Date of assessment: \_\_\_\_\_\_\_\_\_\_\_\_

Gestational age: \_\_\_\_ weeks

1. CP Predominant Motor type:

Spastic  Ataxic

Dyskinetic-Dystonia  Hypotonic

Dyskinetic-Choreoathetosis

1. CP Secondary Motor type:

Spasticity  Ataxia

Dyskinetic-Dystonia  Hypotonia

Dyskinetic-Choreoathetosis

1. CP Distribution:

Primarily unilateral:

Hemiplegia:

Left  Right

Monoplegia:

Left  Right

Primarily bilateral:

Diplegia  Triplegia  Quadriplegia

1. Timing of injury/abnormality:

Prenatal

Perinatal

Post-neonatal (after 28 days, before age 2)  Unknown

1. Specific cause(s) if known:

|  |
| --- |
|  |

1. Predominant Brain Pattern (MRI):

Maldevelopments  Miscellaneous

Predominately white matter injury  Normal

Predominately grey matter injury

1. CP Gross Motor Function:

GMFCS Level I  GMFCS Level IV

GMFCS Level II  GMFCS Level V

GMFCS Level III  Unknown

1. CP Fine Motor Function:

BFMF Level I  BFMF Level IV

BFMF Level II  BFMF Level V

BFMF Level III  Unknown

1. CP Upper Limb Function:

MACS Level I  MACS Level IV

MACS Level II  MACS Level V

MACS Level III  Unknown

1. Communication:

CFCS Level I  CFCS Level IV

CFCS Level II  CFCS Level V

CFCS Level III  Unknown

1. Eating and Drinking:

EDACS Level I  EDACS Level IV

EDACS Level II  EDACS Level V

EDACS Level III  Unknown

1. Seizures/ Epilepsy

Yes  Suspected

No  Unknown

1. Intellectual impairment

Normal/No intellectual impairment  Severe intellectual impairment

Mild intellectual impairment  Profound intellectual impairment

Moderate intellectual impairment  Unknown

1. Visual impairment

Yes

If yes, severity of visual impairment?

Normal  Some impairment  Blind  Unknown

No

Unknown

1. Hearing impairment

Yes

If yes, severity of hearing impairment?

Normal  Some impairment  Bilateral deafness  Unknown

No

Unknown

16. Respiratory support/ ventilation assist Yes  No

If yes, indicate type (Choose all that apply):

CPAP/BiPAP Oxygen at home Mucus clearance device

Tracheostomy Ventilator  Unknown Other, specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## General Instructions

Data elements on this form are known as Participant Condition Characteristics CDEs and will be collected as Supplemental - Highly Recommended CDE [predominant and secondary motor type, timing of injury/abnormality, gross motor function, fine motor function, upper limb function, communication and eating and drinking] (highly recommended and commonly collected in clinical research studies but whose relevance depends on the study design or type of research involved). These items will be used to compare baseline characteristics among study groups and to identify confounding variables.

The remaining will be collected as Supplemental material (a data element which is commonly collected in clinical research studies but whose relevance depends upon the study design (i.e., clinical trial, cohort study, etc.) or type of research involved).

Responses to categories are obtained from health professional assessment, medical records or obtained from parent/legal guardian interview.

For pediatric studies, the data elements on this CRF reflect child characteristics, not caregiver characteristics.

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

* **CP Predominant Motor Type:** Predominant neuromotor type: spastic, dyskinetic-dystonia, dyskinetic-choreoathetosis, ataxic or hypotonic.
* **CP Secondary Motor Type:** Additional tone or movement neuromotor type: spasticity, dyskinetic-dystonia, dyskinetic-choreoathetosis, ataxia and hypotonia.
* **CP Distribution:** Choose one: Primarily unilateral or Primarily bilateral. If Primarily unilateral: choose: Hemiplegia; Right or Left, Monoplegia; Right or Left. If Primarily bilateral choose: Diplegia, Triplegia, Quadriplegia.
* **Timing of Injury/abnormality:** Prenatal, perinatal, post neonatal (after 28 days, before age 2).
* **Predominant Brain Pattern (MRI):** Overarching classification to be checked with MRI group otherwise SCPE high level classification: Malformation, predominantly white matter, predominantly grey, miscellaneous, none.

The MRI classification system (MRICS) was developed to harmonize classification of magnetic resonance imaging (MRI), based on pathogenic patterns as proposed by the SCPE network (Himmelmann, Horber et al. 2017).

A **Maldevelopments:**

A1 Disorders of proliferation, migration or organisation

A2 Other maldevelopments (among others: holoprosencephaly, Dandy Walker malformation, corpus callosum agenesis, cerebellar hypoplasia...)

B **Predominant white matter injury:**

B1 Periventricular leucomalacia (PVL) (mild/severe)

B2 Sequelae of intraventricular hemorrhage (IVH) or periventricular hemorrhagic infarction (PVHI)

B3 Combination of PVL and IVH sequelae

C **Predominant grey matter injury:**

C1 Basal ganglia/thalamus lesions (mild/moderate/severe)

C2 Cortical-subcortical lesions only (watershed lesions in parasagittal distribution / multicystic encephaliamalacia) not covered by C3

C3 Arterial infarctions (middle cerebral artery/other)

D **Miscellaneous:** (among others: cerebellar atrophy, cerebral atrophy, delayed myelination, ventriculomegaly not covered by B, hemorrhage not covered by B, brainstem lesions, calcifications)

E **Normal**

* CP Gross Motor Function: GMFCS Groups individuals aged under 2, 2 to 6, 6 to 12, and 12 to 18 years with CP into one of five levels based on functional mobility as per CanChild Palisano, et al. (Palisano, Rosenbaum et al. 1997, 2008). Below is descriptor for children 6 to 12 years. [GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations](https://canchild.ca/system/tenon/assets/attachments/000/002/114/original/GMFCS_English_Illustrations_V2.pdf).
  + **GMFCS Level I:** Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.
  + **GMFCS Level II:** Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.
  + **GMFCS Level III:** Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.
  + **GMFCS Level IV:** Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community, children are transported in a manual wheelchair or use powered mobility.
  + **GMFCS Level V:** Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Visit the NINDS CDE website for more information about the [Gross Motor Function Classification System](https://www.commondataelements.ninds.nih.gov/report-viewer/24708/Gross%20Motor%20Function%20Classification%20System%20-%20Expanded%20&%20Revised%20(GMFCS%20-%20ER)).

* CP Fine Motor Function: Classification of fine motor capacity in children with CP ages 3 to 18 years, as per Elvrum, et al. (2016, 2017).
  + **BFMF Level I:** One hand: manipulates without restrictions. The other hand: manipulates without restrictions or limitations in more advanced fine motor skills.
  + **BFMF Level II:** (a) One hand: manipulates without restrictions. The other hand: only ability to grasp or hold (b) Both hands: limitations in more advanced fine motor skills.
  + **BFMF Level III:** (a) One hand: manipulates without restrictions. The other hand no functional ability (b) One hand: limitations in more advanced fine motor skills. The other hand: only ability to grasp or worse.
  + **BFMF Level IV:** (a) Both hands: only ability to grasp (b) One hand: only ability to grasp. The other hand: only ability to hold or worse.
  + **BFMF Level V:** Both hands: only ability to hold or worse.

Visit the NINDS CDE website for more information about the [Bimanual Fine Motor Function (BFMF)](https://www.commondataelements.ninds.nih.gov/report-viewer/24747/Bimanual%20Fine%20Motor%20Function%20(BFMF)).

* CP Upper Limb Function: Classification of hand and arm function in children with CP ages 4 to 18 years, as per Eliasson, et al. (2006).
  + **MACS 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.
  + **MACS 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.
  + **MACS Level III:** Handles objects with difficulty; needs help to prepare 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.
  + **MACS 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.
  + **MACS Level V:** Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.

Visit the NINDS CDE website for more information about the [Manual Ability Classification System (MACS)](https://www.commondataelements.ninds.nih.gov/report-viewer/24711/Manual%20Ability%20Classification%20System%20(MACS)).

* Communication: The Communication Function Classification System (CFCS) Classification of everyday communication for people with CP ages 2 to 18 years, as per Hidecker, et al. (2011).
  + **CFCS Level I:** A person independently and effectively alternates between being a sender and receiver of information with most people in most environments.
  + **CFCS Level II:** A person independently alternates between being a sender and receiver with most people in most environments, but the conversation may be slower.
  + **CFCS Level III:** A person usually communicates effectively with familiar communication partners, but not unfamiliar partners, in most environments.
  + **CFCS Level IV:** The person is not always consistent at communicating with familiar communication partners.
  + **CFCS Level V:** A person is seldom able to communicate effectively even with familiar people.

Visit the NINDS CDE website for more information about the [Communication Function Classification System (CFCS)](https://www.commondataelements.ninds.nih.gov/report-viewer/24702/Communication%20Function%20Classification%20System%20(CFCS)).

* Eating and Drinking: Classification of eating and drinking for people with CP ages 4 to 18 years as per Sellers et al. (2014)
  + **EDACS Level I:** Eats and drinks safely and efficiently.
  + **EDACS Level II:** Eats and drinks safely but with some limitations to efficiency.
  + **EDACS Level III:** Eats and drinks with some limitations to safely; there may be limitations to efficiency.
  + **EDACS Level IV:** Eats and drinks with significant limitations to safety.
  + **EDACS Level V:** Unable to eat and drink safely – tube feeding may be considered to provide nutrition.

Visit the NINDS CDE website for more information about the [Eating and Drinking Classification System](https://www.commondataelements.ninds.nih.gov/report-viewer/24705/Eating%20and%20Drinking%20Classification%20System%20(EDACS)).

* **Intellectual impairment:**  The indicator of whether the disorder has affected the participant's/subject's intellectual functioning (American Psychiatric Association 1994, National Academies of Sciences Engineering and Medicine 2015).
* Normal/No intellectual impairment
* Mild intellectual impairment: (Approximate IQ range 50-69) Can live independently with minimum levels of support.
* Moderate intellectual impairment: (Approximate IQ range 36-49): Independent living may be achieved with moderate levels of support, such as those available in group homes.
* Severe intellectual impairment: (Approximate IQ range 20-35) Requires daily assistance with self-care activities and safety supervision.
* Profound intellectual impairment: (IQ <20) Requires 24-hour care.
* Visual impairment: The indicator of whether the disorder has affected the participant's/subject's vision.
  + Normal: No impairment
  + Some Impairment: Some visual impairment (wears glasses)
  + Blind: Functionally blind (may have light perception, ability to see colour differences, see shadows but unable to use)
  + Unknown: Visual status unknown
* Hearing impairment: The indicator of whether the disorder has affected the participant's/subject's hearing.
  + Normal: No impairment
  + Some Impairment: Partial inability to hear
  + Bilateral deafness: Total inability to hear, with or without amplification
  + Unknown: Hearing status unknown
* Respiratory ventilation/ support assist: ‘If yes’, Choose all that apply.

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Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. Dev Med Child Neurol. 2014;56(3):245-251.