

ICPGC Common Data Elements

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Background

These common data elements (CDEs) were developed in 2019 by the International Cerebral Palsy Genomics Consortium Phenotype Working Group and invited CP experts through a Delphi Consensus Method. They are designed to be used for genomics research studies in cerebral palsy. The Minimum Data Set was defined and agreed upon via consensus by the ICPGC Phenotype Working Group – this is the minimum data necessary for upload to the CP Commons.

There are **121 CDEs**: 13 data elements make up the Minimum Data Set (Mandatory), 50x Core, 44x Recommended and 16x Exploratory data fields.

Current working version: Version 1.2, updated 8th October 2020

Demographics (11)

FIELD NAME	CATEGORY	DESCRIPTION	VALUE	NOTES / LOGIC
pedigree	Mandatory	What is the relationship of this individual to the proband?	0, Proband/Index 1, Daughter 2, Granddaughter 3, Grandson 4, Half-brother 5, Half-sister 6, Maternal Aunt 7, Maternal cousin 8, Maternal grandfather 9, Maternal Grandmother 10, Maternal Uncle 11, Brother 12, Father 13, Mother 14, Sister 15, Nephew 16, Niece 17, Paternal Aunt 18, Paternal Cousin 19, Paternal Grandfather 20, Paternal Grandmother 21, Paternal Uncle 22, Son 99, Unknown	Any value between 23-98 or text will generate an error
clinical_status	Mandatory	Does the individual have any clinically relevant phenotype present?	0, Unaffected 1, Affected	Proband should always=1. NB: All subsequent Mandatory fields are only mandatory for individuals classified as 1
birth_year	Mandatory	What is the individuals' year of birth?	XXXX (years)	1900+

sex	Mandatory	What is the sex of the individual?	1, Male 2, Female 3, Intersex 99, Unknown	Boolean
birth_country	Mandatory	What country was the individual born in?	ISO-3166 2-alpha code	Only 2 alpha codes are permissible
country_residence	Rec	What country does the individual currently reside in?	ISO-3166 2-alpha code	
personal_ethnicity	Rec	What ethnicity does the individual identify with?	free text	
genotype_ethnicity	Rec	What is the individuals' ethnicity; as determined by genotype?	free text	
vital_status	Core	What is the individual's vital status?	1, Alive 2, Dead 3, Unknown 4, Not reported	
death_age	Rec	If deceased, what was the individual's age at time of death (years)?	1-99	
cause_of_death	Core	If deceased, what was the individuals primary cause of death (ICD-10 code)	3-7 alphanumeric code with a single period (.) that follows the first 3 alphanumeric characters (e.g. F91.9)	https://icd.who.int/browse10/2019/en

Diagnostics (10)

FIELD NAME	CATEGORY	DESCRIPTION	VALUE	NOTES /LOGIC
CP_phenotype	Mandatory	Does the individual have a permanent (non-paroxysmal) movement disorder?	0, No 1, Yes	
CP_onset	Exploratory	Was onset at age 2 or younger?	0, No 1, Yes	
degenerative	Mandatory	Is the individual's clinical course degenerative?	0, No 1, Yes	
CP_dx	Core	Has the individual been diagnosed with CP?	0, No 1, Yes	
CP_dx_year	Recommended	What year was the individual diagnosed with CP?	YYYY	
confirmed_CP_dx	Core	Was the diagnosis of CP confirmed at age 5 or older?	0, No 1, Yes 2, Not yet five years of age 99, Unknown	
timing_CP_injury	Recommended	During what period did the individuals' CP-related brain disturbance occur?	1, Prenatal 2, Perinatal 3, Post-neonatal 99, Unknown	
ORDO	Core	Has the individual been diagnosed with a known syndrome?	3-6 numeric code	List all applicable ORDO codes (only use a space between each code, NO commas) "Blank" if patient phenotype is unknown.
OMIM	Core	Has the individual been diagnosed with a genetic disorder?	6-digit integer (minimum 100000)	List all applicable OMIM codes (only use a space between each code, NO commas) "Blank" if patient phenotype is unknown.
ICD10	Core	Please describe any medical conditions the individual may have (ICD-10 codes)	3-7 alphanumeric code with a single period (.) that follows the first 3 alphanumeric characters (e.g. F91.9)	List all applicable ICD-10 codes (only use a space between each code, NO commas) "Blank" if patient phenotype is unknown.

Clinical symptoms and physical signs (32)

FIELD	CATEGORY	DESCRIPTION	VALUE	
primary_motor	Mandatory	What is the predominant motor type of the individuals CP?	1, Spastic 2, Dyskinetic - Dystonic 3, Dyskinetic - Choreoathetosis 4, Ataxic 5, Hypotonic	
primary_motor_laterality	Mandatory	What is the laterality of the individuals predominant motor type?	1, Unilateral 2, Bilateral	
prim_spast_topo	Core	What is the individuals' predominant spastic topography?	1, Left hemiplegia 2, Right hemiplegia 3, Diplegia 4, Quadriplegia	This can only be responded if [primary_motor] has a value of (1).
prim_dyskinesia_type	Exploratory	If dyskinetic is predominant motor type, is the movement:	1, Focal 2, Generalised	This can only be responded if [primary_motor] has a value of (2 or 3).
second_motor	Core	What is the secondary motor type that the individual presents with?	1, Spastic 2, Dyskinetic - Dystonic 3, Dyskinetic - Choreoathetosis 4, Ataxic 5, Hypotonic	
second_motor_laterality	Core	What is the laterality of the individuals' secondary motor type?	1, Unilateral 2, Bilateral	
second_spast_topo	Core	Additional description of dyskinesia presentation	1, Left hemiplegia 2, Right hemiplegia 3, Diplegia 4, Quadriplegia	This can only be responded if [second_motor] has a value of (1).
second_dyskinesia_type	Exploratory	What is the individuals' secondary spastic topography?	1, Focal 2, Generalised	This can only be responded if [second_motor] has a value of (2 or 3).
second_NDD	Core	Does the individual have another neurodevelopmental disability?	0, No 1, Yes	

autism	Core	Does the individual have autism?	0, No 1, Yes	
autism_severity	Core	If the individual has an autism, what is the severity of the autism? Refer to DSM-5	1, Level 1: Requiring support 2, Level 2: Requiring substantial support 3, Level 3: Requiring very substantial support	This can only be responded if [autism] has a value of (1).
ADHD	Core	Does the individual have ADHD?	0, No 1, Yes	
ADHD_type	Core	If the individual has ADHD, what type of ADHD?	1, Primarily Hyperactive-Impulsive ADHD 2, Primarily Inattentive ADHD (formerly called ADD) 3, Combined Type ADHD	This can only be responded if [ADHD] has a value of (1).
ADHD_severity	Core	If the individual has an ADHD, what is the severity of the ADHD? Refer to DSM-5	1, Mild 2, Moderate 3, Severe	This can only be responded if [ADHD] has a value of (1).
epilepsy	Mandatory	Does the individual have epilepsy?	0, No 1, Yes 99, Unknown	
epilepsy_type	Core	If the individual has epilepsy, what type of epilepsy?	free text	This can only be responded if [epilepsy] has a value of (1).
ID	Core	Does the child have an intellectual impairment?	0, No 1, Yes	
ID_severity	Core	If the individual has an intellectual impairment, what is the severity of the impairment? (ICD10 codes F70 to F73)	1, Mild (IQ50 - 69) HP: 0001256 2, Moderate (IQ 35 - 49) HP: 0002342 3, Severe (IQ 20 - 34) HP: 0010864 4, Profound (IQ < 20) HP: 0002187 5, Impairment unspecified (IQ < 50)	This can only be responded if [ID] has a value of (1).
second_NDD_other	Core	If other, please specify:	free text	

visual_impairment	Core	Does the individual have a visual impairment?	0, No 1, Yes	
visual_severity	Core	If the individual has a visual impairment, please describe:	free text	This can only be responded if [visual_impairment] has a value of (1).
hearing_impairment	Core	Does the individual have a hearing impairment?	0, No 1, Yes	
hearing_severity	Core	If the individual has a hearing impairment, please describe:	free text	This can only be responded if [hearing_severity] has a value of (1).
congenital_anomalies	Core	Does the individual have any congenital anomalies?	0, No 1, Yes	
congenital_anomalies_type	Core	If the individual has a congenital anomaly/ies, which major anatomical system/s are involved?	1, Nervous system 2, Cardiovascular system 3, Respiratory system 4, Gastrointestinal system 5, Genital organs 6, Urinary system 7, Musculature system 8, Skeletal system 9, Integumentary system (skin) 10, Eye 11, Ear 12, Nose	This can only be responded if [congenital_anomalies] has a value of (1). Add all permissible values applicable – NO commas only spaces between each value.
congenital_anomalies_detail	Recommended	If the individual does have congenital anomalies, please describe: [free text]	free text	Add any free text to describe the congenital anomalies. This can only be responded if [congenital_anomalies] has a value of (1).

radiology_text	Recommended	If the individual has any relevant radiological findings, please describe: [free text]	free text	Add any radiology free text. Please watch for personal identifiers
chronic_pain	Exploratory	Has the individual reported experiencing chronic pain?	0, No 1, Yes - self report 2, Yes - proxy report	
chronic_pain_age	Exploratory	At what age was chronic pain reported?	XX	Integer
chronic_pain_measure	Exploratory	What validated outcome measure was used to assess chronic pain?	free text	
positive_HPOs	Mandatory	Please list positive HPO traits (minimum of 3):	<i>e.g. HP:0100277</i>	Add all applicable HPO that are present in the individual. Spaces between values, NO commas.
negative_HPOs	Exploratory	Please list phenotypic traits that are NOT present	<i>e.g. HP:0012447</i>	Add all applicable HPO that are NOT present in the individual. Spaces between values, NO commas.

CP-Specific Assessments (13)

FIELD NAME	CATEGORY	DESCRIPTION	VALUE	NOTES / LOGIC
GM	Recommended	Was a General Movements Assessment performed at 12 weeks of age, and if so what was the score?	0, No 1, Yes - normal 2, Yes - Abnormal fidgety 3, Yes - Absent fidgety	
HINE	Recommended	Was the Hammersmith Infant Neurological Examination (HINE) performed?	0, No 1, Yes	
HINE_age	Recommended	If the HINE was performed, at what age was the assessment performed?	MM	This can only be responded if [HINE] has a value of (1). Corrected age in months between 2-24 (integer)
HINE_outcome	Recommended	If the HINE was performed, what was the outcome of the assessment?	0-78	This can only be responded if [HINE] has a value of (1). Global score between 0-78 (Integer)
GMFCS	Mandatory	Gross Motor Functioning Classification System (GMFCS)© Score	1, GMFCS I 2, GMFCS II 3, GMFCS III 4, GMFCS IV 5, GMFCS V 99, Unknown	
BFMF	Recommended	Bimanual Fine Motor Function (BFMF) ©Score	1, BFMF I 2, BFMF II 3, BFMF III 4, BFMF IV 5, BFMF V	
MACS	Recommended	Manual Ability Classification System (MACS)© Score	1, MACS I 2, MACS II 3, MACS III 4, MACS IV 5, MACS V	

CFCS	Recommended	Communication Function Classification System (CFCS)© Score	1, CFCS I 2, CFCS II 3, CFCS III 4, CFCS IV 5, CFCS V
VFCS	Exploratory	Visual Function Classification System (VFCS)© Score	1, VFCS I 2, VFCS II 3, VFCS III 4, VFCS IV 5, VFCS V
MRICS	Core	Predominant Brain Pattern (Expanded MRI Classification System)	1, (A) Maldevelopments 2, (A.1) Maldevelopments - Disorders of cortical development (proliferation and/or migration and/or organisation) 3, (A.2) Maldevelopments - Other (ex: holoprosencephaly, Dandy-Walker formation, corpus callosum agenesis, cerebellar hypoplasia) 3, (B) Predominant White Matter Injury (PWMI) 4, (B.1) PWMI - PVL (mild/severe) 5, (B.2) PWMI - Sequelae of IVH or PVH infarction 6, (B.3) PWMI - Combination of PVL and IVH sequelae 7, (C) Predominant Grey matter Injury (PGMI) 8, (C.1) PGMI - Basal ganglia/thalamus lesions (mild/moderate/severe) 9, (C.2) PGMI - cortico-subcortical lesions only (watershed lesions in parasagittal distribution/multicystic encephalomalacia) not covered under C3 10, (C.3) PGMI - Arterial infarctions (middle cerebral artery/other) 11, (D) Miscellaneous changes (ex: cerebellar atrophy, cerebral atrophy, delayed myelination, ventriculomegaly not covered under B, haemorrhage not covered under B, brainstem lesions, calcifications) 12, (E) Normal
swallowing	Recommended	Participant eating/drinking/swallowing	1, Standard mean for age - no modifications required 2, Requires modified diet

VIKING	Recommended	Viking Speech Scale© Score	1, Score I 2, Score II 3, Score III 4, Score IV	
ICF	Recommended	WHO Disability Assessment Schedule 2.0	0-100	Summary disability profile score according to WHODAS2.0 (integer)

Family History (16)

FIELD NAME	CATEGORY	DESCRIPTION	VALUE
mat_age	Core	Maternal age at time of birth	YY Age at birth of proband (integer)
mat_cob	Recommended	Maternal Country of Birth	ISO-3166 2-alpha code
mat_edu	Recommended	Maternal Education	1, Primary school only 2, High school graduate or equivalent 3, Occupational/Technical/Vocational 4, Undergraduate university qualification 5, Postgraduate university qualification 6, Never attended
pat_age	Core	Paternal age at time of birth	YY (age at birth of proband)
pat_cob	Recommended	Paternal Country of Birth	ISO-3166 2-alpha code
pat_edu	Recommended	Paternal Education	1, Primary school only 2, High school graduate nor equivalent 3, Occupational/Technical/Vocational 4, Undergraduate university qualification 5, Postgraduate university qualification 6, Never attended
consanguinity	Core	Is any consanguinity reported?	0, No 1, Yes
CP_family_hx	Core	Is there a family history of CP?	0, No 1, Yes
CP_sibling_hx	Core	Does a sibling have a diagnosis of CP?	0, No 1, Yes

CP_family_hx_detail	Recommended	If there is a family history of CP, please select all members that have been diagnosed with CP?	<p>List all that apply:</p> <p>0, None</p> <p>1, Daughter</p> <p>2, Granddaughter</p> <p>3, Grandson</p> <p>4, Half-brother</p> <p>5, Half-sister</p> <p>6, Maternal Aunt</p> <p>7, Maternal cousin</p> <p>8, Maternal grandfather</p> <p>9, Maternal Grandmother</p> <p>10, Maternal Uncle</p> <p>11, Brother</p> <p>12, Father</p> <p>13, Mother</p> <p>14, Sister</p> <p>15, Nephew</p> <p>16, Niece</p> <p>17, Paternal Aunt</p> <p>18, Paternal Cousin</p> <p>19, Paternal Grandfather</p> <p>20, Paternal Grandmother</p> <p>21, Paternal Uncle</p> <p>22, Son</p>	For every family member that has CP, add the applicable number. SPACES between numbers, if more than one. No commas.
neuro_family_hx	Core	Is there a family history of neurological disorders?	<p>0, No</p> <p>1, Yes</p>	
neuro_family_hx_detail	Recommended	If there is a family history of neurological disorders, please list all family members that have been diagnosed with a neurological disorder. Please separate each family member with a space	<p>0, None</p> <p>1, Daughter</p> <p>2, Granddaughter</p> <p>3, Grandson</p> <p>4, Half-brother</p> <p>5, Half-sister</p> <p>6, Maternal Aunt</p>	For every family member that has a relevant neurological history, add the applicable number. SPACES between numbers, if more than one. No commas.

			7, Maternal cousin 8, Maternal grandfather 9, Maternal Grandmother 10, Maternal Uncle 11, Brother 12, Father 13, Mother 14, Sister 15, Nephew 16, Niece 17, Paternal Aunt 18, Paternal Cousin 19, Paternal Grandfather 20, Paternal Grandmother 21, Paternal Uncle 22, Son 99, Unknown	<p>NB Data Owners: This is NOT Compulsory but Highly Recommended. In order to link these cases to the original proband, Data Owners should create a Family_ID for family members. You do not need to upload genomic data for these family members.</p> <p>If there is a positive family history of neurological conditions, each family member <u>should</u> be added to the dataset as a new row and their [clinical_status] must = 1, and data must be entered into either: known_syndrome (Diagnostics), OMIM (Diagnostics), med_condition (Diagnostics), or positive_HPO (Clinical symptoms and physical signs).</p>
neuro_family_hx_text	Recommended	If there is a family history of neurological disorders, please describe:	Free text	Please provide free text detail describing the relevant neurological family history.
siblings	Recommended	Does the individual have sibling/s?	0, No 1, Yes	
sib_number	Recommended	If the individual has sibling/s, how many siblings?	XX	This can only be responded if [siblings] has a value of (1) [integer].
sib_phenotype	Recommended	Please describe any relevant clinical conditions or phenotypes present in the sibling(s):	Free text	This can only be responded if [sibling] has a value of (1). Watch for personal information

Antenatal and Neonatal Details (39)

FIELD NAME	CATEGORY	DESCRIPTION	VALUE	NOTES /LOGIC
mat_ht	Exploratory	What was the maternal height at beginning of pregnancy with this individual?	XXX	Metric [numeric]
mat_wt	Exploratory	What was the maternal weight at the beginning of the pregnancy with this pregnancy?	XXX	Metric [numeric]
gravidity	Exploratory	Total number of confirmed pregnancies prior to this individual	XX	0+ [integer]
preterm_birth	Core	Was there a preterm birth prior to this individual?	0, No previous preterm birth 1, Yes, there was preterm birth	
perinatal_death	Core	Was there a perinatal death prior to this individual? (includes more than 20 completed weeks, still births and death during neonatal period)	0, No previous perinatal death 1, Yes, there was perinatal death	
conception	Core	Was the individual a product of assisted conception?	1, No 2, Yes - Unknown 3, Yes - IVF 4, Yes - ICSI 5, Yes - GIFT 6, Yes - AI 7, Yes - Ovulation Stimulation only 8, Yes - Other	
first_an_visit	Recommended	Total number of completed weeks of the pregnancy at first antenatal visit	XX	1-40 completed weeks [integer]
mat_principal_morbid	Recommended	Pre-existing maternal morbidity, principal diagnosis	free text	
mat_add_morbid	Recommended	Pre-existing maternal morbidity, additional diagnoses	free text	
gestation_principal_morbid	Recommended	Maternal morbidity (pregnancy - and birth-related), principal diagnosis	free text	

gestation_add_morbid	Recommended	Maternal morbidity (pregnancy- and birth-related), additional diagnoses	free text	
G_smoke	Recommended	Did the mother smoke during pregnancy?	0, No 1, Yes	
G_alcohol	Recommended	How many standard alcoholic drinks did the mother consume per week during pregnancy?	XX	integer
G_drug	Recommended	During the first trimester, did the mother use any recreational drugs?	0, No 1, Yes	
teratogen	Recommended	Please describe any teratogen exposure prior to, or during pregnancy	free text	
fetal_abnormality	Core	Was a fetal abnormality identified by ultrasound during pregnancy?	0, No 1, Yes	
fetal_abnormal_detail	Recommended	If yes, please describe	free text	This can only be responded if [fetal_abnormality] has a value of (1).
birth_facility	Exploratory	What facility was the individual born in?	1, Hospital 2, Birth centre attached to hospital 3, Birth centre free standing 4, Home birth planned 5, Home birth unplanned 6, Born before arrival at hospital 7, Born outside home/hospital without medical assistance 8, Other	
mag_sulphate	Exploratory	Was magnesium sulphate administered to the mother during pregnancy?	0, No 1, Yes	

labour_onset	Recommended	Onset of labour during this individual's birth	1, Spontaneous 2, Induced 3, No labour	
labour_hyperthermia	Exploratory	Did the mother treat with hyperthermia during labour?	0, No 1, Yes	
birth_presentation	Recommended	Presentation at birth	1, Vertex 2, Breech 3, Face 4, Brow 5, Transverse	
delivery	Recommended	Method of delivery	1, Vaginal non-instrumental 2, Vaginal instrumental 3, Emergency c-section 4, Elective c-section	
ga	Core	Gestational age (completed weeks)	20-46	
bw	Core	Birth weight (grams)	200-5000	Metric
head_cir	Core	Head circumference of individual at time of birth (centimetre)	10-60	Metric
plurality	Core	Birth plurality	1, Singleton 2, Twin 3, Triplets 4, Quadruplets 5, Quintuplets 6, Sextuplets 7, Other	
birth_order	Recommended	Birth order if a multiple birth	1, First of multiple 2, Second of multiple 3, Third of multiple 4, Fourth of multiple 5, Fifth of multiple 6, Sixth of multiple 7, Other	This can only be responded if [plurality] has a value of (2+).

zygotic	Core	If this was a multiple birth, was it:	1, Monozygotic 2, Dizygotic 3, Other	This can only be responded if [plurality] has a value of (2+).
amniotic	Core	If this was a multiple birth, was it:	1, Monoamniotic 2, Diamniotic 3, Triamniotic 4, Other	This can only be responded if [plurality] has a value of (2+).
chorionic	Core	If this was a multiple birth, was it:	1, Monochorionic 2, Dichorionic 3, Trichorionic 4, Other	This can only be responded if [plurality] has a value of (2+).
newborn_care	Core	Did the individual receive more than routine newborn care?	0, No 1, Yes, NICU or special care	
phototherapy	Recommended	Did the individual receive phototherapy?	0, No 1, Yes	
hypothermia	Core	Did the individual receive therapeutic hypothermia?	0, No 1, Yes	
ventilation	Core	Did the individual receive mechanical ventilation?	0, No 1, Yes	
neo_infection	Core	Was infection present during the neonatal period?	0, No 1, Yes	
placenta_wt	Recommended	Placental weight (trimmed of extra placental membranes and umbilical cord) (grams)	10-3000	Metric, decimal
gross_placental	Exploratory	Gross placental abnormalities detected	free text	
histo_placental	Exploratory	Histological placental abnormalities detected	free text	