

SURVEILLANCE OF CEREBRAL PALSY IN EUROPE - SCPE

SCPE GUIDELINES

JRC-SCPE Central Registry DATA SUBMISSION CP CASES

SCPE Guidelines n° 1
Version 5.5 April 2019
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SCPE

Guideline Data Submission CP Cases - Version 5.5 April 2019

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List of changes from the previous version:

1. SCPE definition and classification of cerebral palsy section harmonized according to Reference Training Manual, page 3
2. Review of inclusion/exclusion criteria, page 6
3. Notes for Viking speech definition added in item 25, page 13
4. Notes for Syndrome definition added in Item 39, page 16
5. Notes for post-neonatal imaging definition added in Item 56, page 18
6. Notes for MRI_CT_R_TXT added in Item 59, page 20
7. Clarification in the definition of NEONI - item 61, page 20
8. Clarification in the definition of NEONI_AGE - item 62, page 20

Aim: To enable registers to prepare files of CP Cases to be submitted to the SCPE common database, in accordance with

- the SCPE agreed definition and inclusion criteria,
- the predefined format for the requested items

To be disseminated to: all centres (SCPE and others) which can provide data on CP children to the SCPE network

Content:

- I. SCPE definitions and classification of Cerebral Palsy
- II. Description of the scales recommended for describing children with CP
- III. Coding imaging results
- IV. Common database items for describing children with CP
- V. Quality controls
- VI. Recommendations and practical issues when submitting data

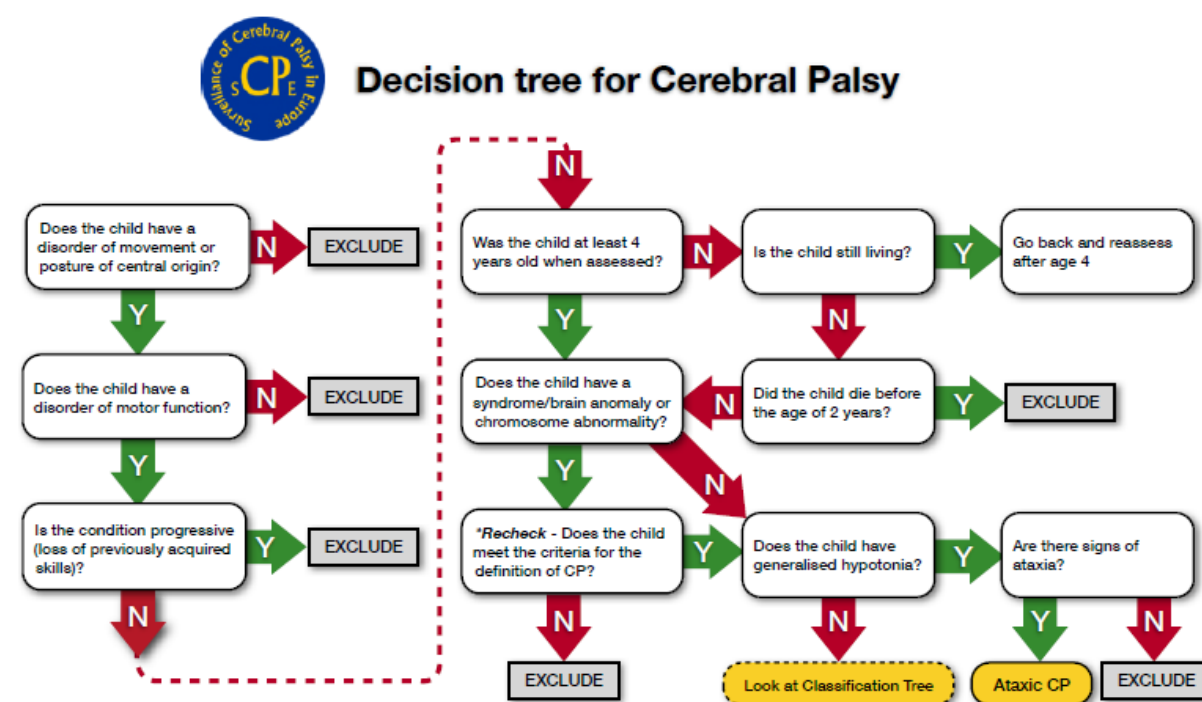
I. SCPE definition and classification of cerebral palsy

SCPE Definition

Cerebral Palsy (CP) is a group disorders involving movement and posture and of motor function; it is permanent, but not unchanging; it is due to a non-progressive interference, lesion, or abnormality of the developing/immature brain. (SCPE, Dev Med Child Neurol 42 (2000) 816-824)

This definition specifically excludes progressive disorders of motor function, defined as loss of previously acquired skills in the first 5 years of life.

Figure 1. Decision tree for Cerebral Palsy



SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Developmental Medicine and Child Neurology. 2000, 42:816-24

Classification based on clinical features

The classification of CP subtypes is based on clinical features and made of the basis of the predominant neurological finding.

It identifies three main groups: spastic, dyskinetic and ataxic cerebral palsy. Functional severity is described using standardized levels (GMFCS for lower limb function and BFMF or MACS for upper limb function).

All CP subtypes have in common an abnormal pattern of movement and posture.

Additional features include:

Spastic CP is characterised by

- Increased tone
- Pathological reflexes (increased reflexes, e.g. hyperreflexia and pyramidal signs e.g. Babinski response)
- Resulting in abnormal pattern of posture and/or movement

It may be unilateral (US-CP - hemiplegia) or bilateral (BS-CP - diplegia and tetraplegia).

Dyskinetic CP is characterised by

- Involuntary, uncontrolled, recurring, occasionally stereotyped movements, primitive reflex patterns predominate, muscle tone is varying

SCPE uses the following definitions for subgrouping dyskinetic CP:

Dystonic CP is dominated by

- abnormal postures (may give the impression of hypokinesia)
- hypertonia (tone fluctuating, but easily elicitable tone increase).

Characteristic are involuntary movements, distorted voluntary movements and abnormal postures due to sustained muscle contractions (slow rotation, extension, flexion of body parts)

Choreo-athetotic CP is dominated by

- hyperkinesia
- hypotonia (tone fluctuating, but mainly decreased).

Chorea means rapid involuntary, jerky, often fragmented movements.

Athetosis means slower, constantly changing, writhing or contorting movements.

Pure dyskinetic movement disorder does not show hyperreflexia with clonus, nor pyramidal signs. But in dyskinetic CP these signs of spastic disorder may be present. The dominating features should determine subtype classification.

Ataxic CP is characterised by

- Loss of orderly muscular co-ordination, so that movements are performed with abnormal force, rhythm and accuracy
- Typical features are:
 - trunk and gait ataxia
 - disturbed balance
 - past pointing - over-, undershooting of goal directed movements
 - tremor is another common sign - mainly a slow intention tremor
 - low tone is also a predominant feature

When it is a mixed CP form, i.e. spasticity with ataxia and/or dyskinesia, the child should be classified according to the dominant clinical feature.

The definition and inclusion/exclusion criteria were agreed upon at the 2nd SCPE plenary meeting, held in Oxford, July 1999, and published in Cans et al. (2000)

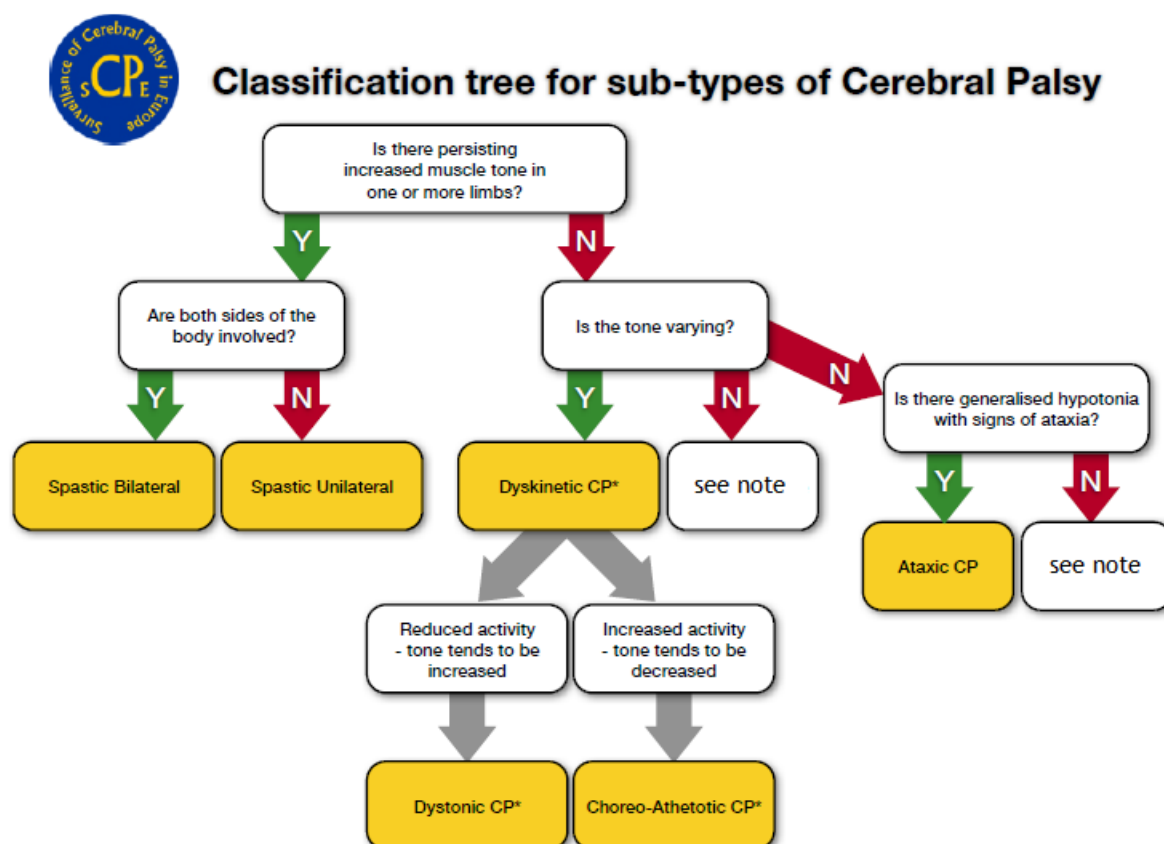
This classification of CP subtypes is summarized in the table below.

SCPE Classification of CP Subtypes based on the predominant neurological findings		All CP subtypes have in common an abnormal pattern of movement and posture. Additional features by subtype:
SPASTIC CP	Bilateral Spastic (BS-CP)	Increased tone Pathological reflexes - increased reflexes, e.g. hyperreflexia - pyramidal signs, e.g. Babinski response resulting in abnormal pattern of movement and posture
	Unilateral Spastic (hemiplegia)	
DYSKINETIC CP *	Dystonic	Involuntary, uncontrolled, recurring, occasionally stereotyped movements, primitive reflex patterns predominate, muscle tone is varying
	Choreo-athetotic	
ATAXIC CP		Loss of orderly muscular coordination, so that movements are performed with abnormal force, rhythm and accuracy

* Dyskinetic CP can be further classified into unilateral and bilateral. This information is collected but not included as a Subgroup classification.

The hierarchical classification for sub-types of Cerebral Palsy agreed is shown in figure 2.

Figure 2. Classification tree for sub-types of Cerebral Palsy



NOTE: Review Figure 1. to confirm that is a CP case, if you don't have enough information go back to the clinician and if you still do not know, discuss it during the annual SCPE plenary meeting.

*Dyskinetic CP can be further classified into unilateral and bilateral.
This information is collected but not included as a Subgroup classification.

SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Developmental Medicine and Child Neurology. 2000, 42:816-24

Inclusion criteria

In order to be included in the SCPE database, cases must fulfil the definition. The neurology must be clearly defined. The diagnosis is made solely on the basis of clinical description. Additional features such as imaging, laboratory results, etc. are not part of the inclusion criteria.

Although 5 years is the optimal age for confirmation of diagnosis, cases would be considered for inclusion in the SCPE database if they fulfil the clinical criteria after their 4th birthday.

Children in whom a diagnosis of CP is made after the age of 2 years, but who die before this diagnosis can be reconfirmed (between 2 and 5 years) are also notified to in the SCPE database. These cases will be 'flagged', and then included in or excluded from the analyses as appropriate.

Children lost to follow-up but with unambiguous diagnosis of CP after the age of 3 years should also be submitted to SCPE database.

Comorbidities: Children with co-morbidity should have these recorded on the database.

Exclusion criteria

Children with hypotonia as the sole neurological finding and children with isolated spinal diseases should be excluded.

The definition specifically excludes progressive conditions resulting in loss of acquired skills.

Children who survive beyond the age of 5 years, and in whom a clinical diagnosis of CP is not confirmed, or in whom a progressive condition is identified are not included in the SCPE study.

Please consider the decision tree:

The definition and inclusion/exclusion criteria were agreed upon at the 2nd SCPE plenary meeting, held in Oxford, July 1999, and published in Cans et al. (2000) DMCN (2000).

Post-neonatally acquired CP

It results from a recognized brain damaging event that is unrelated to factors in the ante-, peri- or neonatal period.

A timing of brain insult beyond 28 days of life is used. All children with CP in whom the origin of Cerebral Palsy relates to the first 28 days of life should not be included as a post neonatal case, even if there is clear point of origin for the CP. These cases will be 'flagged'.

No upper age limit of onset of the brain damage has been identified.

Missing value coding:

- "NC" means "Item not collected in the register".
- "0" or "50" (Apgar) or "Z" (imaging classification) = unknown means value missing for this case although the information on this item is available for some of the cases in the register.
- "" empty variable means "not relevant": for example, if epilepsy is coded as "never" (item 36), we do not await a value for activity of epilepsy (item 37). For an item that is not relevant, leave it blank.

II. Descriptions of the scales recommended for describing children with CP

Motor function scales:

Bimanual Fine Motor Function Classification (BFMF) at minimum age of 4 years:

Level 1: One hand manipulates without restriction; other hand manipulates without limitation *OR* has limitations in more advanced fine motor skills.

Level 2: One hand manipulates without restriction; other hand has ability only to grasp or hold *OR* both hands have limitations in more advanced fine motor skills.

Level 3: One hand manipulates without restriction; other hand has no functional ability *OR* one hand has limitations in more advanced fine motor skills; other hand has ability only to grasp or worse. Child needs help with tasks.

Level 4: Both hands have ability only to grasp; *OR* one hand has ability only to grasp; other hand has ability only to hold or worse. Child needs support and/or adapted equipment.

Level 5: Both hands have ability only to hold or worse. Child requires total assistance, even with adaptations.

Gross Motor Function Classification (GMFCS) between the 4th and 6th birthdays:

Level I: Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

Level II: Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

Level III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children walk with an assistive mobility device on level surfaces and may climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.

Level IV: Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.

Level V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited.

Manual Ability Classification System (MACS):

for more details, please see http://www.macs.nu/files/MACS_English_2010.pdf

Level I: Handles objects easily and successfully. At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement. Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

Level III: Handles objects with difficulty; needs help to preparer and/or modify activities. The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

Level IV: Handles a limited selection of easily managed objects in adapted situations. Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

Level V: Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.

Communication scale

Viking Speech Scale (VSS):

for more details, please see https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/Viking-Speech-Scale-2011-Copyright_EN.pdf

Level I: Speech is not affected by motor disorder

Level II: Speech is imprecise but usually understandable to unfamiliar listeners

Level III: Speech is unclear and not usually understandable to unfamiliar listeners out of context.

Level IV: No understandable speech.

III. Coding imaging results

MRI classification system (MRICS) in post neonatal cases:

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 haemorrhagic 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

MRI classification system (MRICS) in neonatal cases:

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

For further information, please look at the CP neuroimaging classification in the reference and training manual available on the SCPE website: https://eu-rd-platform.jrc.ec.europa.eu/scpe/reference-and-training-manual_en

Below is given additional information for coding imaging results.

How to code and where to put a second pattern?

SCPE has agreed that if there are several patterns, the predominant pattern that is believed most likely to have led to the CP should be classified first; if there is another pathogenic pattern (A, B, C or D), it should be classified separately and written down in the text field (item 62. Or item 67. for neonatal imaging)

What if age at imaging is missing?

Code 0 (unknown) in item 61 and item 66 and give text in item 63. The imaging expert group can then check, whether the description indicates most likely a postneonatal (or neonatal) imaging result and classify it accordingly. If the period is known (postneonatal or neonatal), but not the exact date, the corresponding classification can be used.

What if coding is done on the basis of images and local description differs?

Coding on the basis of imaging has priority and should be the basis for classification (item 62). Please indicate then in the text (item 63): classification was made on the basis of analysing the images directly, radiological description was as follows.....

What if there is only a CT scan?

A new item has been introduced (item 60) so that you can indicate this, including age at scan (item 61). As there is no classification for CT scans, it is recommended to give only the description (item 63). For analysis this can then be used and a methodology for classification has then to be established (which depends on the quality of data).

IV. Common database items for describing children with CP

A total of 65 different items are required.

Each item is described in the following pages. For each one you will find its full name (item), its short name (variable's name), its number of digit when coded, its final code required for the SCPE common database, and definition or explanation where necessary.

SCPE Common database items

1. Item Name of the centre	Variable's name CENTRE 3 digits
Final code in the database: C01 to C32 1 letter (C) and 2 numbers. Numbers should be given by the SCPE coordinator	
2. Item Identification Number of a case	Variable's name ID 8 digits
Final code in the database: e.g. C01_0250 Can contain numbers only, letters only or numbers and letters jointly.	
3. Item Birth date	Variable's name BIRTH_DA 10 digits
Final code in the database dd/mm/yyyy <i>if for confidentiality reason birth date not allowed, please give birth year as follows 01/07/yyyy</i>	

4. Item Has the diagnosed been confirmed after the age of 4 year?	Variable's name CONFIRM 2 digits
--	---

Final code in the database

- 1 = Yes
- 2 = NO; dead
- 3 = NO; lost to follow up but with confirmed diagnosis of CP after the age of 2 years
- 0 = unknown
- NC= not collected

5. Item Mother's permanent place of residence at time of birth	Variable's name BIRTH_RESID 1 digit
---	--

Final code in the database

- 1 = inside the area
- 2 = outside the area
- 0 = unknown
- NC = not collected

6. Item Parents or guardians place of residence at time of registration of the case	Variable's name REGIST_RESID 2 digits
--	--

Final code in the database

- 1 = inside the area
- 2 = outside the area
- 0 = unknown
- NC = not collected

7. Item Status	Variable's name STATUS 2 digits
---------------------------------	--

Final code in the database

- 1 = known to be dead
- 0 = otherwise
- NC = not collected

8. Item Date of death	Variable's name DEATH_DATE 10 digits
--	---

Final code in the database dd/mm/yyyy

ONLY IF STATUS = 1

9. Item Age at death	Variable's name DEATH_AGE 3 digits
---------------------------------------	---

Final code in the database in months

Only if item 8 Date of Death not available, for confidentiality reason or other reason

10. Item Sex	Variable's name SEX 1 digit
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Final code in the database

- 1 = male
- 2 = female
- 0 = unknown

11. Item Birthweight	Variable's name BW 4 digits
---------------------------------------	---

Final code in the database in grams
Give 0 if unknown

12. Item Gestational age	Variable's name GA 2 digits
---	---

Final code in the database in completed weeks
Give 0 if unknown

13. Item Multiple birth	Variable's name MULT_BIRTH 2 digits
--	---

Final code in the database

- 1 = singleton
- 2 = twin
- 3 = triplets
- 4 = quadruplets
- 5 = quintuplets
- 6 = sextuplets
- 7 = septuplets
- 8 = ≥ 2
- 0 = unknown
- NC = not collected

14. Item Birth order	Variable's name BO 2 digits
---------------------------------------	---

Final code in the database

- 1 = first infant
- 2 = second infant
-
- 7 = 7th infant
- 0 = unknown
- NC = not collected

ONLY IF MULT_BIRTH > 1

15. Item Maternal age at birth	Variable's name MOTHER_AGE 2 digits
---	---

Final code in the database in years
Give 0 if unknown / NC not collected

16. Item Parity	Variable's name PARITY 2 digits
----------------------------------	---

Final code in the database

- 0 = none previous delivery
- 1 = 1 previous delivery
- 2 = 2 previous deliveries or more
- 50 = unknown
- NC = not collected

Parity definition: Number of previous pregnancies resulting in either live birth or stillbirth (as defined in country of register). Excludes miscarriages and therapeutic abortions.

17. Item Delivery mode	Variable's name DELIVERY_MODE 2 digits
---	---

Final code in the database

- 10 = vaginal delivery
 - 20 = caesarean section
 - 21 = caesarean section elective/before labour
 - 22 = caesarean section emergency/during labour
 - 0 = unknown
 - NC = not collected
-

18. Item Place of birth	Variable's name BIRTH_PLACE 2 digits
--	---

Final code in the database

- 1 = home or travel or hospitalisation unit other than maternity
- 2 = maternity unit 1-499
- 3 = maternity unit 500-999
- 4 = maternity unit 1000-1499
- 5 = maternity unit 1500-1999
- 6 = maternity unit 2000-3999
- 7 = maternity unit 4000+
- 0 = unknown
- NC = not collected

Place of birth: This item describes the number of total annual births in the maternity unit where the CP child was born

19. Item CP classification 1	Variable's name CP_TYPE 2 digits
---	---

Final code in the database

- 10 = spastic
 - 20 = dyskinetic
 - 21 = dystonic dyskinesia
 - 22 = choreo-athetotic dyskinesia
 - 30 = ataxia
 - 0 = unable to classify (see page 5)
-

20. Item CP classification 2	Variable's name SPAS_TYPE 1 digit
---	--

Final code in the database

- 1 = bilateral
- 2 = unilateral
- 0 = unknown

ONLY IF CP_TYPE = 10, 20, 21, 22

CP classification 2 definition:

bilateral: limbs on both sides of the body are involved

unilateral (e.g. hemiplegia): limbs on one side of the body are involved

21. Item CP classification 3	Variable's name UNI_TYPE 1 digit
---	---

Final code in the database

- 1 = right
- 2 = left
- 0 = unknown

ONLY IF SPAS_TYPE = 2

22. Item
Bimanual Fine Motor Function Classification (BFMF)

Variable's name
BFMF
2 digits

Final code in the database

- 1 = level 1
- 2 = level 2
- 3 = level 3
- 4 = level 4
- 5 = level 5
- 0 = unknown
- NC = not collected

Give information on BFMF at minimum age of 4 years.

You can give information on BFMF only, or on MACS only or on both of them

23. Item
Manual Ability Classification System (MACS)

Variable's name
MACS
2 digits

Final code in the database

- 1 = level 1
- 2 = level 2
- 3 = level 3
- 4 = level 4
- 5 = level 5
- 0 = unknown
- NC = not collected

Give information on MACS at minimum age of 4 years.

You can give information on BFMF only, or on MACS only or on both of them

24. Item
Gross Motor Function Classification (GMFCS)

Variable's name
GMFCS
2 digits

Final code in the database

- 1 = level I
- 2 = level II
- 3 = level III
- 4 = level IV
- 5 = level V
- 0 = unknown
- NC = not collected

Give information on GMFCS between the 4th and 6th birthdays.

25. Item
Viking speech scale

Variable's name
VIKING
2 digits

Final code in the database

- 1 = level I
- 2 = level II
- 3 = level III
- 4 = level IV
- 0 = unknown
- NC = not collected

If you have several evaluations, report the one which done at the age closest to 60 months. The Viking speech scale describes speech rather than communication overall. Please code level of speech production regardless of aetiology or intellectual ability

26. Item Age Viking speech scale	<div>ONLY IF VIKING=1, 2, 3, 4</div>	Variable's name VIKING_AGE 3 digits
Final code in the database - Age in months - 0=unknown - NC = not collected		
27. Item Intellectual impairment		Variable's name INTEL_IMP 2 digits
Final code in the database - 10 = level " <50 " - 11 = level <20 - 12 = level in between 20-49 - 21 = level in between 50-69 - 40 = level ≥70 - 0 = unknown - NC = not collected		
28. Item IQ test	<div>ONLY IF INTEL_IMP not equal to 0 or NC</div>	Variable's name IQ_TEST 2 digits
Final code in the database - 10 = testing - 11 = testing with the IQ value - 12 = testing without the IQ value - 20 = clinical estimate - 0 = unknown - NC = not collected		
29. Item Age at IQ test	<div>ONLY IF IQ_TEST = 10, 11 or 12</div>	Variable's name AGE_IQ 3 digits
Final code in the database in months - 0 = unknown - NC= not collected		
30. Item Visual impairment		Variable's name VI 2 digits
Final code in the database - 1 = yes - 2 = no - 0 = unknown - NC = not collected		
31. Item Severe visual impairment	<div>ONLY IF VI = 1</div>	Variable's name VI_SEVER 2 digits
Final code in the database - 1 = yes - 2 = no - 0 = unknown - NC = not collected		
Severe visual impairment definition: 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 will conform to the SCPE criteria for 'Severe vision impairment'		

32. Item
Hearing impairment

Variable's name
HI
2 digits

Final code in the database

- 1 = yes
- 2 = no
- 0 = unknown
- NC = not collected

33. Item
Severe hearing impairment

Variable's name
HI_SEVER
2 digits

Final code in the database

- 1 = yes
- 2 = no
- 0 = unknown
- NC = not collected

ONLY IF HI = 1

Severe hearing impairment definition: Defined as 'severe' or 'profound' hearing loss, i.e. loss greater than 70dB (before correction, on the better ear)

34. Item
Epilepsy

Variable's name
EPILEPSY
2 digits

Final code in the database

- 1 = never
- 2 = ever
- 0 = unknown
- NC = not collected

Epilepsy definition: epilepsy if diagnosed by medical doctor, excluding febrile or neonatal seizures

35. Item
Activity of epilepsy

Variable's name
EPIL_ACT
2 digits

Final code in the database

- 1 = yes
- 2 = no
- 0 = unknown
- NC = not collected

ONLY IF EPILEPSY = 2

Activity of epilepsy definition: Having active treatment for epilepsy at the time of data capture.
In other words: is the child on medication at time of registration (independently of the presence/absence of seizures)?

36. Item
Age of onset of epilepsy

Variable's name
AGEON_EPIL
2 digits

Final code in the database

- 1 = during first year of life (excluding 3 first days of life)
- 2 = during second year of life
- 3 = during third year of life
- 4 = during fourth year of life
- 5 = during fifth year of life or later
- 0 = unknown
- NC = not collected

ONLY IF EPILEPSY = 2

<p>37. Item Ostomies</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = never - 2 = ever - 0 = unknown - NC = not collected <p>ostomies definition: any procedure that transgresses the abdominal wall to enable feeding (e.g. gastrostomy, jejunostomy)</p>	<p>Variable's name OSTOMY 2 digits</p>
<p>38. Item Age of insertion of -stomy</p> <p>Final code in the database:</p> <p>Age in months</p> <ul style="list-style-type: none"> - 0 = unknown - NC = not collected 	<p>Variable's name OSTOMY_AGE 3 digits</p> <div data-bbox="574 649 845 705" style="border: 1px solid black; padding: 2px; text-align: center;">ONLY IF OSTOMY= 2</div>
<p>39. Item Has the child a diagnosed syndrome?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no/unknown - NC = not collected <p>'Syndromes' should only be those according to Eurocat or Orphanet, any other should be recorded/described in 'Any other CA'(item 45) https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/EUROCAT%20Syndrome%20Guide%20Revision%20Final%20version%20September%202017.pdf</p>	<p>Variable's name SYNDR 2 digits</p>
<p>40. Item Coding diagnosis for Syndrome</p> <p>Final code in the database ICD10 code</p>	<p>Variable's name SYNDR_COD 6 digits</p> <div data-bbox="662 1355 925 1411" style="border: 1px solid black; padding: 2px; text-align: center;">ONLY IF SYNDR = 1</div>
<p>41. Item Text diagnosis for Syndrome</p>	<p>Variable's name SYNDR_TXT 100 digits</p> <div data-bbox="686 1568 965 1624" style="border: 1px solid black; padding: 2px; text-align: center;">ONLY IF SYNDR = 1</div>
<p>42. Item Cardiac malformation</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no - 0 = unknown - NC = not collected <p>Cardiac Malformation definition: please refer to EUROCAT guideline https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/JRC-EUROCAT-Section-3.5-15-Nov-2019.pdf; congenital heart defects Q20 to Q26</p>	<p>Variable's name CARDIAC_MALF 2 digits</p>

43. Item Coding diagnosis for cardiac malformation		Variable's name CARDIAC_COD 6 digits
Final code in the database ICD10 code	<div>ONLY IF CARDIAC_MALF = 1</div>	
44. Item Clear text for cardiac malformation		Variable's name CARDIAC_TXT 100 digits
	<div>ONLY IF CARDIAC_MALF = 1</div>	
45. Item Clear text for describing any additional other congenital anomalies		Variable's name ANY_OTHER_CA_TXT 200 digits
46. Item Postneonatal (After 28 days of birth) CP?		Variable's name POSTNEON 2 digits
Final code in the database - 1 = yes - 2 = no - 0 = unknown - NC = not collected		
47. Item Coding diagnosis for Postneonatal		Variable's name POSTN_CODE1 6 digits
Final code in the database ICD10 code	<div>ONLY IF POSTNEON = 1</div>	
48. Item Text diagnosis for Postneonatal		Variable's name POSTN_CODE2 50 digits
	<div>ONLY IF POSTNEON = 1</div>	
49. Item Age at the time of the insult		Variable's name AGE_POSTN 3 digits
Final code in the database in months - 0 = unknown - NC = not collected	<div>ONLY IF POSTNEON = 1</div>	
50. . Item Admission in a neonatal care unit		Variable's name NCU 2 digits
Final code in the database - 1 = yes - 2 = no - 0 = unknown - NC = not collected		

<p>51. . Item Ventilation (not resuscitation) in this unit?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no - 0 = unknown - NC = not collected <p>Ventilation (not resuscitation) in the neonatal intensive care unit: means that the child has been mechanically ventilated by respirator, and not just resuscitated (e.g. mask insufflation) or intubated only for a short duration (e.g. during transport)</p>	<div>ONLY IF NCU = 1</div>	<p>Variable's name VENT_NCU 2 digits</p>
<p>52. Item Has the child received therapeutic cooling?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no - 0 = unknown - NC = not collected 		<p>Variable's name COOLING 2 digits</p>
<p>53. 5Item Apgar score at 5 minutes?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - [0-10] - 50 = unknown - NC = not collectable 		<p>Variable's name APGAR5 2 digits</p>
<p>54. Item Convulsions within first 72 hours?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no - 0 = unknown - NC = not collected 		<p>Variable's name CONVULS 2 digits</p>
<p>55. Item Has imaging been performed?</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = yes - 2 = no - 0 = unknown - NC = not collected 		<p>Variable's name IMAGING 2 digits</p>
<p>56. Item Postneonatal imaging</p> <p>Final code in the database</p> <ul style="list-style-type: none"> - 1 = MRI - 2 = CT - 3 = US - 0 = unknown - NC = not collected <p>If several types of imaging have been performed, please describe MRI; if no MRI, describe CT scan, if no MRI and CT, describe US</p>	<div>ONLY IF IMAGING=1</div>	<p>Variable's name POST_IMAG 2 digits</p>

<p>57. Item Chronological age at the more recent postneonatal imaging (term corrected age up to 2 years for children born before 37 weeks of GA)</p>	<p>Variable's name MRI_CT_AGE 3 digits</p>
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Value from 2 to 99 in months; please find several examples below

Examples of final code in the database

- **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
- **99** = later
- **0** = unknown
- **NC** = not collected

ONLY IF POST_IMAG = 1, 2 OR 3

<p>58. Item Classification of MRI results</p>	<p>Variable's name MRI_RESULT 2 digits</p>
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The more recent result, and the predominant result according to the five proposed categories (A, B, C, D and E). If possible, give the subcategory

ONLY IF MRI_CT_AGE ≥ 2 & POST_IMAG=1

Final code in the database

- **A = Maldevelopments**
 - **A1** disorders of 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**
- **NC = not collected**

For further information on this classification, please look at the CP neuroimaging classification in the reference and training manual available on the SCPE website: https://eu-rd-platform.jrc.ec.europa.eu/scpe/reference-and-training-manual_en

59. Item
Clear text for the MRI or CT or US result (English)

Variable's name
MRI_CT_R_TXT
200 digits

ONLY IF POST_IMAG =1, 2 OR 3

If the classification was made on the basis of the images directly, then mention it. If you want to propose a second classification, please give it there, in MRI_CT_R_TXT

It may be difficult for you to decide exactly how to code neuroimaging, or which is the predominant pattern. In these cases, please include as much free text as possible, and provide two codes in the free text field if that seems appropriate, so that the expert group can code as precisely as possible. Please bring complex cases to discuss at the SCPE plenary

If you do recognise the predominant pattern, please do code this, then add any additional findings in free text, being precise about what the findings in free text refer to: the predominant pattern, or the additional findings

60. Item
Side of this imaging result

Variable's name
MRI_SIDE
2 digits

Final code in the database

ONLY IF POST_IMAG=1 OR 2 OR 3

- 1 = right
- 2 = left
- 3 = bilateral
- 0 = unknown
- NC = not collected

61. Item
Has imaging been performed before 29 days of age?
(term corrected age for children born before 37 weeks of GA)

Variable's name
NEONI
2 digits

ONLY IF IMAGING = 1

Final code in the database

- 1 = US imaging
- 2 = MRI imaging
- 3 = both US and MRI imaging
- 4 = no neonatal imaging
- 0 = unknown
- NC = not collected

If both neonatal US and MRI imaging have been performed, give the results only for neonatal MRI imaging (questions 62 to 65).

62. Item
Chronological age at the latest neonatal imaging

Variable's name
NEONI_AGE
2 digits

Chronological age; value in weeks

Examples of final code in the database

ONLY IF NEONI = 1, 2 or 3

- 1 = during the first week of life
- 2 = during the 2d week of life
- 0 = unknown
- NC = not collected

63. Item Variable's name
Classification of neonatal imaging results **NEONI_RESULT**
2 digits

The more recent result and the predominant result according to the five proposed categories (A, B, C, D and E); If possible, give the subcategory

Final code in the database

ONLY IF NEONI = 1, 2 or 3

- **A** = Maldevelopments
 - **A1** disorders of 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** posthaemorrhagic 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
- **NC** = not collected

For further information on this classification, please look at the neonatal neuroimaging classification in the reference and training manual available on the SCPE website: https://eu-rd-platform.jrc.ec.europa.eu/scpe/reference-and-training-manual_en

64. Item Variable's name
Clear text for the neonatal imaging result (English) **NEONI_R_TXT**
100 digits

ONLY IF NEONI = 1, 2 or 3

If the classification was made on the basis of the images directly, then mention it. If you want to propose a second classification, please give it there.

It may be difficult for you to decide exactly how to code neuroimaging, or which is the predominant pattern. In these cases, please include as much free text as possible, and provide two codes in the free text field if that seems appropriate, so that the expert group can code as precisely as possible. Please bring complex cases to discuss at the SCPE plenary

If you do recognise the predominant pattern, please do code this, then add any additional findings in free text, being precise about what the findings in free text refer to: the predominant pattern, or the additional findings

65. Item Variable's name
Side of this neonatal imaging result? **NEONI_SIDE**
2 digits

Final code in the database

ONLY IF NEONI = 1, 2 or 3

- **1** = right
 - **2** = left
 - **3** = bilateral
 - **0** = unknown
 - **NC** = not collected
-

V. Quality controls

Checks on CP definition to be done by each centre

- According to peculiarities in each centre/register, the CP definition in use might not be exactly the same as the SCPE CP definition. Moreover, in some registers all motor deficiencies are registered. Thus for each CP case sent to the SCPE common database, the person in charge of the register/centre has to confirm that this CP case fits with the proposed SCPE definition, using the decision tree.
- It must be possible for the centre to provide for each birth year cohort the following information:
 - number and characteristics of CP cases which are not sent to the SCPE common database because not fitting the SCPE CP definition (group B),
 - and the number and characteristics of other motor deficiencies which are sent to the SCPE common database because fitting the SCPE CP definition, although not fitting the centre CP definition (group C)

		CP case fitting SCPE definition	
		Yes	No
CP case fitting the centre definition	Yes	A	B
	No	C	D

Checks on CP definition to be done at the SCPE common database level

- cases born out and resident out of the area will be excluded
- cases dead before 2 years old will be excluded
- cases not re-assessed after 2 years old will be excluded

Integrity constraints to be applied by each centre and at the SCPE common database level also

- integrity constraints on dates (e.g. no 31/04/yy)
- no dead CP cases ascertained before 24 months
- no alive CP cases ascertained before 48 months (except severe ones)
- BW > 700 g and BW < 5500 g for singletons, BW > 500 g and BW < 3500 g for multiple births
- GA > 21 wks and GA < 43 wks
- age at walking > 7 months
- age at IQ test > 36 months
- no BW < 1500 g or GA < 32 wks without admission in a NCU
- no intellectual impairment without any knowledge about the severity of the intellectual impairment

VI. Recommendations and practical issues when submitting data (children with CP)

List of documents that may be useful, and where you can found these documents

Name of the file	Web site localisation:
SCPE 2000 - DMCN paper	Section Publications
ICD codes	https://icd.who.int/browse10/2019/en
EUROCAT SYNDROME GUIDE: Definition and Coding of Syndromes (Revised 2017)	https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/EUROCAT%20Syndrome%20Guide%20Revision%20Final%20version%20September%202017.pdf

This guidelines will be available on the JRC submission portal: <https://scpe-portal.jrc.ec.europa.eu/scpe/>.

Submission process

Only centers that have signed collaboration can submit data.

Electronic data submission process will be used. To upload data, each person who submits data will need to be registered, through ECAS (European Commission Authentication Service).

One file is needed with data on CP children. It is strongly recommended to be able to provide all the requested items, for CP children. However partial data are acceptable as far as it fits the SCPE agreed definition of CP.

We invite you to follow strictly in particular the recommendations below:

- Names of the variables should be exactly those names mentioned above. Be cautious with the variable STATUS which must be 0 even when unavailable or unknown, and same issue with the variable Epilepsy which is 1 if never.

Completeness of ascertainment

Ascertainment of cases for the submitted birth year cohort(s) should be complete, as much complete as other previous birth year cohorts in your register. If you are not enough sure about the completeness of ascertainment, please contact Elodie and check with her if possible to delay the submission of this birth year cohort to one year later.

We do not want submission of incomplete data with late comers notified several month/year after. The completeness of ascertainment for each submitted birth year cohort is on your responsibility, and should be estimated at 90 % or more before being submitted to the SCPE common database.

In case of any difficulty or anything remaining not enough clear, please contact JRC-SCPE@ec.europa.eu and ESellier@chu-grenoble.fr before submitting your data to the SCPE common database.