

List of variables

variable name	storage	display type	format
Identification patient			
N° identification patient		str12	%12s
Inclusion date		int	%dD/N/CY
Sex		byte	%8.0g
Age at inclusion		float	%9.0g
Included by Dr		str9	%9s
Followed by Dr		str14	%14s
Type of speciality		byte	%8.0g
Date of birth		int	%dD/N/CY
City of birth		str16	%16s
Department of birth		int	%8.0g
Country of birth		str8	%9s
Genetic diagnosis			
Place		str51	%51s
Genotype		byte	%8.0g
Age at diagnosis (year)		byte	%8.0g
Age at diagnosis (month)		float	%9.0g
Made by (speciality)		byte	%8.0g
Patients followed (Yes/No)		byte	%8.0g
Beginning of comprehensive care (year)	byte		%8.0g
Beginning of comprehensive care (month)	byte		%8.0g
Medical history			
Father			
(diabetes type1, type2, No)		byte	%8.0g
Mother			
(diabetes type1, type2, No)		byte	%8.0g
Maternal grandmother			
(diabetes type1, type2, No)		byte	%8.0g
Maternal grandfather			
(diabetes type1, type2, No)		byte	%8.0g
Paternal grandmother			
(diabetes type1, type2, No)		byte	%8.0g
Paternal grandfather			
(diabetes type1, type2, No)		byte	%8.0g
Father			
-Ethnic origin		byte	%8.0g
-Year of birth		int	%8.0g
-Weight (kg)		int	%8.0g
-Height (cm)		int	%8.0g
-Chronic illness (Yes/No)		byte	%8.0g
-Description		str37	%37s
Mother			
-Ethnic origin		byte	%8.0g
-Year of birth		int	%8.0g
-Weight (kg)		int	%8.0g
-Height (cm)		int	%8.0g
-Chronic illness (Yes/No)		byte	%8.0g
-Description		str37	%37s
Family			
Familial situation			
-In couple, 1 or 2 parents			
deceased, separation	byte		%8.0g
-If separation, precise year	int		%8.0g
-Familial recomposition	byte		%8.0g
-Custody of the child	byte		%8.0g
-Number of children in family	byte		%8.0g
-Position of PWS in family	byte		%8.0g
Professional situation of the father			
-Qualification, degree	byte		%8.0g
-fulltime/halftime occupation	byte		%8.0g
-occupation	str49		%49s
-modification of professional			

situation due to the disease of your child (Yes/No)	byte	%8.0g
-precision on modification	str80	%80s
Professional situation of the mother		
-Qualification, degree	byte	%8.0g
-fulltime/halftime occupation	byte	%8.0g
-occupation	str49	%49s
-modification of professional situation due to the disease of your child (Yes/No)	byte	%8.0g
-precision on modification	str80	%80s
Standard of living	byte	%8.0g
Security cover for care of PWS child	byte	%8.0g
If insufficient, explain why	str80	%80s

Association of parents

Adhesion to association (Yes/No)	byte	%8.0g
Age at adhesion (year)	int	%8.0g
Age at adhesion (month)	byte	%8.0g
If no adhesion, explain why	byte	%8.0g

Pregnancy and neonatal period

- Pregnancy:

Additional check-up (Yes/No)	byte	%8.0g
If yes, precise	str80	%80s
Specific medication	byte	%8.0g
If yes, precise	str80	%80s
Additional ultrasound scan	byte	%8.0g
If yes, result	str67	%67s
Amniocentesis (Yes/No)	byte	%8.0g
If yes, result	str75	%75s
Gestational age	byte	%8.0g
Caesarean or vaginal delivery	byte	%8.0g

- Birth data:

Birth length (cm)	byte	%8.0g
Apgar score 1min	byte	%8.0g
Apgar score 5min	byte	%8.0g
Hypotonia (Yes/No)	byte	%8.0g
Neonatal hospitalisation (Yes/No)	byte	%8.0g
Duration of hospitalisation	int	%8.0g
Hospitalisation during the first 2 months (Yes/No)	byte	%8.0g
Duration of hospitalisation	int	%8.0g
Gastric tube feeding (Yes/No)	byte	%8.0g
Duration of gastric tube feeding	int	%8.0g
Complications (Yes/No)	byte	%8.0g
If yes, precise complications	str80	%80s

Auxological measurements

- Height and weight:

Weight (kg) at 4 months	float	%9.0g
Height (cm) at 4 months	float	%9.0g
Weight (kg) at 9 months	float	%9.0g
Height (cm) at 9 months	float	%9.0g
Weight (kg) at 2 years	float	%9.0g
Height (cm) at 2 years	float	%9.0g
Weight (kg) at 5 years	float	%9.0g
Height (cm) at 5 years	float	%9.0g
Weight (kg) at 10 years	float	%9.0g
Height (cm) at 10 years	float	%9.0g
Weight (kg) at 15 years	float	%9.0g
Height (cm) at 15 years	float	%9.0g
Weight (kg) at inclusion	float	%9.0g
Height (cm) at inclusion	float	%9.0g

- Obesity:

Age of adiposity rebound (year)	byte	%8.0g
Age of adiposity rebound (month)	byte	%8.0g
Obesity (Yes/No)	byte	%8.0g
Age when reaching obesity grade 1 (year)	byte	%8.0g
Age when reaching obesity grade 1 (month)	byte	%8.0g
Age when reaching obesity grade 2 (year)	byte	%8.0g

Age when reaching obesity grade 2 (month) byte %8.0g
 Copy of growth chart (Yes/No) byte %8.0g

Endocrine dysfunctions

- GH deficiency
 Exploration of GH deficit (Yes/No) byte %8.0g
 1st stimulation test:
 Type of test str19 %19s
 Date str10 %10s
 GH peak (ng/ml or mU/l) float %9.0g
 Result byte %8.0G
 (partial GHD, complete GHD or no GHD)
 2nd stimulation test:
 Type of test str19 %19s
 Date str10 %10s
 GH peak (ng/ml or mU/l) float %9.0g
 Result byte %8.0g
 (partial GHD, complete GHD or no GHD)
 IGF-I before GH treatment int %8.0g
 Date of dosage str10 %10s
 GH treatment (Yes/No) byte %8.0g
 Age start GH (year) byte %8.0g
 Age start GH (month) byte %8.0g
 GH dose 1st year (mg/kg/week) float %9.0g
 GH dose 1st year (mg/week) float %9.0g
 Height gain 1st year (DS) float %9.0g
 Total height gain (DS) float %9.0g
 BMI at start of GH float %9.0g
 BMI after 1 year GH float %9.0g
 Actual BMI float %9.0g
 BMI at stop of GH float %9.0g
 Age at stop of GH (year) byte %8.0g
 Age at stop of GH (month) byte %8.0g
 Reason for stopping GH byte %8.0g

- Hypogonadism:
 Hypogonadism (Yes/No/ND) byte %8.0g
 Confirmation by byte %8.0g
 Treatment (Yes/No) byte %8.0g
 Age at start of treatment (year) byte %8.0g
 Age at start of treatment (month) byte %8.0g
 Type of treatment str16 %16s
 Treatment stopped (Yes/No) byte %8.0g
 Age at stop of treatment (year) byte %8.0g
 Age at stop of treatment (month) byte %8.0g

- Cryptorchidism:
 Cryptorchidism (Yes/No) byte %8.0g
 If yes, unilateral or bilateral byte %8.0g
 Surgery (Yes/No) byte %8.0g
 Age at surgery (year) byte %8.0g
 Age at surgery (month) byte %8.0g

- Hypothyroidism:
 Hypothyroidism (Yes/No/ND) byte %8.0g
 Treatment (Yes/No) byte %8.0g
 Type of treatment str11 %11s
 Age at start of treatment (year) byte %8.0g
 Age at start of treatment (month) byte %8.0g
 Dose (µg/Kg/j) int %8.0g
 Age at stop of treatment (year) byte %8.0g
 Age at stop of treatment (month) byte %8.0g

Psychomotor development and language

Walking age (year) byte %8.0g
 Walking age (month) byte %8.0g
 Dysarthry (No/Moderate/Severe) byte %8.0g
 Elocution trouble byte %8.0g
 Normal scholarisation (Yes/No) byte %8.0g
 If no precise str35 %35s
 Age at start of special scholarisation float %9.0g
 Description of the scholarisation:
 Maternelle (Yes/No) byte %8.0g
 If yes, how many years byte %8.0g
 Primaire (Yes/No) byte %8.0g

If yes, how many years	byte	%8.0g
Collège (Yes/No)	byte	%8.0g
If yes, how many years	byte	%8.0g
Lycée (Yes/No)	byte	%8.0g
If yes, how many years	byte	%8.0g
IME (Yes/No)	byte	%8.0g
If yes, how many years	byte	%8.0g
IMPro (Yes/No)	byte	%8.0g
Other (Yes/No)	byte	%8.0g
If yes, how many years	byte	%8.0g

Management

- Nutritional management:		
By dietetician (Active/Stopped/Never)	byte	%8.0g
Frequency (/year)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Physiotherapy		
Active/Stopped/Never	byte	%8.0g
Frequency (/week)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Speech and language management		
Active/Stopped/Never	byte	%8.0g
Frequency (/week)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Psychomotricity		
Active/Stopped/Never	byte	%8.0g
Frequency (/week)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Ophtalmology		
Strabism (Yes/No)	byte	%8.0g
Type of treatment	str16	%16s
Myopia (Yes/No)	byte	%8.0g
- Tonsillectomy (Yes/No)	byte	%8.0g
Age at tonsillectomy (years)	float	%9.0g
- Adenoidectomy (Yes/No)	byte	%8.0g
Age at adenoidectomy (years)	float	%9.0g
- Other specific management		
precise	str65	%65s
age at start	byte	%8.0g
frequency	byte	%8.0g
duration (years)	byte	%8.0g

Behavioural troubles

- Food-related troubles:		
Actually (severe/moderate/absent)	byte	%8.0g
Historically (severe/moderate/absent)	byte	%8.0g
Age at start (years)	float	%9.0g
Duration (years)	byte	%8.0g
- Anxiety		
severe/moderate/absent	byte	%8.0g
Age at start (years)	float	%9.0g
Age at end (years)	float	%9.0g
- Depression		
severe/moderate/absent	byte	%8.0g
Age at start (years)	float	%9.0g
Age at end (years)	float	%9.0g
- Anxiety		
severe/moderate/absent	byte	%8.0g
Age at start (years)	float	%9.0g
Age at end (years)	float	%9.0g
- Obsessive compulsive disorder		
severe/moderate/absent	byte	%8.0g
Age at start (years)	float	%9.0g
Age at end (years)	float	%9.0g
- Psychotic aspects		

severe/moderate/absent	byte	%8.0g
Age at start (years)	float	%9.0g
Age at end (years)	float	%9.0g
- Psychological management		
Active/Stopped/Never	byte	%8.0g
Frequency (/week)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Psychiatric management		
Active/Stopped/Never	byte	%8.0g
Frequency (/week)	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	float	%9.0g
- Medication		
Yes/No	byte	%8.0g
Posology	byte	%8.0g
Age at start (year)	byte	%8.0g
Age at start (month)	byte	%8.0g
Duration (years)	byte	%8.0g
Indication	str47	%47s

Complications

- Glucose intolerance (OGTT)		
Yes/No/ND	byte	%8.0g
If yes, at what age	byte	%8.0g
Continued/Stopped	byte	%8.0g
- Diabetes mellitus		
Type1/Type2/No/ND	byte	%8.0g
If yes, at what age	byte	%8.0g
Treatment (Yes/No)	byte	%8.0g
If yes, precise	byte	%8.0g
- Hypertension		
Yes/No/ND	byte	%8.0g
Treated (Yes/No)	byte	%8.0g
Start at what age	byte	%8.0g
- Leg oedema		
Yes/No/ND	byte	%8.0g
Start at what age	byte	%8.0g
- Respiratory		
Snoring (Yes/No/ND)	byte	%8.0g
Start at what age	byte	%8.0g
Sleep apnoea confirmed by polysomnography (Yes/No/ND)	byte	%8.0g
Date of polysomnography	str10	%10s
Result	str76	%76s
Treatment (Yes/No)	byte	%8.0g
Precise treatment	str45	%45s
- Orthopedic		
Hip dysplasia (Yes/No)	byte	%8.0g
If yes, treatment	str80	%80s
Scoliosis (Yes/No)	byte	%8.0g
Age of diagnosis (year)	float	%9.0g
Bracing (Yes/No)	byte	%8.0g
If yes, at what age	float	%9.0g
Surgery (Yes/No)	byte	%8.0g
If yes, at what age	float	%9.0g
- Other	str80	%80s