

# Content comparison of HRQOL measures for children and youth with Cerebral Palsy based on ICF-CY

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## BACKGROUND

Content comparison of health related quality of life (HRQOL) measures is currently challenging because of the varying use of concepts and operationalizations.

The new International Classification of Functioning children and youth version (ICF-CY) provides a universal language of functioning and health.

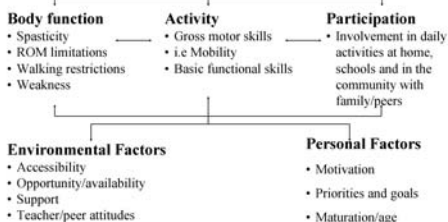
ICF-CY includes 5 components: body structure, body function, activity and participation (a&p), personal and environmental factors summarized in a codified classification system.

## ICF-CY

ICF-CY conceptual model (bio-psychosocial model) contributions:

- ✓ Identify 'participation' as an important dimension of health.
- ✓ All the components of the model are now linked to each other (bi-directional arrows), any aspect of function can and probably will affect another, in a non-linear manner.
- ✓ 'disability' is considered an umbrella term to represent the **dynamic interaction** between person and environment. This change reflects the idea that **'disability' is a social construction** involving an interaction of the person and their community or society.

### ICF-CY: application example Cerebral Palsy



## OBJECTIVE

Our objective was to use the ICF-CY as a standard by which to compare the content of 8 different HRQOL measures.

## METHODS

A targeted literature review was performed to identify most common HRQOL measures used in children and youth with Cerebral Palsy (CP).

MEDLINE and PsycINFO databases were searched up to Sept 2008. From 430 citations retrieved, 8 HRQOL measures were identified.

The content of HRQOL measures was linked to the ICF-CY by two trained health professionals, according to standardized guidelines.

Overall agreement and agreement for each component were calculated using kappa ( $\kappa$ ) statistic and 95% confidence intervals (CI).

Frequency and distribution of concepts by measure and ICF-CY component were calculated.

## RESULTS

Five disease specific and 3 generic measures were identified. The main concepts cover in each item of the questionnaires were extracted and linked to the ICF-CY.

A total of 623 concepts were linked to 139 ICF-CY categories within the 5 components.

Overall  $\kappa$  agreement was 0.76 (95% CI 0.75-0.77). Highest agreement was reached for a&p ( $\kappa = 0.84$ , 95% CI 0.82-0.86).

The measures varied in the number of concepts and the distribution of concepts by ICF-CY components; for example in the a&p component concepts varied from 75% in the CPCHILD to 25% in the HUI-3 (Table1). 42% of concepts were linked to the a&p component.

**Table 1. Distribution of concepts by ICF-CY component and HRQOL measure, N (%)**

ICF-CY Component	Measure <sup>¶</sup>								
	Disease-specific					Generic			
	CPCHILD	CPQOL	CQ	DISABKIDS CP module	PEDSQL CP module	CHQ	HUI-2	HUI-3	Total
Body Functions	7 (11.5)	14 (18.9)	9 (19.1)	8 (29.6)	16 (32.0)	43 (28.1)	51 (44.3)	54 (54.5)	202 (32.4)
Activity & Participation	46 (75.4)	27 (36.5)	28 (59.6)	12 (44.4)	25 (50.0)	60 (39.2)	39 (33.9)	25 (25.3)	262 (42.1)
Environmental Factors	2 (3.3)	22 (29.7)	4 (8.5)	4 (14.8)	6 (12.0)	10 (6.5)	23 (20.0)	16 (16.2)	87 (14.0)
Personal Factors	0(0)	4 (5.4)	1 (2.1)	0 (0)	0 (0)	4 (2.6)	0 (0)	0 (0)	9 (1.4)
Others*	6 (9.8)	7 (9.5)	5 (10.6)	4 (14.3)	3 (6.0)	36 (23.5)	2 (1.7)	0 (0)	63 (10.1)
N° concepts	61	74	47	27	50	153	115	99	623

\*others= not covered, not definable

¶ Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD), Quality of Life for Children with CP (CPQOL), Caregiver Questionnaire (CQ), DISABKIDS CP-module, Pediatric Quality of Life Inventory CP-module (PEDSQL-CP), Childhood Health Questionnaire (CHQ-CF87), Health Utilities Index (HUI-2 and HUI-3)

**Table 2. Examples of ICF-CY categories by HRQOL measure**

ICF-CY code	Category name	CPCHILD	CPQOL	DISABKIDS-CP module	PEDSQL-CP module	CQ	CHQ	HUI 2	HUI 3
	<b>BODY FUNCTION</b>								
b152	Emotional functions		5	6	4			14	13
b2	Sensory functions and pain	1	1			3	2	3	1
	<b>ACTIVITY &amp; PARTICIPATION</b>								
d3	Communication	2	3	1	2	1			
d420	Transferring oneself	3			2	1	2		
d530	Toileting	4	1	1	2	3	1	4	
d540	Dressing	1	1	2	1		1	4	
	<b>ENVIRONMENTAL FACTORS</b>								
e1201	Assistive products and technology for mobility		4					5	4
e3	Support and relationships	1	2	2	2	1		6	3

## CONCLUSIONS

The ICF-CY provided an international accepted, structured framework for the content comparison of CP specific and generic HRQOL measures.

The results of this study will provide clinicians and researchers with additional information, useful when selecting HRQOL measures.

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