

The ICPGC common data elements (CDEs) for genomics studies of CP (v1.4)

Contents

The ICPGC common data elements (CDEs) for genomics studies of CP (v1.4).....	1
Background	2
Minimum Data Set (13*).....	3
Demographics (6).....	6
Diagnostics (9).....	7
Family History (15).....	8
Antenatal and Neonatal Details (39).....	11
Clinical Traits (27).....	15
CP-Specific Assessments (13).....	18

Background

These common data elements were developed in 2019-2020 by the International Cerebral Palsy Genomics Consortium Phenotype Working Group (DOI: [10.1111/dmcn.15245](https://doi.org/10.1111/dmcn.15245)). The data elements are ranked in a hierarchy of Mandatory (MDS), Core, Recommended, or Exploratory.

They are designed to be used for genomics research studies in cerebral palsy to promote data harmonisation for data sharing purposes.

They are intended to be dynamic as we continue to refine and review these CDEs based on user feedback.

There are **122 CDEs**: 13 data elements make up the Minimum Data Set. The CDEs are broken up into different categories, with the Core CDEs at the top of each category.

Please note metric values only.

Please note, that if you wish to upload your data to the CP Commons, your clinical data will need to be coded according to these CDEs. There are an additional two data elements that are required for the CP Commons.

All multiple responses are separated by a SPACE only, no COMMAS.

If you would like any more information about these CDEs or preparing your data to submit to the CP Commons, please contact Yana Wilson (ywilson@cerebralpalsy.org.au).

Version: 1.4 // updated 30 March, 2022.



Minimum Data Set (13*)

	Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy
CP Commons only*	submitter_id	Unique ID for each individual assigned by the data submitting team. The ID must be two steps removed from any personal information.	String	Length = 20	This is only a requirement for the CP Commons.		
	family_id	Unique ID assigned to each family by the submitting team (i.e. duos, trios, twins, quads, pedigree).	String	Length = 20	This is only a requirement for the CP Commons.		
Minimum Data Set	date_collected	What year was the data collected in the original study?	Integer	Length = 4 (YYYY)	International Organisation for Standardization ISO-8601 Gregorian calendar year only		Mandatory
	Pedigree	What is the relationship of this individual to the proband?	Integer	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	Logical Observation Identifiers Numbers and Codes (LOINC) Proband should always be 1.	Phenotips	Mandatory

clinical_status	Does the individual have any clinically relevant phenotype present?	Integer	0, Unaffected 1, Affected	Proband should always be 1.	Phenotips	Mandatory
cp_phenotype	Does the individual have a permanent (non-paroxysmal) disorder of movement or posture of central origin?	Integer	0, No - EXCLUDE 1, Yes	Rosenbaum et al., 2007; Surveillance of CP in Europe (SCPE)		Mandatory
degenerative	Is the condition progressive (loss of previously acquired skills)?	Integer	0, No - EXCLUDE 1, Yes	Rosenbaum et al., 2007		Mandatory
birth_year	What is the individual's year of birth?	Integer	Length = 4 (YYYY)	International Organisation for Standardization ISO-8601 Gregorian calendar year only	NINDS (CP), GRDR, EPIRARE, RD-Connect, ACPR, Adelaide Biobank, CP-NET, SCPE	Mandatory
sex	What is the sex of the individual?	Integer	1, Male 2, Female 3, Intersex / Undetermined 99, Unknown	Systematized Nomenclature of Medicine—Clinical Terms (SNOMED-CT)	NINDS (CP), GRDR, RD-Connect, ACPR, SCPE, CP-NET	Mandatory
birth_country	What country was the individual born in?	String	Length = 2	ISO-3166 2-alpha code	NINDS (CP), GRDR, EPIRARE, RD-Connect, ACPR, CP-NET	Mandatory
positive_HPOs	Please list positive Human Phenotype Ontology (HPO) traits:	String	Length = minimum 32 (minimum 3 traits)	Human Phenotype Ontology HPO code: 9-digit alphanumeric code with a colon. Spaces between values, NO commas.	RD-Connect, Phenotips	Mandatory
primary_motor	What is the individuals predominant CP motor type?	Integer	1, Spastic 2, Dyskinetic - Dystonia 3, Dyskinetic - Choreoathetosis 4, Ataxic 5, Hypotonic		ACPR, SCPE, CP-NET	Mandatory
primary_motor_laterality	What is the laterality of the individuals predominant motor type?	Integer	1, Unilateral 2, Bilateral	Surveillance of CP in Europe (SCPE)	Adelaide Biobank, SCPE	Mandatory

epilepsy	Does the individual have epilepsy?	Integer	0, No 1, Yes 99, Unknown	Logical Observation Identifiers Numbers and Codes (LOINC)	ACPR, SCPE, CP-NET, Adelaide Biobank, NINDS (CP)	Mandatory
GMFCS	Gross Motor Functioning Classification System (GMFCS)© Score	Integer	1, GMFCS I 2, GMFCS II 3, GMFCS III 4, GMFCS IV 5, GMFCS V 99, Unknown	GMFCS : 5-level classification system.	ACPR, CP-NET, SCPE, Adelaide Biobank, NINDS (CP)	Mandatory

Demographics (6)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy	
vital_status	Is the person alive?	Integer	1, Yes 2, No 3, Refused 4, Unknown	LOINC	RD-Connect, GRDR, SCPE	Core	
Demographics	cause_of_death	If deceased, what was the individuals primary cause of death.	String	Length = 3-7 (XXX.X)	International Classification of Disease (ICD-10) code corresponding to principal cause of death. 3-7 alphanumeric code with a single period (.) that follows the first 3 alphanumeric characters (e.g. F91.9)	RD-Connect, CP-NET	Core
	death_age	If deceased, what was the individual's age at time of death?	Integer	Length = 3	Age in months only	SCPE	Recommend
	country_residence	What country does the individual currently reside in?	String	Length = 2	ISO-3166 2-alpha code	NIH/NINDS/GRDR, EPIRARE, RD-Connect	Recommend
	personal_ethnicity	What ethnicity does the individual identify with?	String	Length = 100 Free text			Recommend
	genotype_ethnicity	What is the individuals' ethnicity; as determined by genotype?	String	Length = 100 Free text			Recommend

Diagnostics (9)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy
CP_dx	Has the individual been diagnosed with CP or suspected of having CP?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, SCPE	Core
confirmed_CP_dx	Was the diagnosis of CP been confirmed	Integer	0, No 1, Yes 2, Not yet of age 99, Unknown		ACPR, Adelaide Biobank, CP-NET, SCPE	Core
ORDO	Has the individual been diagnosed with a known syndrome (ORDO codes)?	Integer	Length = 3-6	Orphanet Rare Disease Ontology (ORDO) code : 3-6 numeric code See Vasant et al., 2014 for more details. List all applicable	RD-Connect, Phenotips, ACPR	Core
OMIM	Has the individual been diagnosed with a genetic disorder (OMIM codes)?	Integer	Length = 6	OMIM code corresponding to any genetic conditions the individual has been diagnosed with. List all applicable	RD-Connect, Phenotips, ACPR	Core
MONDO	Please describe any medical conditions the individual may have (MONDO ontology):	String	Length = 13	Mondo Disease Ontology 13-digit alphanumeric code with a colon between letters and numbers. List all applicable e.g. <i>MONDO:0009562</i>		
ICD10	Please describe any medical conditions the individual may have (ICD-10 codes):	String	Length = 3-7 (XXX.X)	ICD-10 code corresponding to any medical conditions the individual may have List all applicable	RD-Connect, Phenotips, ACPR	Core
CP_dx_age	Age when the individual was first diagnosed with CP?	Integer	Length = 1-3	Age in months	ACPR, CP-NET	Recommend
timing_CP_injury	During what period did the individuals' CP-related brain disturbance occur?	Integer	1, Prenatal and perinatal 2, Post-neonatal 3, Unknown 99, Unknown	Australian CP Register	ACPR, SCPE, Biobank, CP-NET	Recommend
cp_onset	Was onset of permanent (non-paroxysmal) movement disorder at age 2 or younger?	Integer	0, No 1, Yes	Rosenbaum et al., 2007		Exploratory

Diagnostics

Family History (15)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy
mat_age	Maternal age at time of birth of proband	Integer	Length = 2	Australian and New Zealand Neonatal Network Data Dictionary (ANZNN) Age in years only	ACPR, Adelaide Biobank, CP-NET, NINDS, SCPE	Core
pat_age	Paternal age at time of birth of proband	Integer	Length = 2	Age in years only	ACPR, Adelaide Biobank, CP-NET, NINDS	Core
consanguinity	Is any consanguinity reported?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, EPIRARE, RD-Connect	Core
CP_family_hx	Is there a family history of CP?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, NINDS	Core
neuro_family_hx	Is there a family history of neurological disorders?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET	Core
Family History			0, None 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			
	CP_family_hx_detail	If there is a family history of CP, please select all members that have been diagnosed with CP?	Integer		LOINC Family Relations	Recommended

			21, Paternal uncle 22, Son			
neuro_family_hx_detail	If there is a family history of neurological disorders, please list all family members that have been diagnosed with a neurological disorder.	Integer	0, None 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	LOINC Family Relations		Recommended
neuro_family_hx_text	If there is a family history of neurological disorders, please describe:	String	Length = 250 Free text			Recommended
mat_cob	Maternal Country of Birth	String	Length = 2	ISO-3166 2-alpha code	ACPR, NINDS	Recommended
mat_edu	Maternal Education (completed)	Integer	1, Primary school only 2, High school graduate or equivalent 3, Occupational / Technical / Vocational qualifications 4, Undergraduate university qualifications 5, Postgraduate university qualifications 6, Never attended	Completed education only		Recommended

pat_cob	Paternal Country of Birth	String	Length = 2	ISO-3166 2-alpha code	ACPR, NINDS	Recommended
pat_edu	Paternal Education (completed)	Integer	1, Primary school only 2, High school graduate or equivalent 3, Occupational / Technical / Vocational 4, Undergraduate university qualifications 5, Postgraduate university qualifications 6, Never attended	Completed education only		Recommended
siblings	Does the individual have sibling/s?	Integer	0, No 1, Yes			Recommended
sib_number	If the individual has sibling/s, how many siblings?	Integer	Length = 1-2			Recommended
sib_phenotype	Please describe any relevant clinical conditions or phenotypes present in the sibling(s):	String	Length = 250 Free text			Recommended

Antenatal and Neonatal Details (39)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy
preterm_birth	Was there a preterm birth prior to this individual?	Integer	0, No 1, Yes		ACPR, CP-NET	Core
perinatal_death	Was there a perinatal death prior to this individual? (includes more than 20 completed weeks, still births and death during neonatal period)	Integer	0, No 1, Yes		ACPR, CP-NET	Core
conception	Was the individual conceived through assisted conception?	Integer	0, No 1, Yes – Ovulation Stimulation only 3, Yes – Artificial Insemination (AI) 4, Yes – In Vitro Fertilisation (IVF) 5, Yes – Intra Cytoplasmic Sperm Injection (ICSI) 6, Yes – Gamete Intrafallopian Transfer (GIFT) 7, Yes – Other 8, Yes - Unknown	ACPR	ACPR, CP-NET, RD-Connect	Core
delivery	Method of delivery	Integer	1, Vaginal non-instrumental 2, Vaginal instrumental 3, Elective c-section 4, Emergency c-section 99, Unknown	ANZNN	ACPR, Adelaide Biobank, CP-NET, SCPE	Core
ga	Gestational age	Integer	Length = minimum 2	Completed weeks	ACPR, Adelaide Biobank, CP-NET, RD-Connect	Core
bw	Birth weight	Numeric	Length = minimum 3	Grams only	ACPR, Adelaide Biobank, CP-NET, GRDR, NINDS	Core
head_cir	Head circumference of individual at time of birth	Numeric	Length = minimum 2	Centimetres only	ACPR, CP-NET, NINDS	Core
plurality	Birth plurality	Integer	1, Singleton 2, Twin 3, Triplet 4, Quadruplets	ANZNN	ACPR, Adelaide Biobank, CP-NET, SCPE	Core

Antenatal and Neonatal Details

			5, Quintuplets 6, Sextuplets 7, Other			
zygotic	If this was a multiple birth, what was the zygosity:	Integer	1, Monozygotic 2, Dizygotic 3, Other	CP-NET	CP-NET	Core
amniotic	If this was a multiple birth, what was the amnionicity:	Integer	1, Monoamniotic 2, Diamniotic 3, Triamniotic 4, Other	CP-NET	CPP-NET	Core
chorionic	If this was a multiple birth, what was the chorionicity:	Integer	1, Monochorionic 2, Dichorionic 3, Trichorionic 4, Other	CP-NET	CP-NET	Core
newborn_care	Did the individual receive more than routine newborn care?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, SCPE	Core
hypothermia	Did the individual receive therapeutic cooling?	Integer	0, No 1, Yes		ACPR, CP-NET, SCPE	Core
ventilation	Did the individual receive mechanical ventilation?	Integer	0, No 1, Yes		CP-NET, SCPE	Core
neo_infection	Was infection present during the neonatal period?	Integer	0, No 1, Yes		ACPR, CP-NET	Core
fetal_abnormality	Was a fetal abnormality identified by ultrasound during pregnancy?	Integer	0, No 1, Yes		ACPR, SCPE	Core
fetal_abnormal_detail	Please describe the fetal ultrasound abnormality:	String	Length = 100 Free text		SCPE	Recommended
first_antenatal_visit	Total number of completed weeks of the pregnancy at first antenatal visit	Integer	Length = minimum 1			Recommended
mat_principal_morbid	Pre-existing maternal morbidity, principal diagnosis	String	Length = 200 Free text			Recommended
mat_additional_morbid	Pre-existing maternal morbidity, additional diagnoses	String	Length = 200 Free text			Recommended

gestation_principal_morbid	Maternal morbidity (pregnancy - and birth-related), principal diagnosis	String	Length = 200 Free text		Recommended
gestation_add_morbid	Maternal morbidity (pregnancy- and birth-related), additional diagnoses	String	Length = 200 Free text		Recommended
G_smoke	Did the mother smoke during pregnancy?	Integer	0, No 1, Yes	CP-NET	Recommended
G_alcohol	How many standard alcoholic drinks did the mother consume per week during pregnancy?	Integer	Length = minimum 1	CP-NET	Recommended
G_drug	During the first trimester, did the mother use any recreational drugs?	Integer	0, No 1, Yes	CP-NET	Recommended
teratogen	Please describe any teratogen exposure prior to, or during pregnancy	String	Length = 100 Free text	CP-NET	Recommended
labour_onset	Onset of labour during this individual's birth	Integer	1, Spontaneous 2, Induced 3, No labour	CP-NET	Recommended
birth_presentation	Presentation at birth:	Integer	1, Cephalic – including face and brow 2, Breech 3, Other – includes transverse lie	ANZNN	Recommended
birth_order	Birth order if a multiple birth:	Integer	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	SCPE / ACPR	ACPR, Adelaide Biobank, CP-NET, SCPE Recommended
phototherapy	Did the individual receive phototherapy?	Integer	0, No 1, Yes	ACPR	Recommended
placenta_wt	What was the placental weight in grams (trimmed of extra placental membranes and umbilical cord)?	Numeric	Length = 5	Grams only (50-1500)	CP-NET Recommended
gross_placental	Describe any gross placental abnormalities detected:	String	Length = 100 Free text	CP-NET	Exploratory

histo_placental	Describe any histological placental abnormalities detected:	String	Length = 100 Free text		CP-NET	Exploratory
mat_ht	What was the maternal height at beginning of pregnancy with this individual?	Numeric	Length = minimum 3]	Centimetres only	Adelaide Biobank	Exploratory
mat_wt	What was the maternal weight at the beginning of the pregnancy with this pregnancy?	Numeric	Length = minimum 2	Grams only	Adelaide Biobank	Exploratory
gravity	Total number of confirmed pregnancies prior to this individual:	Integer	Length = minimum 1		CP-NET	Exploratory
birth_facility	What facility was the individual born in?	Integer	1, Non tertiary hospital – Born in a hospital without a level III neonatal intensive care nursery. 2, Tertiary hospital – Born in a hospital with a level III neonatal intensive care nursery. 3, Home birth – Birth planned for and occurred at home. 4, Born before arrival – Born at home (unplanned event), or in an ambulance, or any other area outside a hospital with obstetric facilities. 99, Unknown	ANZNN		Exploratory
mag_sulphate	Was magnesium sulphate administered to the mother during pregnancy?	Integer	0, No 1, Yes		ACPR, CP-NET, SCPE	Exploratory
labour_hyperthermia	Did the mother treat with hyperthermia during labour?	Integer	0, No 1, Yes			Exploratory

Clinical Traits (27)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy
prim_spast_topo	What is the individuals' predominant spastic topography?	Integer	1, Left hemiplegia 2, Right hemiplegia 3, Diplegia 4, Quadriplegia		ACPR, Adelaide Biobank, SCPE, CP-NET	Core
second_motor	What is the secondary motor type that the individual presents with?	Integer	1, Spastic 2, Dyskinetic - Dystonic 3, Dyskinetic - Choreoathetosis 4, Ataxic 5, Hypotonic			Core
second_motor_laterality	What is the laterality of the individuals' secondary motor type?	Integer	1, Unilateral 2, Bilateral	SCPE		Core
second_past_topo	Additional description of dyskinesia presentation	Integer	1, Left hemiplegia 2, Right hemiplegia 3, Diplegia 4, Quadriplegia			Core
second_neurodev	Does the individual have another neurodevelopmental disability?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, NINDS	Core
epilepsy_type	If the individual has epilepsy, what type of epilepsy?	String	Length = 100 Free text			Core
id	Does the child have an intellectual impairment?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, SCPE	Core
id_severity	If the individual has an intellectual impairment, what is the severity of the impairment? (ICD10 codes F70 to F73)	Integer	1, Mild (IQ50 - 69) 2, Moderate (IQ 35 - 49) 3, Severe (IQ 20 - 34) 4, Profound (IQ < 20) 5, Impairment unspecified (IQ < 50)	SCPE	ACPR, SCPE These are equivalent to ICD-10 F70-73, F79. Equivalent HPO codes	Core
autism	Does this individual been diagnosed with an Autism Spectrum Disorder (ASD)?	Integer	0, No 1, Yes		CP-NET	Core
autism_severity	If the individual has an ASD, what is the severity (according to DSM-5):	Integer	1, Level 1: Requiring support 2, Level 2: Requiring substantial support 3, Level 3: Requiring very substantial support	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).		Core

Clinical Traits

adhd	Does the individual have an Attention Deficit / Hyperactivity Disorder (ADHD)?	Integer	0, No 1, Yes		CP-NET	Core
adhd_type	If the individual has ADHD, what type of ADHD (according to DSM-5)?	Integer	1, Primarily Hyperactive-Impulsive ADHD 2, Primarily Inattentive ADHD (formerly called ADD) 3, Combined Type ADHD	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).		Core
adhd_severity	If the individual has an ADHD, what is the severity of the ADHD (according to the DSM-5):	Integer	1, Mild 2, Moderate 3, Severe	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).		Core
visual_impairment	Does the individual have a visual impairment?	Integer	0, No 1, Yes		ACPR, SCPE, CP-NET, Adelaide Biobank, NINDS	Core
visual_severity	If the individual has a visual impairment, please describe:	String	Length = 100 Free text		SCPE	Core
hearing_impairment	Does the individual have a hearing impairment?	Integer	0, No 1, Yes		ACPR, Adelaide Biobank, CP-NET, SCPE, NINDS	Core
hearing_severity	If the individual has a hearing impairment, please describe:	String	Length = 100 Free text		SCPE	Core
congenital_anomalies	Does the individual have any congenital anomalies?	Integer	0, No 1, Yes		ACPR, CP-NET, Adelaide Biobank	Core
congenital_anomalies_type	If the individual has a congenital anomaly/ies, which major anatomical system/s are involved?	Integer	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, face, and neck 11, Chromosomal 12, Metabolic 13, Haematological/immune		CP-NET	Core

congenital_anomalies_detail	Please describe any reportable congenital anomalies:	String	Length = 100 Free text		Recommended
second_ndd_other	Please describe any additional NDD (i.e. Global developmental delay, Tourette's etc) that have not been reported elsewhere:	String	Length = 250 Free text	ACPR, Adelaide Biobank, CP-NET	Recommended
radiology_text	Please describe any relevant radiological findings:	String	Length = 100 Free text		Recommended
prim_dyskinesia_type	If dyskinetic is predominant motor type, is the movement:	Integer	1, Focal 2, Generalised		Exploratory
second_dyskinesia_type	If dyskinetic is second motor type, is the movement:	Integer	1, Focal 2, Generalised		Exploratory
chronic_pain	Has the individual reported experiencing chronic pain?	Integer	0, No 1, Yes - self report 2, Yes - proxy report		Exploratory
chronic_pain_age	At what age was chronic pain reported?	Integer	Length = 1-3	Age in months	Exploratory
chronic_pain_measure	What validated outcome measure was used to assess chronic pain?	String	Length = 100 Free text		Exploratory

CP-Specific Assessments (13)

Field Name	Description	Value Structure	Value Domain	Reference	Compatible Resources	Hierarchy	
CP-Specific Assessments	MRICS	Predominant Brain Pattern (Expanded MRI Classification System)	Integer	1, (A) Maldevelopments 2, (A.1) Maldevelopments - Disorders of cortical development (proliferation and/or migration and/or organisation) 3, (A.3) Maldevelopments - Other (ex: holoprosencephaly, Dandy-Walker formation, corpus callosum agenesis, cerebellar hypoplasia) 4, (B) Predominant White Matter Injury (PWMI) 5, (B.1) PWMI - PVL (mild/severe) 6, (B.2) PWMI - Sequelae of IVH or PVH infarction 7, (B.3) PWMI - Combination of PVL and IVH sequelae 8, (C) Predominant Grey Matter Injury (PGMI) 9, (C.1) PGMI - Basal ganglia / thalamus legions (mild/moderate/severe) 10, (C.2) PGMI - Cortico-subcortical lesions only (watershed legions in parasagittal distribution / multicystic encephalomalacia) not covered under C3 11, (C.3) PGMI - Arterial infarctions (middle cerebral artery / other) 12, (D) Miscellaneous changes (ex: cerebellar atrophy, cerebral atrophy, delayed myelination, ventriculomegaly not covered under B, haemorrhage not covered under B, brainstem lesions, calcifications) 13, (E) Normal	For further information on this classification, please refer to Himmelmann et al., 2016 .	ACPR, SCPE	Core
	MACS	Manual Ability Classification System (MACS)© Score	Integer	1, MACS I 2, MACS II 3, MACS III 4, MACS IV 5, MACS V	For further information on this classification, please refer to Öhrvall et al., 2010 .	ACPR, CP-NET, SCPE, Adelaide Biobank, NINDS	Recommended
	CFCS	Communication Function Classification System (CFCS)© Score	Integer	1, CFCS I 2, CFCS II 3, CFCS III 4, CFCS IV 5, CFCS V	For further information on this classification, please refer to Hidecker et al., 2011 .	ACPR, CP-NET, NINDS	Recommended

BFMF	Bimanual Fine Motor Function (BFMF)© Score	Integer	1, BFMF I 2, BFMF II 3, BFMF III 4, BFMF IV 5, BFMF V	For further information on this classification, please refer to Himmelmann et al., 2016.	SCPE, NINDS	Recommended
VIKING	Viking Speech Scale score	Integer	1, Score I 2, Score II 3, Score III 4, Score IV	For further information on this classification, please refer to Pennington et al., 2013.	ACPR, SCPE, NINDS	Recommended
EDACS	Eating and Drinking Ability Classification System	Integer	1, EDACS I 2, EDACS II 3, EDACS III 4, EDACS IV 5, EDACS V	For further information on this classification, please refer to Sellers et al., 2013.	ACPR, NINDS	Recommended
swallowing	Describe the participants eating/drinking/swallowing:	Integer	1, Standard mean for age - no modifications required 2, Requires modified diet			Recommended
GM	Was a General Movements Assessment performed at 12 weeks of age, and if so what was the score?	Integer	0, No 1, Yes, normal 2, Yes, abnormal fidgety 3, Yes, absent fidgety	For further information on this classification, please refer to Einspieler et al., 2005.	ACPR, NINDS	Recommended
HINE	Was the Hammersmith Infant Neurological Examination (HINE) performed?	Integer	0, No 1, Yes	For further information on this classification, please refer to the Hammersmith website.		Recommended
HINE_age	If the HINE was performed, at what age was the assessment performed?	Integer	Length = 1-2	Corrected age in months (2-24)		Recommended
HINE_outcome	If the HINE was performed, what was the outcome of the assessment?	Integer	Length = 2	0-78		Recommended
ICF	WHO Disability Assessment Schedule 2.0	Integer	Length =1-3	Please report the individuals WHODAS 2.0 score (0-100)	NINDS	Recommended

VFCS	Visual Function Classification System © Score	Integer	1, VFCS I 2, VFCS II 3, VFCS III 4, VFCS IV 5, VFCS V	For further information on this classification, please refer to the Baranello et al., 2019.	Exploratory
------	---	---------	---	---	-------------