THE COMPREHENSIVE CA-CP STUDY
Data Coding Guidelines

Variable	Description/Notes	Coding

Unique identifier of case
ID
		Region code_ Case type_Case number
		
		Region code
		2 digits, to be determined
		Case type
		1 CP case
		2 CA only case (if participating in Phase II)
		
		Case number (5 digits, from 00000 to 99999)
		
		e.g. 09 (Region code)
		      1 (Case type)
		   00001 (Case number XXXXX)
		Final ID=09100001

Data from cerebral palsy OR congenital anomaly register		
Gestational age at delivery **GA**	Gestational age in completed weeks	xx (weeks) 0=Unknown
Birthweight **BW**	Birthweight in grams	xxxx (grams) 0=Unknown
Plurality of birth **MULT_BIRTH**	Number of infants born at the same delivery	1=Singleton 2=Twin 8=>Two 0=Unknown 99=Not collected
Co-fetal loss **COFET_LOSS**	Death of a co-multiple during pregnancy	1=Death of a co-multiple 2=No death of a co-multiple/singleton 0=Unknown 99=Not collected
Year of birth **BIRTH_YEAR**	Year of birth	yyyy
Status **STATUS**	Living or known to be deceased	1=known to be dead 0=otherwise

		99=not collected
Age at death **DEATH_AGE**	* Only if STATUS=1 Age at death in months Only if date of death not available, for confidentiality or other reason	xxx (months)
Sex **SEX**		1=Male 2=Female 0=Unknown
Maternal age at delivery **MOTHER_AGE**	Years	xx (years) 0=Unknown 99=Not collected
Data from cerebral palsy register		
Post-neonatal cause of CP? **POSTNEON**	Is there a post-neonatal cause of CP? * Brain injury must occur before the age of 2 year for inclusion as a CP case	1=Yes 2=No 0=Unknown 99=Not collected
Code for Post-neonatal cause of CP **POSTN_CODE1**	ICD-10 code for post-neonatal cause of CP * Only if POSTNEON=1	ICD10 code (6 digits)
Text description of Post-neonatal cause of CP **POSTN_CODE2**	Text description of post-neonatal cause of CP * Only if POSTNEON=1	Text description (50 digits)
Age at the time of the insult **AGE_POSTN**	Age at the time of post-neonatal insult in months * Only if POSTNEON=1	xx (months) 0=Unknown 99=Not collected
CP subtype **CP_TYPE**	CP classification 1	10=Spastic 20=Dyskinetic 21=Dystonic dyskinesia 22=Choreo-athetotic dyskinesia 30=Ataxia 0=Unknown/other
Spastic CP topography **SPAS_TYPE**	CP classification 2 * Only if CP_TYPE=10 * Spastic bilateral = limbs on both sides of the body are involved * Spastic unilateral (hemiplegia) = limbs on one side of the body are involved	1=Bilateral 2=Unilateral 0=Unknown

Unilateral CP topography **UNI_TYPE**	CP classification 3 * Only if SPAS_TYPE=2	1=Right 2=Left 0=Unknown
Gross motor severity **GMFCS**	Gross Motor Function Classification System Give information on GMFCS between the 4th and 6th birthdays	1=level I 2=level II 3=level III 4=level IV 5=level V 0=Unknown 99=Not collected
Gross motor severity (grouped) **GMFCS_GROUP**	Gross Motor Function Classification System (Grouped) * Only if region is not able to provide specific GMFCS levels, e.g. when previous "walking ability" data has been recoded into GMFCS categories	1=GMFCS I or II (or equivalent) 3=GMFCS III (or equivalent) 4=GMFCS IV (or equivalent) 5=GMFCS V (or equivalent) 0=Unknown 99=Not collected
Intellectual impairment **INTEL_IMP**		10=Moderate to profound impairment or IQ < 50 21=Mild impairment or IQ 50-69 40=Normal intellect or IQ ≥ 70 0=Unknown 99=Not collected
Visual impairment **VI**		1=Yes 2=No 0=Unknown 99=Not collected
Severe visual impairment **VI_SEVER**	* Only if VI=1 * Severe visual impairment: defined as blind or no useful vision (after correction, on the better eye). If the level of vision loss is <6/60 (Snellen scale) or <0.1 (Decimal scale) in both eyes, this conforms to criteria for 'severe visual impairment'.	1=Yes 2=No 0=Unknown 99=Not collected
Hearing impairment **HI**		1=Yes 2=No 0=Unknown 99=Not collected

Severe hearing impairment **HI_SEVER**	* Only if HI=1 * Severe hearing impairment: defined as 'severe' or 'profound' hearing loss i.e. loss greater than 70dB (before correction, on the better ear)	1=Yes 2=No 0=Unknown 99=Not collected
Epilepsy **EPILEPSY**	Epilepsy definition: defined by two unprovoked seizures, excluding febrile or neonatal seizures	1=Never 2=Ever 0=Unknown 99=Not collected
Speech impairment **SI**	Any speech impairment	1=Yes 2=No 0=Unknown 99=Not collected
Severe speech impairment **SI_SEVER**	Non-verbal * Only if SI=1 * Note that severe speech impairment equates to Viking Speech Scale (VSS) level IV	1=Yes 2=No 0=Unknown 99=No collected
Imaging performed? **IMAGING**	Has imaging (post-neonatal or neonatal) been performed? If post-neonatal imaging performed, complete item: POST_IMAG If neonatal imaging performed, complete items: NEONI NEONI_AGE NEONI_RESULT NEONI_R_TXT NEONI_SIDE	1=Yes 2=No 0=Unknown 99=Not collected
Post-neonatal imaging **POST_IMAG**	Type of post-neonatal imaging performed	1=MRI 2=CT 0=Unknown 99=Not collected
Chronological age at the most recent post-neonatal imaging **MRI_CT_AGE**	* Only if post-neonatal imaging performed Value from 2 to 99 in months. Please see examples below. If imaging was performed before discharge from the neonatal unit, please record under neonatal imaging. Examples of final code:	xx (months) 99=Later than 8 years of age 0=Unknown 999=Not collected

	2=during the second month of life 12=at 1 year of age 18=at 18 months of age 24=at 2 years of age 96=at 8 years of age	
Post-neonatal MRI results **MRI_RESULT**	* Only if MRI_CT_AGE known and ≥2 and POST_IMAG=1	A=Maldevelopments A1=Disorders or proliferation or migration or organisation A2=Other maldevelopments B=Predominant white matter injury B1=Periventricular leukomalacia, PVL B2=Sequelae of intraventricular haemorrhage (IVH) or periventricular hemorrhagic infarction (PVHI) B3=Combination of PVL and IVH sequelae C=Predominant grey matter injury C1=Basal ganglia/thalamus lesions C2=Cortico subcortical lesions only not covered by C3 C3=Arterial infarctions D=Miscellaneous changes E=Normal Z=Unknown 99=Not collectable
Clear text for MRI or CT result **MRI_CT_R_TXT**	*Only if IMAGING=1 and MRI_CT_AGE known and ≥2 Text description of MRI or CT result if imaging performed at or above age 2 years. If the classification was made on the basis of images directly, then mention it. If you want to propose a second classification, give it here.	Text description 0=Unknown 99=Not collected
Side of this imaging result **MRI_SIDE**	* Only if IMAGING=1 and MRI_CT_AGE known and ≥2	1=Right 2=Left 3=Bilateral 0=Unknown 99=Not collected

Imaging performed before discharge from neonatal care unit? **NEONI**	* Only if IMAGING=1 Has imaging been performed before discharge from the neonatal care unit? If both neonatal US and MRI imaging have been performed, give the results for neonatal MRI imaging.	1=US imaging 2=MRI imaging 3=Both US and MRI imaging 4=No neonatal imaging 0=Unknown 99=Not collected
Chronological age at the more recent neonatal imaging **NEONI_AGE**	* Only if NEONI=1, 2 or 3 Chronological age, value in weeks. Examples of coding: 1=During the first week of life 2=During the second week of life 3=During the third week of life up to… 8=During the eighth week of life	xx=weeks (1 to 8 only) 00=Unknown 99=Not collectable
Classification of neonatal imaging results **NEONI_RESULT**	* Only if NEONI=1, 2 or 3 The more recent result and the predominant result according to the five proposed categories (A, B, C, D, E). If possible, give the subcategory.	A=Maldevelopments A1=Disorders or proliferation or migration or organisation A2=Other maldevelopments B=Predominant white matter injury B1=Echogenicity or MR signal intensity abnormalities B2=Periventricular haemorrhagic infarction (IVH grade IV) B3=Post-haemorrhagic ventricular dilatation C=Predominant grey matter injury C1=Basal ganglia/thalamus lesions C2=Watershed lesions (parasagittal lesions) C3=Arterial infarctions (middle cerebral artery) C4=Haemorrhage D=Miscellaneous changes E=Normal Z=Unknown 99=Not collectable
Clear text for the neonatal imaging result **NEONI_R_TXT**	* Only if NEONI=1, 2 or 3 If the classification was made on the basis of images directly, then mention it.	Text description

	If a second classification is proposed, mention it.	
Side of this neonatal imaging result **NEONI_SIDE**	* Only if NEONI=1, 2 or 3	1=Right 2=Left 3=Bilateral 0=Unknown 99=Not collected
Associated syndromes **SYNDR**	Syndromes should be included if recognised by the Smith's book: Smith's Recognisable Patterns of Human Malformation (5th edition), Kenneth Lyons Jones, M.D. Coded list of identified syndromes available in the SCPE Guideline "Syndromes".	1=Yes 2=No 0=Unknown 99=Not collected
Coding diagnosis for syndromes **SYNDR_COD1**	* Only if SYNDR=1 Code in the ICD10 database	ICD10 code (6 digits)
Text diagnosis for syndromes **SYNDR_COD2**	* Only if SYNDR=1 Text diagnosis for syndromes	Text description
Associated congenital anomalies other than brain malformation **OTHER_CA**	Associated congenital anomalies should be included if mentioned in the Smith's book. If several anomalies, choose the first Q codes order to include.	1=Yes 2=No 0=Unknown 99=Not collected
Coding diagnosis for associated congenital anomalies other than brain malformation **OTHER_CA_COD**	* Only if OTHER_CA=1 ICD10 code	ICD10 code
Clear text for associated congenital anomalies other than brain malformation **OTHER_CA_TXT**	* Only if OTHER_CA=1 50 digits free text	Text description
Brain malformation **BRAIN_MALF**	Antenatal developmental abnormality of the brain. Exclude postnatal developmental anomaly (e.g. acquired hydrocephaly, microcephaly). Include developmental abnormality due to infectious agents (e.g. CMV, toxoplasma) during the antenatal period only.	1=Yes 2=No 0=Unknown 99=Not collected
Coding diagnosis for brain malformation **BRAIN_CODE**	* Only if BRAIN_MALF=1 Code in the ICD10 database	ICD10 code
Clear text for brain malformation **BRAIN_TXT**	* Only if BRAIN_MALF=1 50 digits free text	Text description
Do other congenital anomalies exist?		1=Yes, other brain congenital anomaly

DOCA		2=Yes, other congenital anomaly but not in brain 3=Yes, other brain congenital anomaly and a location not in brain 4=No 0=Unknown 99=Not collected
Any additional congenital anomaly variables?	*If an individual register has further information about congenital anomalies not covered by the above variables, please send these variables with your coding system.*	
Data from congenital anomaly register		
Maternal illness before pregnancy MAT_ILL_1 (to MAT_ILL_10)	Maternal illness before pregnancy (ICD code) Please code each illness separately, from MAT_ILL_1 to MAT_ILL_10	ICD code
Maternal illness before pregnancy – text description MAT_ILL_TXT_1 (to MAT_ILL_TXT_10	Maternal illness before pregnancy (text description) Please code each illness separately, from MAT_ILL_TXT_1 to MAT_ILL_TXT_10	Text description
Family history of congenital anomalies in siblings FAM_SIB	Family history of congenital anomalies in siblings of case	1 = Yes 2 = No 0 = Unknown 99 = Not collected
Family history of congenital anomalies in siblings – text description FAM_SIB_TXT	* Only if FAM_SIB=1 Family history of congenital anomalies in siblings of case – text description of anomaly	Text description of anomaly
Family history of congenital anomalies in other relatives FAM_OTHER	Family history of congenital anomalies in other relatives of case (excluding siblings)(to third degree relatives)	1 = Yes 2 = No 0 = Unknown 99 = Not collected
Family history of congenital anomalies in other relatives – text description FAM_OTHER_TXT	* Only if FAM_OTHER=1 Family history of congenital anomalies in other relatives of case (excluding siblings)(to third degree relatives)	Text description of anomaly
For each reported anomaly:		
Congenital anomaly code ANOM1 (to ANOM10)		ICD code
Congenital anomaly text description ANOM1_TXT		Text
Age at diagnosis of congenital anomaly		1 = At birth

ANOM1_DIAG		2 = Less than one week 3 = 1-4 weeks 4 = 1-12 months 5 = Over 12 months 6 = Prenatal diagnosis in live fetus 7 = At abortion (spontaneous) 9 = Not known 10 = Postnatal diagnosis, age not known
Prenatal age at diagnosis of congenital anomaly **ANOM1_PRENATAL**	If prenatal diagnosis of congenital anomaly, GA at discovery in completed weeks	XX 99 = Not known
Surgery performed for anomaly **ANOM1_SURG**	For 2005 cases onward only	1=Yes 2=No
Anomaly subgroup *ANOM1_SUB*	*To be determined by computer algorithm – not to be provided by participating registers*	