

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Measure	Category	Answer Type	Measure Answer	Units (for value box)
Unique registry ID	Demographics	Free Text		(2digFIPS/2dig BirthYr/ 1digCenter/3digAscession) NEED TO
Was enrollment in registry refused?	Demographics	Yes No		
Who consented enrollment in registry?	Demographics	Pick List	Missing/unknown data, both parents, mother only, father only, guardian	
Permission to contact about research	Demographics	Yes No	Permission to contact: I agree to be contacted with information on potential future research applicable to my/my child's disorder that becomes available.	
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 me/my child are eligible for compensation.	
Patient is enrolled in other research studies	Demographics	Pick List	Missing/unknown data, no, yes - other Region 4 emergency studies, yes - other Region 4 clinical/medication studies, yes - other Region 4 psychosocial studies, yes - studies related to this disorder not conducted through Region 4, yes - other research	
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 deemed not necessary	
Has patient been followed by >1 center for this disorder?	Demographics	Pick List	Missing/unknown data, yes, no	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

If patient has been followed by >1 center for this disorder note in which states these centers were located (enter 99999 if N/A; 88888 if unknown)	Demographics	Free Text		
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	
If patient has been followed by >1 center for this disorder, what type of provider was treating the patient?	Demographics	Check boxes	Missing/unknown data, adult endocrinologist, geneticist, family practice physician, internist, nurse practitioner, pediatric endocrinologist, pediatrician	
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, pulmonology, physical therapy, psychiatry, psychology, public health nursing, respiratory therapy, urology, speech-	
Community resources received by patient	Demographics	Check boxes	Missing/unknown data, none, daycare, family support group related to this disorder, 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 (CAC/CADI waiver, other waivers)	
If deceased, date of death (if N/A enter 01/01/1901)	Demographics	Date Field		
Ethnic category	Demographics	Pick List	Missing/unknown data, Hispanic or Latino, not Hispanic or Latino	
Racial category	Demographics	Pick List	Missing/unknown data, American Indian/Alaska Native, Asian, Native Hawaiian or other Pacific Islander, Black or African American, White	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Mother's maiden name at birth	Demographics	Free Text		
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	
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	
Is primary caregiver proficient in written English?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
Is primary caregiver proficient in spoken English?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
Was written/web-based information on this disorder provided in primary caregiver's primary language?	Socioeconomic Status	Pick List	Missing/unknown data, yes, no	
Primary insurance at birth (enter 88888 if unknown)	Socioeconomic Status	Free Text		
Marital status at birth	Socioeconomic Status	Pick List	Missing/unknown data, married, not married	
Family members (number of siblings, half-siblings, adopted); enter 88888 if unknown	Socioeconomic Status	Free Text		

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Mother's height self-report at time of patient enrollment in registry (or 88888 if unknown)	Family History	Decimal		(cm)
Father's height self-report at time of patient enrollment in registry (or 88888 if unknown)	Family History	Decimal		(cm)
Are parents affected with CAH?	Family History	Pick List	Missing/unknown data, mother affected, father affected, mother not affected, father not affected	
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, ovarian tumors, pituitary adenoma, polycystic ovarian syndrome, precocious puberty, short stature, sibling death,	
If infant/sibling death(s): enter sibling #, date(s) of death, cause(s) of death if known, and sex of sibling male/female if known (enter 99999 if N/A or 88888 if unknown)	Family History	Free Text		
Sibling #1 (oldest sibling) evaluated for this disorder?	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	
Sibling #2 (second oldest sibling) evaluated for this disorder?	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	
Sibling #3 (third oldest sibling) evaluated for this disorder?	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	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Sibling #4 (fourth oldest sibling) evaluated for this disorder?	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	
Sibling #5 (fifth oldest sibling) evaluated for this disorder?	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	
Sibling #6 (sixth oldest sibling) evaluated for this disorder?	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	
If sibling(s) affected with this disorder enter sibling # and sibling unique registry ID number(s) here (enter 99999 if N/A)	Family History	Free Text		
Was prenatal testing for this disorder done during this pregnancy?	Prenatal History	Pick List	Missing/unknown data, yes, no, offered but declined by parent	
Method(s) if prenatal testing for this disorder done	Prenatal History	Check boxes	Missing/unknown data, N/A, amniocentesis (biochemical/enzyme), amniocentesis (DNA), chorionic villus (biochemical/enzyme), chorionic villus (DNA), fetal skin biopsy, periumbilical blood sampling (fetal blood), prenatal ultrasound (brain abnormality), prenatal ultrasound (renal	
Maternal steroid treatment received during this pregnancy?	Prenatal History	Check boxes	Missing/unknown data, no, yes - dexamethasone, yes - betamethasone, yes - prednisone, yes - other steroid	
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	
If maternal steroid treatment received during this pregnancy, what was the daily dose of steroid (enter 99999 if N/A or 88888 if unknown)?	Prenatal History	Decimal		

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

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 unknown)?	Prenatal History	Decimal		(weeks gestation)
If maternal steroid treatment received during this pregnancy, week of gestation at end of treatment (enter 99999 if N/A or 88888 if unknown)?	Prenatal History	Decimal		(weeks gestation)
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	
Was mother receiving other medications during pregnancy (enter 99999 if N/A or 88888 if unknown)?	Prenatal History	Free Text		
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	
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	
Weeks of gestation at birth (enter 88888 if unknown)	Neonatal History	Decimal		weeks
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, transfused	
Birth weight (enter 88888 if unknown)	Measurements	Decimal		(kg)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Birth height (enter 88888 if unknown)	Measurements	Decimal		(cm)
Birth head circumference (OFC) (enter 88888 if unknown)	Measurements	Decimal		(cm)
State newborn screen serial number (enter 88888 if unknown)	Newborn Screening	Integer		
If newborn screened, days of age at time primary care provider or endocrine provider were notified of FIRST abnormal newborn screen for this child (enter 88888 if unknown)	Newborn Screening	Decimal		(days)
17-hydroxyprogesterone (17-OHP) on FIRST newborn screen (enter 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
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)
2nd tier 17-hydroxyprogesterone (17-OHP) + androstenedione/cortisol ratio from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		
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	
2nd tier results 21-deoxycortisol from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

2nd tier results 11-deoxycortisol from FIRST newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
17-hydroxyprogesterone (17-OHP) on SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
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)
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		
2nd tier cortisol results from SECOND newborn screen	Newborn Screening	Pick List	Missing/unknown data, N/A - 2nd tier screen not done, yes, no	
2nd tier results 21-deoxycortisol from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
2nd tier results 11-deoxycortisol from SECOND newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
17-hydroxyprogesterone (17-OHP) on THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
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)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

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		
2nd tier cortisol results from THIRD newborn screen	Newborn Screening	Pick List	Missing/unknown data, N/A - 2nd tier screen not done, yes, no	
2nd tier results 21-deoxycortisol from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
2nd tier results 11-deoxycortisol from THIRD newborn screen (enter 99999 if N/A or 88888 if unknown)	Newborn Screening	Decimal		(ng/mL)
Baseline serum 17-hydroxyprogesterone (17-OHP) level (enter 99999 if NA or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
Baseline serum deoxycorticosterone (DOC) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
Baseline serum 17-hydroxypregnenolone (17-OHPreg) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
Baseline serum corticosterone (B) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
Baseline serum cortisol (F) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Baseline serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
Baseline serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
Baseline serum dehydroxyepiandrosterone (DHEA) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/dl
Baseline serum dihydrotestosterone (DHT) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		pg/ml
Baseline renin level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		ng/ml/hr
Was a cosyntropin (ACTH) stimulation test performed?	Diagnostic Testing	Pick List	Missing/unknown information, yes, no	
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)
ACTH stimulated serum 17-hydroxyprogesterone (17-OHP) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum deoxycorticosterone (DOC) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

ACTH stimulated serum 17-hydroxypregnenolone (17-OHPreg) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum corticosterone (B) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum cortisol (F) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)
ACTH stimulated serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum dehydroxyepiandrosterone (DHEA) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
ACTH stimulated serum dehydroxyepiandrosterone sulfate (DHEA-S) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ug/dL)
Was a β -hCG stimulation test performed?	Diagnostic Testing	Pick List	Missing/unknown information, yes, no	
Dose and frequency of β -hCG stimulation test? (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

If β -hCG stimulation test performed, at what age? (enter 99999 if N/A, or 88888 if unknown).	Diagnostic Testing	Integer		years
β -hCG stimulated serum testosterone (T) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
β -hCG stimulated serum androstenedione (D4A) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(ng/dL)
β -hCG stimulated serum dihydrotestosterone (DHT) level (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Decimal		(pg/mL)
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 detected	
If common or targeted mutation panel performed, please list laboratory	Diagnostic Testing	Free Text		
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 mutations were detected	
Mutation description on patient: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Mutation description on patient: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Mutation description on biological mother: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Mutation description on biological mother: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Mutation description on biological father: Allele 1 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Mutation description on biological father: Allele 2 (format example 985A>G) (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Karyotype results	Diagnostic Testing	Pick List	Missing/unknown data, karyotype was not done, 46XX, 46XY, mosaicism or other (go to next question and explain)	
If karyotype is a mosaicism or other, please describe (enter 99999 if N/A or 88888 if unknown)	Diagnostic Testing	Free Text		
Was genetic counseling for this disorder provided?	Past Health History	Pick List	Missing/unknown data, yes, no	
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	
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 – pediatric endocrinologist, by another provider – pediatrician	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

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 oxidoreductase (POR), not determined	
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	
Age at time of initial face to face intervention for this disorder (enter 88888 if unknown)	Past Health History	Free Text		(days, months, years)
Symptom(s) - manifestations at time of initial intervention for this disorder	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, skeletal malformations, tachypnea, vaginal bleeding, vomiting, other (go to next question and explain)	
Other symptom(s) - manifestations at time of initial intervention for this disorder	Past Health History	Free Text		
Weight at time of initial intervention for this disorder (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(kg)
Height at time of initial intervention for this disorder (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(cm)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Head circumference (OFC) at time of initial intervention for this disorder (enter 88888 if unknown or 77777 if not done)	Past Health History	Decimal		(cm)
Blood pressure at time of initial intervention for this disorder	Past Health History	Pick List	Missing/unknown data, blood pressure not measured, hypertension, hypotension, normal blood pressure	
If patient has abnormal blood pressure, at what age was abnormal blood pressure originally observed (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
Tanner Stage of pubic hair development at time of initial intervention for this disorder	Past Health History	Pick List	Missing/unknown data, not done, I, II, III, IV, V	
Tanner Stage of breast development at time of initial intervention for this disorder	Past Health History	Pick List	Missing/unknown data, N/A, not done, I, II, III, IV, V	
Menstrual history at time of initial intervention for this disorder	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	
Lab tests collected at initial intervention for this disorder	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) - Abn, Urine (24 hours) for 17-ketosteroids - WNL, Urine (24 hours) for 17-ketosteroids - high, Urine (24 hours) for 17-ketosteroids - low, Urine (24 hours) for 17-	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Lab tests other general (indicate type and if WNL or Abn) collected at initial intervention for this disorder (enter 99999 if N/A or 88888 if unknown)	Past Health History	Free Text		
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)
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)
Patient's age at menarche, if female (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
Patient's age at puberty, if male (enter 99999 if N/A or 88888 if unknown)	Past Health History	Decimal		(years, months)
If patient had atypical genitalia at time of initial intervention for this disorder, 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 labioscrotal folds, single perineal opening, vaginal pouch	
If patient had micropenis or penile enlargement at time of initial intervention for this disorder, size of penis: enter as length, width in cm (enter 99999 if N/A or 88888 if unknown)	Past Health History - Genital	Decimal		(cm)
If patient had clitoromegaly at time of initial intervention for this disorder, size of clitoris: enter as length,width in cm (enter 99999 if N/A or 88888 if unknown)	Past Health History - Genital	Decimal		(cm)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

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	
Testicular volume (enter volume as left testicle, right testicle) at time of initial intervention for this disorder (enter 99999 if N/A or 88888 if unknown or	Past Health History - Genital	Decimal		(mL)
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 labioscrotal fusion, rugated labioscrotal folds, single perineal opening, vaginal pouch	
Pelvic/testicular/genitogram ultrasound results at initial intervention for this disorder?	Past Health History - Imaging	Pick List	Missing/unknown data, not done, normal, abnormal pelvic ultrasound, abnormal testicular ultrasound, abnormal - gonads not visualized, non-diagnostic	
If abnormal pelvic ultrasound results, explain finding (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		
If abnormal testicular ultrasound results, explain finding (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		
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	
If patient had a urogenital sinus, enter size (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Decimal		(cm)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Results of bone age at initial intervention for this disorder (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Free Text		(years, months)
Date of bone age at initial intervention for this disorder (enter 99999 if N/A or 88888 if unknown)	Past Health History - Imaging	Date Field		
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	
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	
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)
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	
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	
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	
Are oral steroids prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, N/A, yes-liquid, yes-tablet, no	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

If oral steroids are prescribed, name of product (enter N/A if not applicable)	Past Health History - Pharmacotherapy	Free Text		
If on oral steroids, daily dose prescribed (enter 99999 if N/A or 88888 if unknown)	Past Health History - Pharmacotherapy	Decimal		(mg/day)
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	
At what age were oral steroids first initiated (enter 99999 if NA or 88888 if unknown)	Past Health History - Pharmacotherapy	Decimal		(years, months)
Is fludrocortisone prescribed?	Past Health History - Pharmacotherapy	Pick list	Missing/unknown data, yes, no	
If on fludrocortisone, dose prescribed (enter 99999 if N/A or 88888 if unknown)?	Past Health History - Pharmacotherapy	Decimal		(mg/day)
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	
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)

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

Other medications (see optional DocSite detailed medication survey)	Past Health History - Pharmacotherapy	Check boxes	Missing/unknown data, none, anti-anxiety, 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, sleeping medications, testosterone - gel, testosterone - IM, testosterone – patch, vitamin D, vitamins - daily,	
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)
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)
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)
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	
Patient/primary caregiver was given a written emergency medical letter specific to this disorder?	Emergency Management	Pick List	Missing/unknown data, yes, no	
Patient/primary caregiver was given a sick day plan specific to this disorder?	Emergency Management	Pick List	Missing/unknown data, yes, no	
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	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

At time of enrollment, was patient provided instruction on how and when to administer an intramuscular hydrocortisone injection?	Emergency Management	Pick List	Missing/unknown data, N/A - non-classical form, no, yes	
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	
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	
Were behavioral concerns suspected prior to enrollment?	Development	Pick List	Missing/unknown data, yes (go to next question and explain), no	
If behavioral concerns were suspected prior to enrollment, explain	Development	Free Text		
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	
Were there any psychological concerns related to this disorder prior to enrollment?	Development	Pick List	Missing/unknown data, yes (go to next question and explain), no	
If psychological concerns were present prior to enrollment, explain	Development	Free Text		
Was patient referred for Special Education evaluation prior to enrollment?	Education	Pick List	Missing/unknown data, yes, no	

Congenital adrenal hyperplasia (CAH) Enrollment Survey: Infancy Through Puberty

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	
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+	
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 health impaired (OHI), other	