**NINDS CDE Project**

**Engagement and Quality of Life Assessments/Data Working Group**

**Working group: Engagement/QOL**

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**Date: 1Aug16**

Please answer the following questions below.

1. **Approach for selection of elements** (How did you go about drafting the recommendations and/or reviewing the current tools/instruments, and did you have any criteria for selection and classification?)

The initial list of tools/instruments was created by the lead and the board liaison. The list of tools was distributed amongst the group members for review. Each tool/instrument was evaluated for population, age range, specific diagnostic groups, reliability/validity of the tools, demonstrated use in patients with cerebral palsy, norm references, use with individuals with disabilities, reference groups, time required to complete the instrument, and mode of completion. All tools were reviewed and discussed to determine the classification based on the NINDS classification criteria.

1. **Differential application to types of cerebral palsy** *(Do the instruments/elements you recommended differ between the types of cerebral palsy?)*

Most of the instruments reviewed do not differentiate between types (unilateral/bilateral) or levels (GMFCS I-V). The only instrument specifically developed for specific level of patients with CP is the CPChild, developed for children GMFCS levels IV and V.

1. **Summary recommendations**

None of the instruments reviewed by the group were classified as Core. Only three instruments were specific to individuals with CP. The highly recommended quality of life instruments are specific to individuals with CP. The highly recommended participation instruments have demonstrated usefulness in individuals with CP.

1. **Comparison to other cerebral palsy standards** (Are there any notable similarities/differences in the CDE recommendations as compared with other standards?)
2. **Issues unique to cerebral palsy** *(Were there any issues encountered when developing the CDE standards which are unique to cerebral palsy or which highlight a unique concern about cerebral palsy data collection?*

Many of the instruments reviewed were not specific for or differentiated between types of levels of individuals with CP. Assessment of quality of life is a difficult construct, especially for individuals who are non-verbal or who have cognitive impairments as a component of their CP.

1. **Unmet needs; unanswered questions** *(What unmet need / unanswered questions were identified via the CDE process in cerebral palsy? What areas are in need of further research and development?)*

Due to the wide spectrum of abilities of CP, development of instruments which are specific to both the type and level of CP would be beneficial.

**Engagement and Quality of Life Assessments/Data CDE Recommendations**

| **Classification** | **Quality of Life** | **Participation** |
| --- | --- | --- |
| **Core** |  |  |
| **Disease Specific** | * Pediatric Quality of Life Inventory Cerebral Palsy Module (PedsQL-CP)
* Cerebral Palsy Quality of Life (CPQOL)
* Caregiver priorities and Child Health Index of Life with Disabilities (CPCHILD)
 | * Lifestyle Assessment Questionnaire for CP (LAQ-CP of LAQ-G)
 |
| **Supplemental – Highly Recommended** | * Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD)
* Cerebral Palsy Quality of Life (CP QOL)
* Pediatric Quality of Life Inventory (PedsQL)
* Pediatric Quality of Life Inventory Cerebral Palsy Module (PedsQL-CP)
 | * Assessment of Life Habits (LIFE-H)
* Child Engagement in Daily Life
* Participation and Environment Measure for Children and Youth (PEM-CY)
* Young Children's Participation and Environment Measure (YC-PEM)
 |
| **Supplemental** | * DISABKIDS
* Generic Children’s Quality of Life Measure (GCQ)
* KIDSCREEN-52 HRQOL
 | * Assessment of Preschool Children’s Participation (APCP)
* Children’s Assessment of Participation and Enjoyment Scale (CAPE)/ Preferences for Activities of Children (PAC)
* School Function Assessment (SFA)
 |
| **Exploratory** | * Assessment of Quality of Life (AQoL)
* Child Health and Illness Profile (CHIP-CE)
* Child Health Assessment Questionnaire (CHAQ)
* Child Health Questionnaire
* EuroQoL-5 Dimension Questionnaire-Youth (EQ-5DY)
* Health Utilities Index (HUI)
* Healthy Days Core Module 4
* Multidimensional Students’ Life Satisfaction Scale (MSLSS)
* NeuroQoL
* Short Form 36-Item Health Survey (SF-36)
* World Health Organization Quality of Life Assessment (WHOQOL-BREF)
 | * Child and Adolescent Scale of Participation (CASP)
* Evaluation of Social Interaction (ESI) (2nd Edition)
* Lifestyle Assessment Questionnaire for CP (LAQ-CP of LAQ-G)
* Participation Assessment with Recombined Tools-Objective (PART-O)
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