***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

A close-up of a service satisfaction survey

Description automatically generated

**Supplementary Figure 2**

A graph showing a patient education

Description automatically generated

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 x 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 x 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%)  1-5 years: 0% (0/43) (0%)  6-9 years: 27.9% (12/43) (26.7%)  10-14 years: 39.5% (17/43) (38.7%)  15-19 years: 32.6% (14/43) (34.5%) | <12 months: 9.2% (14/152) (8.5%)  1-5 years: 29.6% (45/152) (29.5%)  6-9 years: 25.6% (39/152) (21.5%)  10-14 years: 26.3% (40/152) (23.0%)  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%)  20-29 years: 10.6% (16/151) (7.2%)  30-39 years: 39.1% (59/151) (33.0%)  40-49 years: 39.7% (60/151) (50.4%)  >50 years: 9.9% (15/151) (8.9%) | Consultant Endocrinologist: 70.6% (24/34) (74.1%)  Consultant SPIN: 11.8% (4/34) (13.0%)  Registrar: 5.9% (2/34) (6.5%)  Nurse: 11.8% (4/34) (6.5%) |
| How would you describe the sex of the patient? | Male: 44.2% (19/43) (41.3%)  Female: 55.8% (24/43) (58.7%)  Prefer not to say 0.0% (0/43) (0.0%) | Male: 46.7% (71/152) (42.0%)  Female: 52.6% (80/152) (57.8%)  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%)  Black: 3.2% (1/31) (5.9%)  Mixed: 9.7% (3/31) (12.3%)  Other: 3.2% (1/31) (1.6%)  White: 58.1% (18/31) (51.0%) | Asian: 13.2% (20/152) (11.7%)  Black: 1.3% (2/152) (0.9%)  Mixed: 5.3% (8/152) (5.4%)  Other: 2.0% (3/152) (4.7%)  White: 78.3% (119/152) (77.2%) | - |
| ***Time treated / practicing*** | | | |
| 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%)  < 12 months: 0.0% (0/31) (0.0%)  1-2 years: 6.5% (2/31) (7.4%)  3-5 years: 12.9% (4/31) (14.8%)  6-10 years: 12.9% (4/31) (15.0%)  >10 years: 64.5% (20/31) (59.2%) | 1 visit: 2.0% (3/152) (2.7%)  < 12 months: 11.2% (17/152) (12.3%)  1-2 years: 15.1% (23/152) (12.5%)  3-5 years: 24.3% (37/152) (22.3%)  6-10 years: 27.0% (41/152) (23.9%)  >10 years: 20.4% (31/152) (26.2%) | 1-2 years: 5.9% (2/34) (3.7%)  3-5 years: 14.7% (5/34) (11.1%)  6-10 years: 23.5% (8/34) (14.8%)  >10 years: 55.9% (19/34) (70.4%) |
| 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%)  2: 38.7% (12/31) (33.7%)  3: 25.8% (8/31) (32.0%)  4: 6.5% (2/31) (7.8%)  >4: 12.9% (4/31) (10.9%) | 1: 12.6% (19/152) (15.0%)  2: 27.8% (42/152) (31.5%)  3: 24.5% (37/152) (22.8%)  4: 18.5% (28/152) (14.6%)  >4: 16.6% (25/152) (16.0%) | 1: 2.9% (1/33) (5.6%)  2-5: 17.6% (6/33) (8.3%)  6-10: 29.4% (10/33) (31.5%)  11-20: 26.5% (9/33) (24.1%)  21-50: 11.8% (4/33) (15.7%)  >50: 11.8% (4/33) (14.8%) |
| ***Satisfaction with services*** | | | |
| 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%)  Somewhat dissatisfied: 0.0% (0/42) (0.0%)  Neutral: 2.4% (1/42) (2.3%)  Somewhat satisfied: 19.0% (8/42) (19.1%)  Completely satisfied: 76.2% (32/42) (77.4%) | Completely dissatisfied: 0.7% (1/151) (0.0%)  Somewhat dissatisfied: 1.3% (2/151) (0.8%)  Neutral: 2.6% (4/151) (4.6%)  Somewhat satisfied: 27.8% (42/151) (35.4%)  Completely satisfied: 67.5% (102/151) (59.3%) | Completely dissatisfied: 0.0% (0/34) (0.0%)  Somewhat dissatisfied: 0.0% (0/34) (0.0%)  Neutral: 11.8% (4/34) (22.2%)  Somewhat satisfied: 76.5% (26/34) (69.4%)  Completely satisfied: 11.8% (4/34) (8.3%) |
| ***Discussions in clinic*** | | | |
| 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%)  No, I didn’t want to: 0.0% (0/31) (0.0%)  No, I would have liked to: 9.7% (3/31) (12.3%)  Yes, but not enough: 6.5% (2/31) (3.1%)  Yes, thoroughly: 80.6% (25/31) (79.8%) | Not sure: 4.1% (6/147) (2.0%)  No, I didn’t want to: 2.0% (3/147) (0.7%)  No, I would have liked to: 3.4% (5/147) (1.2%)  Yes, but not enough: 19.0% (28/147) (26.3%)  Yes, thoroughly: 71.4% (105/147) (69.8%) | Never: 2.9% (1/18) (0.9%)  Sometimes: 20.6% (7/18) (13.9%)  Often: 41.2% (14/18) (44.4%)  Always: 35.3% (12/18) (40.7%) |
| How to increase steroid doses when unwell | Not sure: 12.5% (3/24) (6.4%)  No, I didn’t want to: 8.3% (2/24) (12.3%)  No, I would have liked to: 0.0% (0/24) (0.0%)  Yes, but not enough: 4.2% (1/24) (4.2%)  Yes, thoroughly: 75.0% (18/24) (77.0%) | Not sure: 0.7% (1/147) (0.6%)  No, I didn’t want to: 4.1% (6/147) (5.5%)  No, I would have liked to: 0.7% (1/147) (0.3%)  Yes, but not enough: 6.8% (10/147) (7.3%)  Yes, thoroughly: 87.8% (129/147) (86.3%) | Never: 0.0% (0/18) (0.0%)  Sometimes: 0.0% (0/18) (0.0%)  Often: 11.8% (4/18) (11.1%)  Always: 88.2% (30/18) (88.9%) |
| Psychological effects | Not sure: 16.7% (2/12) (19.5%)  No, I didn’t want to: 8.3% (1/12) (8.4%)  No, I would have liked to: 16.7% (2/12) (16.1%)  Yes, but not enough: 41.7% (5/12) (38.5%)  Yes, thoroughly: 16.7% (2/12) (17.6%) | Not sure: 5.5% (8/146) (2.8%)  No, I didn’t want to: 15.8% (23/146) (16.5%)  No, I would have liked to: 27.4% (40/146) (29.1%)  Yes, but not enough: 20.5% (30/146) (30.4%)  Yes, thoroughly: 30.8% (45/146) (21.2%) | Never: 2.9% (1/34) (0.9%)  Sometimes: 70.6% (24/34) (71.3%)  Often: 26.5% (9/34) (27.8%)  Always: 0.0% (0/34) (0.0%) |
| 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 you 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?  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%) |
| ***Frequency of assessments and access to services*** | | | |
| 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