

## NINDS CDE Project

**Working group: Participant Characteristics & Disease/Injury Related Events**

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Please answer the following questions below.

**1. Approach for selection of elements**

The original list of items was based off common items collected by CP Registers from around the world. This list was augmented by reviewing “participant characteristics” and “disease/injury related events” from other diagnostic groups from the NINDS common data elements project. All items were reviewed and discussed by all members of the group to determine the classification based on the NINDS classification criteria.

**1. Differential application to types of cerebral palsy**

None of the instruments/elements recommended from this working group differed across cerebral palsy motor or subtypes.

**2. Summary recommendations**

Four of the CDEs reviewed by the group were classified as Core. Only four instruments were specific to individuals with CP. There were seven CDEs suggested as Supplemental – Highly Recommended. The majority of the CDEs were considered by our group to be Supplemental. There are some that are bolded that we now think should be Supplemental – Highly Recommended.

<b>Classification</b>	
<b>Core</b>	Birth date, birth country, country of residence, gender
<b>Supplemental – Highly Recommended</b>	Maternal date of birth, level of education attained, health insurance, timing of CP, if timing of CP is postneonatal – exact cause, gestational age, birthweight, multiple birth, predominant and secondary motor type, CP gross motor and upper limb function.
<b>Supplemental</b>	Postcode, paternal date of birth, maternal and paternal country of birth, languages fully fluent in home, maternal and paternal education, school placement, caregiver employment status, caregiver marital or partner status, multiple birth number, Apgar scores at 1 and 5 minutes, pregnancy complications, seizures in the newborn period, admission to intensive care as a newborn, age of CP diagnosis, predominant brain pattern on MRI, fine motor function, spasticity subtype, communication, communication function, epilepsy, cognition, vision, vision severity, hearing, hearing severity

**3. Comparison to other cerebral palsy standards**

Cerebral palsy registers throughout the world were used as a starting point. Where there is full agreement amongst registers, those items have been included and measured in the same way.

**4. Issues unique to cerebral palsy**

No issues unique to cerebral palsy that weren’t able to be addressed.

5. **Unmet needs; unanswered questions**

There currently is no definitive “classification of etiology” of cerebral palsy due to the heterogeneous nature of the disorder, and because there is very rarely one definitive cause, rather a causal pathway that contains any number of risk factors. Currently, objective measures only have been included such as “admission to intensive care”, “gestational age”. If classifications for etiology are developed they should be incorporated into the CP common data elements.

### Participant Characteristics and Disease/Injury Related Events CDE Recommendations

Classification	Classification	Motor Function	Spasticity/Movement	Speech/Language/Communication	Functional Outcomes
<b>Core</b>					
<b>Supplemental – Highly Recommended</b>	<ul style="list-style-type: none"> <li>• Communication Function Classification System (CFCS)</li> <li>• Eating and Drinking Ability Classification System (EDACS)</li> <li>• Gross Motor Function Classification System- Expanded &amp; Revised (GMFCS- ER)</li> <li>• Manual Ability Classification System (MACS)</li> </ul>	<ul style="list-style-type: none"> <li>• Alberta Infant Motor Scale (AIMS)</li> <li>• Gross Motor Function Measure (GMFM-88, GMFM-66)</li> <li>• Prechtl's Assessment of General Movements [General Movement Assessments]</li> <li>• Test of Infant Motor Performance (TIMP)</li> </ul>	<ul style="list-style-type: none"> <li>• Barry Albright Dystonia Scale (BADs)</li> <li>• Tardieu Scale</li> </ul>	<ul style="list-style-type: none"> <li>• Peabody Picture Vocabulary Test 4th Edition (PPVT™-4)</li> </ul>	
<b>Supplemental</b>		<ul style="list-style-type: none"> <li>• Manual Muscle Testing- Using the Medical Research Council Muscle Grading Scale</li> <li>• Maximum Voluntary Isometric Contraction Testing (MVICT)</li> </ul>	<ul style="list-style-type: none"> <li>• Hypertonia Assessment tool (HAT)</li> <li>• Modified Ashworth Scale</li> <li>• Selective Control Assessment of the Lower Extremity (SCALE)</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical Evaluation of Language Fundamentals – Fifth Edition (CELF-5)</li> <li>• Clinical Evaluation of Language Fundamentals Preschool 2 (CELF Preschool 2)</li> <li>• Comprehensive Test of Phonological Processing, Second Edition (CTOPP-2)</li> <li>• Edinburgh Cognitive and Behavioural ALS Screen (ECAS)</li> <li>• Goldman-Fristoe Test of Articulation 2 (GFTA-2)</li> <li>• Language Sample Analysis</li> <li>• Percentage of Consonants Correct-Revised (PCC-R)</li> <li>• Preschool Language Scales –</li> </ul>	<ul style="list-style-type: none"> <li>• 10 Meter Timed Walk</li> <li>• Functional Mobility Scale</li> <li>• Functional Independence Measure for Children (WeeFIM)</li> <li>• Instrumented Gait Analysis</li> <li>• Motor Function: 6 Minute Walk Test</li> <li>• NIH Toolbox Walking Speed (4-Meter Walk Gait Speed Test)</li> <li>• Observational Gait Scale</li> <li>• Pediatric Evaluation of Disability Inventory (PEDI)</li> <li>• Pediatric Outcomes Data Collection Instrument (PODCI)Gait Deviation</li> </ul>

Classification	Classification	Motor Function	Spasticity/Movement	Speech/Language/Communication	Functional Outcomes
				Fifth Edition (PLS-5) <ul style="list-style-type: none"> <li>• Pure Tone Threshold Audiometry</li> <li>• Speech Language Profile Groups (SLPG)</li> <li>• Verbal Motor Production Assessment for Children (VMPAC)</li> <li>• Viking Speech Scale (VSS)</li> </ul>	Index <ul style="list-style-type: none"> <li>• Stride Analysis and Gait Variability</li> <li>• Timed Up and Go (TUG)</li> </ul>
<b>Exploratory</b>	<ul style="list-style-type: none"> <li>• Bimanual Fine Motor Function (BFMF)</li> </ul>			<ul style="list-style-type: none"> <li>• Dynamic Evaluation of Motor Speech Skills (DEMSS)</li> <li>• Test of Children's Speech (TOCS)</li> </ul>	<ul style="list-style-type: none"> <li>• Functional Independence Measure (FIM)</li> </ul>