/42) (20.7%) Yes: 57.1% (24/42) (63.5%)	Doesn't take medication: 0.7% (1/152) (0.6%) No, I want to know more: 4.6% (7/152) (3.4%) Unsure: 0.0% (0/152) (0.0%) Yes, but want to know more: 42.8% (65/152) (47.2%) Yes: 52.0% (79/152) (48.8%)	
Do you think that a doctor at a different hospital might treat your child's CAH differently? (Clinicians: Would patients be managed differently at a different hospital?)		No: 22.4% (34/152) (15.2%) Unsure: 53.9% (82/152) (60.4%) Yes: 23.7% (36/152) (24.4%)	Unlikely: 30.3% (10/33) (26.7%) Possible: 66.7% (22/33) (67.6%) Very likely: 3.0% (1/33) (5.7%)
Metrics assessed in clinic			
Has your child had the following things checked in the last 12 months in relation to their CAH: (Clinicians: How frequently do you check the following?)			
Weight	-	Yes: 97.4% (147/151) (96.8%) No: 2.0% (3/151) (2.9%) Unsure: 0.7% (1/151) (0.3%)	Never: 0.0% (0/34) (0.0%) Less than once a year: 0.0% (0/34) (0.0%) At least once a year: 0.0% (0/34) (0.0%) Frequently: 0.0% (0/34) (0.0%) Every visit: 100.0% (34/34) (100%)
Height	-	Yes: 97.4% (147/151) (96.8%) No: 2.0% (3/151) (2.9%) Unsure: 0.7% (1/151) (0.3%)	Never: 0.0% (0/34) (0.0%) Less than once a year: 0.0% (0/34) (0.0%) At least once a year: 0.0% (0/34) (0.0%) Frequently: 0.0% (0/34) (0.0%) Every visit: 100.0% (34/34) (100%)
Blood pressure	-	Yes: 88.6% (132/149) (87.7%) No: 8.7% (13/149) (9.3%) Unsure: 2.7% (4/149) (2.9%)	Never: 0.0% (0/34) (0.0%) Less than once a year: 2.9% (1/34) (0.9%) At least once a year: 8.8% (3/34) (2.8%) Frequently: 17.6% (6/34) (17.6%) Every visit: 70.6% (24/34) (78.7%)
Examined without clothes (Clinician: pubertal staging)	-	Yes: 64.6% (95/147) (57.5%) No: 32.7% (48/147) (41.1%) Unsure: 2.7% (4/147) (1.4%)	Never: 0.0% (0/34) (0.0%) Less than once a year: 5.9% (2/34) (11.1%) At least once a year: 17.6% (6/34) (14.8%) Frequently: 55.9% (19/34) (51.9%) Every visit: 20.6% (7/34) (22.2%)
X-ray to assess bone age	-	Yes: 55.6% (84/151) (47.5%) No: 41.7% (63/151) (50.2%) Unsure: 2.6% (4/151) (2.3%)	Never: 0.0% (0/33) (0.0%) Less than once a year: 42.4% (14/33) (53.3%) At least once a year: 54.5% (18/33) (45.7%) Frequently: 3.0% (1/33) (1.0%) Every visit: 0.0% (0/33) (0.0%)

Lab 17OHP	-	Yes: 79.9% (119/149) (80.1%) No: 8.7% (13/149) (10.8%) Unsure: 11.4% (17/149) (9.1%)	Never: 6.1% (2/33) (2.0%) Less than once a year: 9.1% (3/33) (2.9%) At least once a year: 48.5% (16/33) (65.7%) Frequently: 15.2% (5/33) (16.7%) Every visit: 21.2% (7/33) (12.7%)
Lab Androstenedione hormone	-	Yes: 72.8% (110/151) (69.8%) No: 6.6% (10/151) (9.2%) Unsure: 20.5% (31/151) (21.0%)	Never: 5.9% (2/34) (1.9%) Less than once a year: 8.8% (3/34) (2.8%) At least once a year: 52.9% (18/34) (68.5%) Frequently: 11.8% (4/34) (14.8%) Every visit: 20.6% (7/34) (12.0%)
Lab Renin	-	Yes: 78.4% (116/148) (74.8%) No: 8.8% (13/148) (10.0%) Unsure: 12.8% (19/148) (15.2%)	Never: 0.0% (0/34) (0.0%) Less than once a year: 2.9% (1/34) (0.9%) At least once a year: 61.8% (21/34) (66.7%) Frequently: 17.6% (6/34) (21.3%) Every visit: 17.6% (6/34) (11.1%)
Dried blood spot 17OHP	-	Yes: 49.3% (73/148) (45.3%) No: 45.9% (68/148) (49.9%) Unsure: 4.7% (7/148) (4.8%)	Never: 33.3% (11/33) (40.2%) Less than once a year: 0.0% (0/33) (0.0%) At least once a year: 15.2% (5/33) (17.6%) Frequently: 21.2% (7/33) (12.7%) Every visit: 30.3% (10/33) (29.4%)
A urine test to check for hormones	-	Yes: 8.8% (13/148) (7.4%) No: 79.7% (118/148) (86.7%) Unsure: 11.5% (17/148) (5.8%)	Never: 41.2% (14/34) (48.1%) Less than once a year: 47.1% (16/34) (40.7%) At least once a year: 11.8% (4/34) (11.1%) Frequently: 0.0% (0/34) (0.0%) Every visit: 0.0% (0/34) (0.0%)
<i>Frequency of assessments and access to services</i>			
What do you think about how closely your CAH is monitored? (Clinicians: Are you equipped with enough resources to manage CAH?)	Too many appointments: 0.0% (0/41) (0.0%) Right no. of appointments: 92.7% (38/41) (90.8%) Want more appointments: 7.3% (3/41) (9.2%) Unsure: 0.0% (0/41) (0.0%)	Too many appointments: 0.7% (1/152) (1.3%) Right no. of appointments: 77.6% (118/152) (77.6%) Want more appointments: 17.7% (27/152) (18.4%) Unsure: 3.9% (6/152) (2.6%)	Want more appointments: 14.7% (5/34) (13.9%) Want more ancillary services: 20.6% (7/34) (26.9%) Want to be able to do more tests: 11.8% (4/34) (10.2%) Yes: 52.9% (18/34) (49.1%)
Clinicians: How good is your access to specialist nursing?	-	-	Unable: 0.0% (0/34) (0.0%) Difficult: 0.0% (0/34) (0.0%) Reasonable: 14.7% (5/34) (17.6%) Easy: 85.3% (29/34) (82.4%)
Clinicians: How good is your access to psychological support?	-	-	Unable: 2.9% (1/34) (2.8%) Difficult: 41.2% (14/34) (51.9%) Reasonable: 41.2% (14/34) (31.5%) Easy: 14.7% (5/34) (13.9%)
Clinicians: How good is your access to dietitian support?	-	-	Unable: 17.6% (6/34) (15.7%) Difficult: 52.9% (18/34) (45.4%) Reasonable: 26.5% (9/34) (33.3%) Easy: 2.9% (1/34) (5.6%)

Clinicians: How good is your access to physiotherapy support?	-	-	Unable: 20.6% (7/34) (18.5%) Difficult: 47.1% (16/34) (51.9%) Reasonable: 29.4% (10/34) (24.1%) Easy: 2.9% (1/34) (5.6%)
Clinicians: How good is your access to genital surgery?	-	-	Unable: 8.8% (3/34) (8.3%) Difficult: 1.8% (4/34) (10.2%) Reasonable: 35.3% (12/34) (38.9%) Easy: 44.1% (15/34) (42.6%)
Number of free text comments	5/43	56/152	25/34

Supplementary table 3

Thematic analysis of free text comments

Theme of comments	Number of comments within theme	Quote from comment
Comments from patients under 20 years of age		
Transition	1/5	as a child they give you a 'doom and gloom' outlook on life
Standard of care	2/5	The management of my condition transformed from terrible to very good as soon as I got moved
Standard of care	2/5	Both doctors made considerable effort to ensure both parent and child have a full understanding of CAH
Surgery	1/5	Why can't we still get our surgery when we were born
Education	1/5	I would like more information
Comments from carers of patients under 20		
Medication	2/56	I wish that a slow release hydrocortisone was available
Medication	2/56	I do worry with the links of mental health/depression
Peer support	2/56	would be nice to be put in touch with other families of children with CAH
Peer support	2/56	would like to meet some families who [have the] same problem
Support	6/56	Would like to be able to get in touch with the CAH more easily
Support	6/56	to discuss our management and psychologically
Support	6/56	I find the staff nurses to be very helpful and informative
Support	6/56	Feel supported enough
Support	6/56	We would like ... to speak to a psychologist
Support	6/56	Parents should be offered more support
Education	11/56	no-one has to the time to discuss it the long term implications of cah
Education	11/56	There should be more programs to discuss this condition

Education	11/56	Training of injectable steroids [is needed for] teachers in school
Education	11/56	What discussions do we need to have about heart disease?
Education	11/56	better explanations to children [about] CAH
Education	11/56	The main difficulty has been trying to connect medication to his nursery
Education	11/56	I would be thankful for some information ... on DSD as we approach puberty
Education	11/56	Would like to understand why things change during puberty.
Education	11/56	I would like to know a bit more about what different of stages may be like
Education	11/56	I would like to see focused mental health care and age appropriate education
Education	11/56	We worry about what to do when our children become sick
Transition	4/56	transition is being taken seriously
Transition	4/56	no transition to adult services available
Transition	4/56	it has now started to impact her adult life
Transition	4/56	management is completely different [in adult services]
Standard of care	26/56	standard of care is shocking
Standard of care	26/56	We are so lucky
Standard of care	26/56	[outreach clinics] appear to result in less monitoring
Standard of care	26/56	I am so grateful for all the medical advice and support
Standard of care	26/56	we have to wait 8 weeks for results
Standard of care	26/56	the NHS is over run
Standard of care	26/56	care is amazing
Standard of care	26/56	I am very happy with how they manage her condition
Standard of care	26/56	I am very happy with the care we receive
Standard of care	26/56	having been under three different hospitals, the difference in approach is marked
Standard of care	26/56	prefer to have access to 24hr profiles

Standard of care	26/56	Switching to local hospital from tertiary centre ... was big improvement
Standard of care	26/56	I would like to have androstenedione and renin checked
Standard of care	26/56	24 hour profiles should be routinely offered to ensure correct dosing
Standard of care	26/56	The Endocrine team at ... have been fantastic
Standard of care	26/56	He was actually missed
Standard of care	26/56	We feel that results of blood tests are not always discussed openly
Standard of care	26/56	I'm very happy with the care
Standard of care	26/56	We have been unable to get blood tests for a few years as my child has got issues with needles
Standard of care	26/56	24 hour blood profile is not offered
Standard of care	26/56	I feel that overall my daughter has been treated very well
Standard of care	26/56	Always satisfied
Standard of care	26/56	Our team ... do a wonderful job
Standard of care	26/56	there have been no problems whatsoever
Standard of care	26/56	they have been amazing
Standard of care	26/56	A 24 [hour] stay appointment needs to have its place
Advice	2/56	The advice differs so much from one doctor to another
Advice	2/56	The advice maybe slightly different
Pandemic	1/56	levels of care have dropped off since the pandemic
Screening	1/56	Can we not have a test in place before the child's birth like they have in america
Surgery	1/56	I think parents should be given the option to [pursue] early surgery
Comments from clinicians caring for those with CAH		
Standard of care	19/25	would like to get more psycholohgy support
Standard of care	19/25	Ideally we would hold a dedicated clinic just for young people with CAH
Standard of care	19/25	We use saliva samples

Standard of care	19/25	We use saliva samples
Standard of care	19/25	We use saliva samples
Standard of care	19/25	we have aspirations for care [that we cannot fulfill]
Standard of care	19/25	involvement with counsellors is vital
Standard of care	19/25	no specialised CAH clinics
Standard of care	19/25	We have a 24/7 consultant led on-call service
Standard of care	19/25	Dietician and psychology support can be improved.
Standard of care	19/25	can always be better
Standard of care	19/25	I would like to see a full time [clinical nurse specialist]
Standard of care	19/25	Variable... dosing of hydrocortisone and transition
Standard of care	19/25	linking with ... primary and secondary care challenging
Standard of care	19/25	Services are variable
Standard of care	19/25	[Large] Variation in practice
Standard of care	19/25	all children with CAH [should be seen] in tertiary care
Standard of care	19/25	shared care with a DGH tend to have less good care
Standard of care	19/25	psychology ... is not adequate anywhere
Surgery	3/25	We have access to surgery but don't do it
Surgery	3/25	We are pro the child deciding for themselves when they are 18 years old
Surgery	3/25	Controversy about virilised girls and surgical option is difficult
Education	1/25	a remote course that can be attended by parents and children may be quite useful
Research	2/25	Has improved since CHASE [research]
Research	2/25	I think the [special interest group] should have more clinical nurse specialists

Link to original questionnaires

tinyurl.com/3n4bhxvd