

Congenital Adrenal Hyperplasia (CAH) Data Elements - Enrollment

1	Measure	Category	Answer Type	Measure Answer	Units (for value box)
2	Unique registry ID	Demographics	Free Text		(2digFIPS/2digBirthYr/1digCenter/3digAccession) NEED TO THINK ABOUT THIS SO DON'T ASSIGN AN IBEM FROM SAME CENTER
3	Was enrollment in registry refused?	Demographics	Yes No		
4	Who consented enrollment in registry?	Demographics	Pick List	Both parents, mother only, father only, both guardians, female guardian, male guardian	
	Was assent obtained?	Demographics	Pick List	Missing/unknown data, no, yes	
5	Permission to contact about research	Demographics	Yes No	Permission to contact: I agree to be contacted with information on potential future research applicable to me and/or child's condition that becomes available.	
6	Permission for compensation	Demographics	Yes No	Permission for compensation: I agree that identifying information about me/my child may be used or disclosed as necessary to provide compensation if I and/or my child are eligible for compensation.	
7	Patient is enrolled in research studies	Demographics	Check boxes	Missing/unknown data, no, yes (if yes, please specify in next question)	
	Research studies patient is enrolled in	Demographics	Free Text		

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8	Follow up status	Demographics	Pick List	Active, Inactive - Deceased, Inactive - Lost to follow up, Inactive - Moved to another State participating in registry, Inactive - Moved to another State not participating in registry, Inactive -Refused follow up, Inactive - Treatment	
9	Has patient been followed by >1 center for this condition?	Demographics	Pick List	Missing/unknown data, no, yes - select state from pull down list, yes - select state from pull down list, yes - select state from pull down list	
11	If patient has been followed by >1 center, did patient grant permission to share data via registry between treating center?	Demographics	Pick List	Missing/unknown data, N/A, Yes, No	
12	If patient has been followed by >1 center for this condition, what type of provider was treating the patient?	Demographics	Check boxes	Missing/unknown data, adult endocrinologist, geneticist, family practice physician, gynecologist, internist, nurse practitioner, pediatric endocrinologist, pediatrician, reproductive endocrinologist, psychologist, psychiatrist,	
13	Other health services received by patient	Demographics	Check boxes	Missing/unknown data, none, audiology, behavioral/developmental pediatrics, cardiology, dermatology, genetics, genetic counseling, hematology/oncology, home health care, nephrology, neurology, neuropsychology, OB-GYN, occupational therapy, ophthalmology, orthopedics, otolaryngology,	
14	Community resources received by patient	Demographics	Check boxes	Missing/unknown data, none, daycare, family support group related to this condition, family support - other, Medical Home, nutritional services (WIC/MAC), personal care attendant (PCA), preschool, Head Start, respite care, social services - county, social services - medical, social services - developmental disability, waived services	
15	If deceased, date of death (if N/A enter 01/01/1901)	Demographics	Date Field		
16	Ethnic category	Demographics	Pick List	Missing/unknown data, Hispanic or Latino, not Hispanic or Latino	

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17	Racial category	Demographics	Pick List	Missing/unknown data, American Indian/Alaska Native, Asian, Native Hawaiian or other Pacific Islander, Black or African American, Multi-racial, White	
18	Mother's maiden name at birth	Demographics	Free Text		
19	Maternal education: highest level of education	Socioeconomic Status	Pick List	Missing/unknown data, 1-8 years, 9-12 years (no diploma), completed high school, training after high school, some college, college graduate, post-graduate	
20	Paternal education: highest level of education	Socioeconomic Status	Pick List	Missing/unknown data, 1-8 years, 9-12 years (no diploma), completed high school, training after high school, some college, college graduate, post-graduate	
21	Is primary caregiver proficient in written English?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
22	Is primary caregiver proficient in spoken English?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
23	Was written/web-based information on this condition provided in primary caregiver's primary language?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
24	Primary insurance at time of enrollment	Socioeconomic Status	Pick List	Missing/unknown data, Private, Public, None, Self Pay	
25	Marital status of primary caregiver at time of enrollment	Socioeconomic Status	Pick List	Missing/unknown data, married, not married	

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26	Family members at time of enrollment (total including number of siblings, half-siblings, adopted, etc)	Socioeconomic Status	Check boxes	Missing/unknown data, # of siblings, # of half siblings, # of parents, # of grandparents, # of step siblings, # of adopted siblings	
	Family members currently living in the household at time of enrollment	Socioeconomic Status	Pick List	Missing/unknown data, # of siblings under 18, # of half siblings under 18, # of step siblings under 18, # of adopted siblings under 18, # of parents, # of grandparents, # of adults	
27	Mother's height self-report at time of patient enrollment in registry (or 88888 if unknown)	Family History	Decimal	NOTE: auto convert to cm.	(inches)
28	Father's height self-report at time of patient enrollment in registry (or 88888 if unknown)	Family History	Decimal	NOTE: auto convert to cm.	(inches)
29	Are parents affected with CAH?	Family History	Check boxes	Missing/unknown data, mother affected, father affected, mother not affected, father not affected	
30	Select family history	Family History	Check boxes	Missing/unknown data, acne, adrenalectomy, amenorrhea primary, amenorrhea - secondary, azoospermia, cerebrovascular death, consanguinity - yes, consanguinity no, diabetes - type 1, diabetes - type 2, endometriosis, hirsutism, hypertension, hypotension, hypoglycemia, hypothyroidism, hyperthyroidism, infant death - female, infant death - male, infertility - females, infertility - males, irregular menses, male pattern hair loss, miscarriages, obesity, oligospermia, osteoporosis, ovarian adrenal rests,	
31	Any infant/sibling deaths?	Family History	Pick list	Missing/unknown data, no, yes -1 death, yes - 2 deaths, yes - 3 deaths	
	Date and age of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text	<p style="text-align: center;">_____ Month/Day/Year</p> <p style="text-align: center;">_____ Age</p>	

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	Cause(s) of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text		
	Sex of infant/sibling #1 who died	Family History	Pick List	Missing/unknown, male, female	
	Date and age of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text	_____ Month/Day/Year _____ Age	
	Cause(s) of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text		
	Sex of infant/sibling #1 who died	Family History	Pick List	Missing/unknown, male, female	
	Date and age of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text	_____ Month/Day/Year _____ Age	
	Cause(s) of Infant/sibling death #1 (enter 88888 if unknown)	Family History	Free Text		
	Sex of infant/sibling #1 who died	Family History	Pick List	Missing/unknown, male, female	
32	Sibling #1 (oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	

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33	Sibling #2 (second oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	
34	Sibling #3 (third oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	
35	Sibling #4 (fourth oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	
36	Sibling #5 (fifth oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	
37	Sibling #6 (sixth oldest sibling) evaluated for this condition?	Family History	Pick List	Missing/unknown data, not tested, tested - affected (if affected and consented to registry participation, create new registry case and free text registry unique ID below), tested - unaffected, N/A	
38	If sibling(s) affected with this condition enter sibling # and sibling unique registry ID number(s) here (enter 99999 if N/A)	Family History	Free Text		
39	Was prenatal testing for this condition done during this pregnancy?	Prenatal History	Pick List	Missing/unknown data, yes, no, offered but declined by parent	
40	Method(s) if prenatal testing for this condition done	Prenatal History	Check boxes	Missing/unknown data, N/A, amniocentesis (biochemical/enzyme), amniocentesis (DNA), chorionic villus (biochemical/enzyme), chorionic villus (DNA), fetal skin	
41	Maternal steroid treatment received during this pregnancy?	Prenatal History	Check boxes	Missing/unknown data, no, yes - dexamethasone, yes - betamethasone, yes - prednisone, yes - other steroid	

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42	If maternal steroid treatment received during this pregnancy, reason for treatment?	Prenatal History	Check boxes	Missing/unknown data, N/A, mother affected with CAH, premature labor, prenatal treatment for suspected or known fetal CAH, other	
43	If maternal steroid treatment received during this pregnancy, what was the daily dose of steroid (enter 99999 if N/A or 88888 if	Prenatal History	Decimal		
44	If prenatal steroid treatment received during this pregnancy, week of gestation at time of initiation of treatment (enter 99999 if N/A or 88888 if	Prenatal History	Decimal		(weeks gestation)
45	If maternal steroid treatment received during this pregnancy, week of gestation at end of treatment (enter 99999 if N/A or 88888 if	Prenatal History	Decimal		(weeks gestation)
46	If maternal steroid treatment received during this pregnancy, maternal steroid side effects	Prenatal History	Check boxes	Missing/unknown data, N/A - not prescribed, none, hypertension, mood swings, striae, weight gain, other	
47	Was mother receiving other medications during pregnancy (enter 99999 if N/A or 88888 if unknown)?	Prenatal History	Free Text		
48	Other pregnancy complications and/or risk factors	Prenatal History	Check boxes	Missing/unknown data, none, premature labor, preeclampsia, bleeding, placenta previa, placenta abruption, infection, gestational diabetes, depression, hypertension, hypothyroidism, hyperthyroidism, virilization	
49	Was fertility assisted in this pregnancy?	Prenatal History	Check boxes	Missing/unknown data, no, clomid, in vitro fertilization, gamete intra-fallopian transfer (GIFT), zygote intra-fallopian transfer (ZIFT), intra-cytoplasmic sperm injection, sperm donation, egg donation, surrogate	
50	Weeks of gestation at birth (enter 88888 if unknown)	Neonatal History	Decimal		weeks

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51	Additional information about newborn period	Neonatal History	Check boxes	Missing/unknown data, none, antibiotics, breastfed, CNS bleeding, CNS infection, CNS injury, distress, hypoglycemia, hypotension, hypertension, hypoxia, meconium stain amniotic fluid, nuchal cord, sepsis, TPN,	
52	Birth weight (enter 88888 if unknown)	Measurements	Decimal		(kg)
53	Birth height (enter 88888 if unknown)	Measurements	Decimal		(cm)
54	Birth head circumference (OFC) (enter 88888 if unknown)	Measurements	Decimal		(cm)
55	State newborn screen serial number (enter 88888 if unknown)	Newborn Screening	Integer		
56	If newborn screened, days of age at time primary care provider or endocrine provider were notified of FIRST abnormal newborn screen (enter 88888 if unknown)	Newborn Screening	Decimal		(days)
57	17-hydroxyprogesterone (17-OHP) on FIRST newborn screen (enter 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
58	2nd tier 17-hydroxyprogesterone (17-OHP) results from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
59	2nd tier 17-hydroxyprogesterone (17-OHP) + androstenedione/cortisol ratio from FIRST newborn screen (enter 88888 if N/A or 99999 if unknown)	Newborn Screening	Decimal		

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60	2nd tier results cortisol detected from FIRST newborn screen	Newborn Screening	Pick List	Missing/unknown data, N/A - 2nd tier screen not done, yes, no	
61	2nd tier results 21-deoxycortisol from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
62	2nd tier results 11-deoxycortisol from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
63	17-hydroxyprogesterone (17-OHP) on SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
64	2nd tier 17-hydroxyprogesterone (17-OHP) results from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
65	2nd tier 17-hydroxyprogesterone (17-OHP) + androstenedione/cortisol ratio from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		
66	2nd tier cortisol results from SECOND newborn screen	Newborn Screening	Pick List	Missing/unknown data, N/A - 2nd tier screen not done, yes, no	
67	2nd tier results 21-deoxycortisol from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
68	2nd tier results 11-deoxycortisol from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)

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69	17-hydroxyprogesterone (17-OHP) on THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
70	2nd tier 17-hydroxyprogesterone (17-OHP) results from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
71	2nd tier 17-hydroxyprogesterone (17-OHP) + androstenedione/cortisol ratio from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		
72	2nd tier cortisol results from THIRD newborn screen	Newborn Screening	Pick List	Missing/unknown data, N/A - 2nd tier screen not done, yes, no	
73	2nd tier results 21-deoxycortisol from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
74	2nd tier results 11-deoxycortisol from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
75	Baseline serum 17-hydroxyprogesterone (17-OHP) level (enter 99999 if NA or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
76	Baseline serum deoxycorticosterone (DOC) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
77	Baseline serum 17-hydroxypregnenolone (17-OHPreg) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)

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78	Baseline serum corticosterone (B) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
79	Baseline serum cortisol (F) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)
80	Baseline serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
81	Baseline serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
82	Baseline serum dehydroxyepiandrosterone (DHEA) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
83	Baseline serum dihydrotestosterone (DHT) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		pg/ml
84	Baseline renin level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/ml/hr
85	Was a cosyntropin (ACTH) stimulation test performed?	Diagnostic Testing	Pick List	Missing/unknown information, yes, no	
86	Dose of cosyntropin for high dose ACTH stimulation test	Diagnostic Testing	Pick List	Missing/unknown data, N/A - cosyntropin stimulation test not done, 125 mcg, 250 mcg, other dose	(mcg/dose)

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87	ACTH stimulated serum 17-hydroxyprogesterone (17-OHP) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
88	ACTH stimulated serum deoxycorticosterone (DOC) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
89	ACTH stimulated serum 17-hydroxypregnenolone (17-OHPreg) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
90	ACTH stimulated serum corticosterone (B) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
91	ACTH stimulated serum cortisol (F) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)
92	ACTH stimulated serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
93	ACTH stimulated serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
94	ACTH stimulated serum dehydroxyepiandrosterone (DHEA) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
95	ACTH stimulated serum dehydroxyepiandrosterone sulfate (DHEA-S) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)

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96	Was a β -hCG stimulation test performed?	Diagnostic Testing	Pick List	Missing/unknown information, yes, no	
97	Dose and frequency of β -hCG stimulation test? (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
98	If β -hCG stimulation test performed, at what age? (enter 99999 if N/A, or 88888 if unknown).	Diagnostic Testing	Integer		years
99	β -hCG stimulated serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
100	β -hCG stimulated serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
101	β -hCG stimulated serum dihydrotestosterone (DHT) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(pg/mL)
102	Molecular testing: Common or targeted mutation panel	Diagnostic Testing	Pick List	Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration(s) of unknown significance detected, yes but no mutations were	
103	If common or targeted mutation panel performed, please list laboratory	Diagnostic Testing	Free Text		
104	Molecular testing: Full sequencing	Diagnostic Testing	Pick List	Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - abnormal: presumed compound heterozygote 2nd mutation not identified, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration(s) of unknown significance detected, yes but no	

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105	Mutation description on patient: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
106	Mutation description on patient: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
107	Mutation description on biological mother: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
108	Mutation description on biological mother: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
109	Mutation description on biological father: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
110	Mutation description on biological father: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
111	Karyotype results	Diagnostic Testing	Pick List	Missing/unknown data, karyotype was not done, 46XX, 46XY, mosaicism or other (go to next question and explain)	
112	If karyotype is a mosaicism or other, please describe (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
113	Was genetic counseling for this condition provided?	Past Health History	Pick List	Missing/unknown data, yes, no	

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114	If genetic counseling was provided, who provided genetic counseling?	Past Health History	Pick List	Missing/unknown data, endocrinologist - adult, endocrinologist - pediatric, geneticist, genetic counselor, family practice physician, internist, nurse practitioner, pediatrician	
115	Initial diagnosis of CAH found by:	Past Health History	Check boxes	Missing/unknown data, abnormal newborn screen, prenatal testing, post-mortem testing, by provider, by another provider – adult endocrinologist, by another provider – family practice physician, by another provider – geneticist, by another provider – internist, by another provider – nurse practitioner, by another provider – pediatrician	
116	Type of CAH	Past Health History	Pick List	21-OHD – salt-wasting, 21-OHD – simple-virilizing, 21-OHD - non-classical, 3b-HSD-II – classical, 3b-HSD-II – non-classical, 11-OHD –classical, 11-OHD – non-classical, 17a-OHlase/17,20-lyase combined complete, 17a-OHlase/17,20-lyase combined partial, lipoid (StAR) – classical, lipoid (StAR) – non-classical, P450	
117	Number of CAH related hospitalizations prior to enrollment in registry	Past Health History	Pick List	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10	
118	Age at time of initial face to face intervention for this condition (enter 88888 if unknown)	Past Health History	Free Text		(days, months, years)
119	Symptom(s) - manifestations at time of initial intervention for this condition	Past Health History	Check boxes	Missing/unknown data, none, acanthosis nigricans, acne, anovulation, dehydration, developmental delay, dysmorphic features, growth acceleration, gynecomastia, hirsutism, hypertonia, hypotonia, hypoglycemia, hyperpigmentation, hypertensive nephrosclerosis, infertility, insulin resistance, irregular menses, irritability, left ventricular hypertrophy, lethargy, male pattern hair loss, metabolic acidosis, osteopenia, osteoporosis, polycystic ovarian syndrome, poor feeding, precocious puberty, pubic hair development, retinopathy, seizures	
120	Other symptom(s) - manifestations at time of initial intervention for this condition	Past Health History	Free Text		

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121	Weight at time of initial intervention for this condition (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(kg)
122	Height at time of initial intervention for this condition (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(cm)
123	Head circumference (OFC) at time of initial intervention for this condition (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(cm)
124	Blood pressure at time of initial intervention for this condition	Past Health History	Pick List	Missing/unknown data, blood pressure not measured, hypertension, hypotension, normal blood pressure	
125	If patient has abnormal blood pressure, at what age was abnormal blood pressure originally observed (enter 99999 if N/A or 00000 if not done)	Past Health History	Decimal		(years, months)
126	Tanner Stage of pubic hair development at time of initial intervention for this condition	Past Health History	Pick List	Missing/unknown data, not done, I, II, III, IV, V	
127	Tanner Stage of breast development at time of initial intervention for this condition	Past Health History	Pick List	Missing/unknown data, N/A, not done, I, II, III, IV, V	
128	Menstrual history at time of initial intervention for this condition	Past Health History	Pick List	Missing/unknown data, N/A - patient is male, N/A - prepubertal female, primary amenorrhea, secondary amenorrhea (no menses for >6 months) oligomenorrhea, regular menses	

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129	Lab tests collected at initial intervention for this condition	Past Health History	Check boxes	Missing/unknown data, none, ABG-WNL, ABG-high ABG-low, ALT-WNL, ALT-Abn, AST-WNL, AST-Abn, AlkPhos-WNL, AlkPhos-Abn, Anion Gap-WNL, Anion Gap-Abn, BUN-WNL, BUN-Abn, Ca++-WNL, Ca++-high, Ca++-low, Cr-WNL, Cr-Abn, Cl-WNL, Cl-high, Cl-low, CO2-WNL, CO2-high, CO2-low, FSH-WNL, FSH-high, FSH-low, GGT-WNL, GGT-Abn, Gluc-WNL, Gluc-low, Gluc-high, glucose (fasting) - WNL, glucose (fasting) - low, glucose (fasting) - high, insulin (fasting) - WNL, insulin (fasting) - Abn, K+-WNL, K+-high, K+-low, LH-WNL, LH-high, LH-low, Na+-WNL, Na+-high, Na+-low, Phosphorus – WNL, Phosphorus – high, Phosphorus – low, Total Cholesterol (fasting) – WNL, Total Cholesterol (fasting) – Abn, Total Cholesterol (random) – WNL, Total Cholesterol (random)	
130	Lab tests other general (indicate type and if WNL or Abn) collected at initial intervention for this condition (enter 99999 if N/A or 88888 if unknown)	Past Health History	Free Text		
131	If patient ever had an elevated fasting glucose level, at what age was the patient? (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
132	If patient ever had an elevated fasting insulin level, at what age was the patient? (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
133	Patient's age at menarche, if female (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
134	Patient's age at puberty, if male (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)

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135	If patient had atypical genitalia at time of initial intervention for this condition, what type of atypical finding was noted? (complete Urogenital Survey now)	Past Health History - Genital	Check boxes	Missing/unknown data, N/A - genitalia were normal, abdominal testes, abnormal anogenital distance, anorchia, bifid scrotum, chordee, clitoromegaly, complete labioscrotal fusion, cryptorchidism, glandular hypospadias, hyperpigmentation, inguinal testes, labial testes, proximal penile hypospadias, distal penile hypospadias, penoscrotal hypospadias, micropenis, penile enlargement, partial labioscrotal fusion, rugated	
136	If patient had micropenis or penile enlargement at time of initial intervention for this condition, size of penis: enter as length, width in	Past Health History - Genital	Decimal		(cm)
137	If patient had clitoromegaly at time of initial intervention for this condition, size of clitoris: enter as length,width in cm (enter 99999 if	Past Health History - Genital	Decimal		(cm)
138	Was genital surgery performed before enrollment?	Past Health History - Surgery	Pick List	Missing/unknown data, N/A - no genital abnormalities indicating need for surgery, yes (complete Urogenital Survey now), no	
139	Testicular volume (enter volume as left testicle, right testicle) at time of intial intervention for this condition (enter 99999 if N/A or	Past Health History - Genital	Decimal		(mL)
140	At time of enrollment, did patient present with atypical genitalia?	Past Health History - Genital	Check boxes	Missing/unknown data, N/A - enrollment is initial intervention, N/A - genitalia were normal, abdominal testes, abnormal anogenital distance, anorchia, bifid scrotum, chordee, clitoromegaly, complete labioscrotal fusion, cryptorchidism, glandular hypospadias, hyperpigmentation, inguinal testes, labial testes, proximal penile hypospadias, distal penile hypospadias, penoscrotal hypospadias, micropenis, penile enlargement, partial	
141	Pelvic/testicular/genitogram ultrasound results at initial intervention for this condition?	Past Health History - Imaging	Pick List	Missing/unknown data, not done, normal, abnormal pelvic ultrasound, abnormal testicular ultrasound, abnormal - gonads not visualized, non-diagnostic	

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142	If abnormal pelvic ultrasound results, explain finding (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		
143	If abnormal testicular ultrasound results, explain finding (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		
144	If patient had a urogenital sinus, what was the confluence of the urogenital sinus with the vagina?	Past Health History - Imaging	Pick List	Missing/unknown data, N/A, low, high	
145	If patient had a urogenital sinus, enter size (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Decimal		(cm)
146	Results of bone age at initial intervention for this condition (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		(years, months)
147	Date of bone age at initial intervention for this condition (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Date Field		
148	Method of reading bone age	Past Health History - Imaging	Pick List	Missing/unknown data, N/A, bone age not done, Greulich Pyle, Tanner Whitehouse, other	
149	Has a dexa scan been performed prior to enrollment?	Past Health History - Imaging	Check boxes	Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other	
150	If a dexa scan was found to be abnormal, what was the patient's age at first abnormal dexa scan?	Past Health History - Imaging	Decimal		(years of age)

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151	If abnormal dexa scan (z-score \leq -3 to -2), specify site	Past Health History - Imaging	Check boxes	Missing/unknown, N/A, hip, heel, pelvis, spine, total body, wrist, other	
152	If abnormal dexa scan (z-score \leq -4 to -3), specify site	Past Health History - Imaging	Check boxes	Missing/unknown, N/A, hip, heel, pelvis, spine, total body, wrist, other	
153	If abnormal dexa scan (z-score \leq -4), specify site	Past Health History - Imaging	Check boxes	Missing/unknown, N/A, hip, heel, pelvis, spine, total body, wrist, other	
154	Are oral steroids prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, N/A, yes-liquid, yes-tablet, no	
155	If oral steroids are prescribed, name of product (enter N/A if not applicable)	Past Health History - Pharmacotherapy	Free Text		
156	If on oral steroids, daily dose prescribed (enter 99999 if N/A or 88888 if unknown)	Past Health History - Pharmacotherapy	Decimal		(mg/day)
157	If on oral steroids, frequency prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other	
158	At what age were oral steroids first initiated (enter 99999 if NA or 88888 if unknown)	Past Health History - Pharmacotherapy	Decimal		(years, months)
159	Is fludrocortisone prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, yes, no	

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160	If on fludrocortisone, dose prescribed (enter 99999 if N/A or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(mg/day)
161	If on fludrocortisone, frequency prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other	
162	If on fludrocortisone, at what age was Florinef first initiated (enter 99999 if NA or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(years, months)
163	Other medications	Past Health History - Pharmacotherapy	Check boxes	Missing/unknown data, none, antianxiety, antidepressants, antihypertensives, antipsychotics, aromatase inhibitor - anastrozole, aromatase inhibitor - letrozole, calcitonin, calcium, contraceptives - oral, diuretics - calcium channel blocker, diuretics - loop diuretics, diuretics - potassium sparing, diuretics - thiazide, estrogen - oral, estrogen - patch, estrogen+progesterone-oral, estrogen+ progesterone-transdermal, estrogen+androgen-oral, estrogen-vaginal, GnRH analog, growth hormone, insulin, insulin sensitizers, iron, medroxyprogesterone - oral, testosterone - oral,	
164	If on growth hormone, at what age was growth hormone first initiated (enter 99999 if NA or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(years, months)
165	If on GnRH analog (Lupron), at what age was GnRH analog first initiated (enter 99999 if NA or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(years, months)
166	If on aromatase inhibitor, at what age was aromatase inhibitor first initiated (enter 99999 if NA or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(years, months)
167	Patient/primary caregiver was given the 24 hour on-call contact information for an endocrine provider?	Emergency Management	Pick List	Missing/unknown data, yes, no	

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168	Patient/primary caregiver was given a written emergency medical letter specific to this condition?	Emergency Management	Pick List	Missing/unknown data, yes, no	
169	Patient/primary caregiver was given a sick day plan specific to this condition?	Emergency Management	Pick List	Missing/unknown data, yes, no	
170	Patient was enrolled in a web-based emergency alert program?	Emergency Management	Pick List	Missing/unknown data, yes - MEMSCIS, yes - other web-based program, no	
171	At time of enrollment, was patient provided instruction on how and when to administer an intramuscular hydrocortisone	Emergency Management	Pick List	Missing/unknown data, N/A - non-classical form, no, yes	
172	Who provided the instruction on how and when to administer an intramuscular hydrocortisone injections?	Emergency Management	Pick List	Missing/unknown data, N/A - non-classical form, no, yes - provider, yes - nurse	
173	Was neuropsychological testing performed prior to enrollment?	Development	Pick List	Missing/unknown data, N/A - no neuropsych evaluation has been done on this patient, above average, average, below average	
174	Were behavioral concerns suspected prior to enrollment?	Development	Pick List	Missing/unknown data, yes (go to next question and explain), no	
175	If behavioral concerns were suspected prior to enrollment, explain	Development	Free Text		
176	If behavioral concerns were suspected prior to enrollment, was patient referred for further evaluation at that time?	Development	Check boxes	Missing/unknown data, yes - to behavioral pediatrics, yes - to neuropsychologist, yes - to psychiatrist, yes - to psychologist, yes - to therapist/counselor, yes - to other	

Congenital Adrenal Hyperplasia (CAH) Data Elements - Enrollment

177	Were there any psychological concerns related to this condition prior to enrollment?	Development	Pick List	Missing/unknown data, yes (go to next question and explain), no	
178	If psychological concerns were present prior to enrollment, explain	Development	Free Text		
179	Was patient referred for Special Education evaluation prior to enrollment?	Education	Pick List	Missing/unknown data, yes, no	
180	Were Special Educational services received by this patient prior to enrollment?	Education	Pick List	Missing/unknown data, yes -IEP/IFSP, yes - 504 plan, yes other, no	
181	If Special Educational services were received prior to enrollment: age (in years) child qualified for services?	Education	Pick List	Missing/unknown data, N/A - no Special Ed services were received, N/A - patient is >21 years old, <1, >1-2, >2-3, >3-4, >4-5, 6-10, 11-17, 18+	
182	Reason Special Educational services were received prior to enrollment?	Education	Check boxes	Missing/unknown data, N/A (no Special Ed services are currently received), cognitive disability, fine motor disability, gross motor disability, learning disability, social-emotional disability, speech-language disability, other	
183	At time of enrollment, were educational materials relating to this condition provided to the parent/guardian and/or patient?	Education	Pick List	Missing/unknown data, no, yes	
184	If educational materials relating to this condition were provided, what were the materials? (enter 99999 if N/A, 88888 if unknown)	Education	Free Text		