## Outcome Domain:

Perceived Generic and Disease-Specific Health-Related Quality of Life

### Domain Description and Relevance in TBI:

“TBI may create significant limitations in multiple areas of functioning and well-being, often reducing perceived quality of life with regard to multiple generic and disease specific dimensions.” – Wilde et al 2010

Table CDE Classification by Type of TBI Study and Relevant Population for Recommended Perceived Generic and Disease-Specific Health-Related Quality of Life Outcome Measures.

| Outcome Measure Name | Relevant TBI Population | Acute Hospitalized | Moderate/ Severe Rehabilitation | Concussion/ Mild TBI | Epidemiology |
| --- | --- | --- | --- | --- | --- |
| Pediatric Quality of Life Inventory: Generic core | Pediatric TBI | Basic | Basic | Basic | Supplemental |
| Quality of Life after Brain Injury (QOLIBRI) | Adult TBI | Supplemental | Supplemental | Supplemental | Supplemental |
| Satisfaction with Life Scale (SWLS) | Adult TBI | Supplemental | Basic | Basic | Supplemental |

### References

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## Pediatric Quality of Life Inventory (PedsQL)

### DESCRIPTION

The PedsQL is a 23-item measure that can be used to assess health-related quality of life in children. The measure includes items in the domains of physical, emotional, social and school functioning. Age-appropriate child forms are available between the ages of 5 and 18, and parent proxy forms can be used down to age 2. Respondents indicate how much each item has been a problem in the past month; responses for 8-18 year old children and for parents are rated on a 5-point Likert scale, while younger children rate their responses on a 3-point scale. A total score and two summary scores for physical health and psychosocial health can be calculated.

### PERMISSIBLE VALUES

The total score is on a scale from 1-100, with higher scores indicating a higher health-related quality of life. Summary scores and scores for each subscale are computed by averaging the component item responses, and range between 0-4.

### PROCEDURES

The test can be completed in under 5 minutes. Parents and children 8 years or older may self-administer the PedsQL or the administrator can read the instructions to the child.

### COMMENTS

The PedsQL is appropriate for children and adolescents ages 2-18 years.

### RATIONALE

“It has been used in pediatric TBI and has been translated into over 48 languages including Spanish.” – McCauley et al. 2012

### REFERENCES

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## Quality of Life after Brain Injury (QOLIBRI)

### DESCRIPTION

The QOLIBRI-TBI is a TBI disease-specific instrument to measure HRQoL after TBI. Its multidimensional structure contains 37 items on 4 Satisfaction scales "Cognition", "Self", "Daily Life & Autonomy", “Relationships", 2 Bothered scales "Emotions" and "Physical Problems" and a total score. For screening purposes there is an additional overall scale available with 6 items.

### PERMISSIBLE VALUES

The scoring algorithm provides percent scores for the six subscales (with 100% indicating best QoL), and one total score. Higher scores on all scales indicate higher HRQOL after TBI.

### PROCEDURE

Self report, face-to-face interview,5-10 minutes, available : comprehensive version with 37 items, a screening (6 items), and short version (11 items) and CAT (Computer Adaptive Test) in preparation.

### COMMENTS

Persons after TBI, 17-68 years, translations available in Chinese, Spanish, English, Finnish, French, Italian, German, Dutch, Polish, etc.).

### RATIONALE

Until now the only disease specific HRQOL-instrument for persons after TBI. Comprehensive outcome tool for clinic outcome studies and individual use. In two international psychometric studies with 921 and 1528 mild-to-severe TBI patients FA, CFA and SEM support a six-scale QOL profile and a total QOL score. Scale internal consistencies and test-retest reliability between 0.75 and 0.89, for total score > .90. Similar reliabilities in groups of participants with lower and higher cognitive performance. Correlations of QOLIBRI-TBI scores and SF-36: higher with SF-36 mental (.60) than SF-36 physical (.40) component, which was expected because of content of QOLIBRI-TBI. Correlation between QOLIBRI-TBI and SWLS (.58), functional outcome (GOSE, 0.40) and (negative) correlations with HADS anxiety (>.55) and depression (>0.65). No or marginal correlation with GCS, age and time since injury (<.10).

### REFERENCES

Von Steinbüchel et al. (2005), von Steinbüchel et al., (2009, submitted)

## Satisfaction with Life Scale (SWLS)

### DESCRIPTION

The SWLS consists of 5 items answered on a 7-point Likert scale ranging from 1=strongly disagree to 7=strongly agree.

### PERMISSIBLE VALUES

Total score ranges from 7-35. Higher scores indicate better satisfaction with life.

### PROCEDURE

Individual of interest is the respondent. Paper-and-pencil measure. Administration time is 2-3 minutes.

### COMMENTS

Can be used with adult individuals with severe disability, moderate disability, good recovery.

### RATIONALE

Normative data is available in the TBI population. The SWLS has been used by the TBI Model Systems national database since 1998.

### REFERENCES

Diener E, Emmons R, Larsen J, Griffin S. The Satisfaction with Life Scale. J Personality Assessment 1985;49:71-75.