## Outcome Domain:

Global Outcome

## Domain Description and Relevance in TBI:

“Global outcome measures summarize the overall impact of TBI incorporating functional status, independence and role participation.” – Wilde et al 2010

**Table 1.**

Table CDE Classification by Type of TBI Study and Relevant Population for Recommended Global Outcome Measures.

| Outcome Measure Name | Relevant TBI Population | Acute Hospitalized | Moderate/ Severe Rehabilitation | Concussion/ Mild TBI | Epidemiology |
| --- | --- | --- | --- | --- | --- |
| Disability Rating Scale (DRS) | Adult  | Supplemental | Basic | Supplemental | Supplemental |
| Glasgow Outcome Scale | Adult  | Supplemental | Supplemental | Supplemental | Supplemental |
| Glasgow Outcome Scale – Extended (GOSE) | Adult  | Core | Core | Core | Core |
| Glasgow Outcome Scale – Extended Pediatric Revision (GOS-E Peds) | Pediatric  | Basic | Basic | Supplemental | Supplemental |
| Mayo-Portland Adaptability Inventory (MPAI-4) | Adult  | Supplemental | Supplemental | Supplemental | Supplemental |
| Pediatric Quality of Life Inventory (PedsQL) | Pediatric  | Supplemental | Supplemental | Supplemental | Supplemental  |
| Pediatric Test of Brain Injury | Pediatric  | Supplemental | Supplemental | Supplemental | Supplemental |
| Short Form-12 Health Survey (SF-12) | Adult  | Supplemental | Supplemental | Supplemental | Supplemental |
| Short Form-36 Medical Outcome Study (SF-36 v2) | Adult  | Supplemental | Supplemental | Supplemental | Supplemental |

### References:

McCauley SR, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, Chapman SB, Ewing-Cobbs L, Gerring JP, Gioia GA, Levin HS, Michaud LJ, Prasad MR, Swaine BR, Turkstra LS, Wade SL, Yeates KO. Recommendations for the Use of Common Outcome Measures in Pediatric Traumatic Brain Injury Research. J Neurotrauma. 2012 March; 29: 678-705. PubMed PMID: 21644810.

Wilde EA, Whiteneck GG, Bogner J, Bushnik T, Cifu DX, Dikmen S, French L, Giacino JT, Hart T, Malec JF, Millis SR, Novack TA, Sherer M, Tulsky DS, Vanderploeg RD, von Steinbuechel N. Recommendations for the use of common outcome measures in traumatic brain injury research. Arch Phys Med Rehabil. 2010 Nov;91(11):1650-1660.e17. [DOI: 10.1016/j.apmr.2010.06.033]

## Disability Rating Scale (DRS)

### DESCRIPTION

The DRS contains 8 items. The first three items ("Eye Opening," "Communication Ability", and "Motor Response") are a modification of the Glasgow Coma Scale (scored in reverse), and reflect impairment and level of consciousness. Cognitive ability for "Feeding", "Toileting" and "Grooming" reflect level of disability. "Level of Functioning" and "Employability" reflect handicap.

### PERMISSIBLE VALUES

Minimum score is 0 (without disability) and maximum score is 29 (extreme vegetative state).

### PROCEDURES

Completed by clinician (physician, therapist, nurse, psychologist, social worker); some training required and videotape, online training is recommended (see https://www.tbims.org/combi/drs/drstat.html). Administration time is 10 minutes.

### COMMENTS

Developed and tested with older juvenile and adult individuals with moderate to severe TBI in inpatient rehabilitation setting. It can be used at all levels of functioning, from coma to return to community).

### RATIONALE

The scale is attractive because it is one of a few measures that can be used in both acute and chronic recovery intervals for moderate to severe TBI, and is useful in monitoring recovery. It has been widely used in studies of TBI and may have greater sensitivity to change than the Glasgow Outcome Scale.

### REFERENCES

Rappaport, M., Hall K.M., Hopkins, K., Belleza, T., Cope, D.N. (1982). Disability Rating Scale for Severe Head Trauma: Coma to Community. Archives of Physical Medicine and Rehabilitation, 63: 118-123.

## Glasgow Outcome Scale (GOS), Glasgow Outcome Scale - Extended (GOSE), and Pediatric Revision to Glasgow Outcome Scale – Extended (GOSE Peds)

### DESCRIPTION

The GOS is a one item scale with 5 possible ratings - Dead, Vegetative State, Severe Disability, Moderate Disability, and Good Recovery. The GOSE is a revision of the GOS that divides the upper three ratings into upper and lower categories - lower severe disability, upper severe disability, lower moderate disability, upper moderate disability, lower good recovery, upper good recovery. The GOSE Peds uses the same 8-point scale as the GOSE, but a structured interview appropriate for children is used to arrive at the result on the scale.

### PERMISSIBLE VALUES

Ratings for the GOS range from 1 to 5 (Dead to Good Recovery). Ratings for the GOSE and GOSE Peds range from 1 to 8 (Dead to Upper Good Recovery).

### PROCEDURES

The GOS, GOSE, and GOSE Peds are generally rated by a clinician or research assistant who is familiar with the patient or who conducts a structured interview to obtain needed information. Depending on prior familiarity with the patient, the scale can be completed in as little as 5 minutes.

### COMMENTS

The GOS and GOSE can be used to assess adults and children with TBI of any severity. Some have questioned the validity of the GOS/GOSE with children; therefore the GOSE Peds is recommended for use with children under 17 years of age.

### RATIONALE

The GOS is the most commonly used global outcome in studies of TBI so use of this scale permits comparison to an extensive extant literature on TBI. The GOSE can easily be recoded to the GOS. Extensive literature shows excellent reliability and validity for these scales.

### REFERENCES

Beers, S., Hahner, T., and Adelson, P. (2005). Validity of a pediatric version of the Glasgow Outcome Scale-Extended (GOSE Peds). J. Neurotrauma 22, 1224.

Jennett B, Bond M. Assessment of outcome after severe brain injury. A practical scale. Lancet 1975;1:480-484.

Wilson JTL, Pettigrew LEL, Teasdale GM. Structured interviews for the Glasgow Outcome Scale and the Extended Glasgow Outcome Scale: Guidelines for their use. J Neurotrauma 1998;15:573-85.

## Mayo-Portland Adaptability Inventory (MPAI-4)

### DESCRIPTION

The MPAI-4 consists of thirty items rated on a 5-point scale (0-4) ranging from normal for age to severely restricted. Items represent key indicators in three inter-related subdomains represented by three subscales: Ability Index (physical and cognitive abilities), Adjustment Index (emotional and behavioral self-regulation, interpersonal activities), and Participation Index (community integration). An overall score and scores for each index may be obtained. Specified modifications to the rating scales allow the measure to be applied across the age span from childhood through adulthood.

### PERMISSIBLE VALUES

Total score range = 0-115. Raw total and index scores may be converted to T-scores with reference to a national sample of 386 individuals with brain injury.

### PROCEDURES

The test may be completed by consensus of a professional team, by a single professional, by a person with brain injury, or by a significant other. Ratings are based on all available information. Completion usually requires 20-30 minutes. Comparison of ratings from various sources, i.e., professional vs. person with brain injury vs. significant others may reveal variations in perception of and value placed on limitations. The 8-item Participation Index can be used independently and administered in person or by telephone to assess Involvement in daily activities in the home and community; completion time is about 10 minutes.

### COMMENTS

Adults and children with acquired brain injury. Translations are available in German, Spanish, Danish, Swedish, French, Italian, and Portuguese.

### RATIONALE

The measure was selected to provide more detailed assessment of global outcome as well as restrictions in abilities, adaptation, and participation after brain injury. It possesses sound psychometric properties with development grounded in both item response and classic psychometric theory. Published studies document concurrent, construct, and predictive validity. The measure is widely used for planning and evaluating postacture rehabilitation. There is limited use in research studies to-date.

### REFERENCES

Malec JF, Moessner AM, Kragness M, Lezak MD. Refining a measure of brain injury sequelae to predict postacute rehabilitation outcome: rating scale analysis of the Mayo-Portland Adaptability Inventory (MPAI). J Head Trauma Rehabil 200;15(1):670-82.

Malec JF. The Mayo-Portland Participation Index: A brief and psychometrically sound measure of brain injury outcome. Arch Phys Med Rehabil 2004;85:1989-96.

Detailed manual, forms, and translations available for download at: [The Center for Outcome Measurement in Brain Injury Mayo-Portland Adaptability Inventory Summary](http://www.tbims.org/combi/mpai)

## 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

Aitken, M., McCarthy, M., Slomine, B., Ding, R., Durbin, D., Jaffe, K., Paidas, C., Dorsch, A., Christensen, J., and Mackenzie, E. (2009). Family burden after traumatic brain injury in children. Pediatrics 123, 199-206.

Calvert, S., Miller, H., Curran, A., Hameed, B., McCarter, R., Edwards, R., Hunt, L., and Sharples, P. (2008). The King’s outcome scale for childhood head injury and injury severity and outcome measures in children with traumatic brain injury. Developmental Medicine and Child Neurology 50(6), 426-431.

Curran, A., Miller, H., McCarter, R., Sharples, P., and The Kids Head Injury Study Group (2003). Measuring quality of life after traumatic brain injury in children: How does the Health Utilities Index (HUI) compare to the Pediatric Quality of Life measure (PedsQL)? Arch Dis Child 88, A24.

Erickson, S., Montague, E., and Gerstle, M. (2010). Health-related quality of life in children with moderate-to-severe traumatic brain injury. Dev Neurorehabil 13, 175-181.

McCarthy, M. L., MacKenzie, E. J., Durbin, D. R., Aitken, M. E., Jaffe, K. M., Paidas, C. N., Slomine, B. S., Dorsch, A. M., Berk, R. A., Christensen, J. R., and Ding, R. (2005). The Pediatric Quality of Life Inventory: an evaluation of its reliability and validity for children with traumatic brain injury. Arch Phys Med Rehabil 86(10), 1901-1909.

McCarthy, M. L., MacKenzie, E. J., Durbin, D. R., Aitken, M. E., Jaffe, K. M., Paidas, C. N., Slomine, B. S., Dorsch, A. M., Christensen, J. R., and Ding, R. (2006). Health-related quality of life during the first year after traumatic brain injury. Arch Pediatr Adolesc Med 160(3), 252-260.

Moon, R., Sutton, T., Wilson, P., Kirkham, F., and Davies, J. (in press). Pituitary function at long-term follow up of childhood traumatic brain injury. J Neurotrauma.

Slomine, B., McCarthy, M., Ding, R., Mackenzie, E., Jaffe, K., Aitken, M., Durbin, D., Christensen, J., Dorsch, A., and Paidas, C. (2006). Health care utilization and needs after pediatric traumatic brain injury. Pediatrics 117(4), e663-e674.

Varni, J., Burwinkle, T., Seid, M., and Skarr, D. (2003). The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr 3(6), 329- 341.

Varni, J., Seid, M., and Kurtin, P. (2001). PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care 39(8), 800-812.

Varni, J., Seid, M., and Rode, C. (1999). The PedsQL: measurement model for the pediatric quality of life inventory. Med Care 37(2), 126-139.

## Pediatric Test of Brain Injury

### DESCRIPTION

The PTBI measures neurocognitive and linguistic skills after brain injury in children. It is designed to be used in the acute stage for a baseline measure and then in subsequent stages of recovery. It is criterion-referenced and provides cutoffs for appropriate levels of ability for different ages for 10 subtests.

### PERMISSIBLE VALUES

An ability score can be calculated for each subtest

### PROCEDURES

Administration is approximately 30 minutes long and is in an interview format. Administration of the test can occur in one or two sessions.

### COMMENTS

For children 6 to 16 years of age who are recovering from TBI.

### RATIONALE

“This measure was selected … based upon its specific use and validation in children with acquired brain injury or TBI and its potential usefulness across the spectrum of recovery.” – McCauley et al. 2012

### REFERENCES

Hotz, G., Helm–Estabrooks, N., Nelson, N.W., and Plante, E. (2010). Pediatric Test of Brain Injury (PTBI). Paul H. Brookes Publishing Co., Inc.: Baltimore

## Short Form-12 Health Survey

### DESCRIPTION:

The SF-12 Health Survey is a shorter version of the SF-36 Health Survey, containing 12 items from the SF-36, and is a subjective measure of a patient’s health and well-being. Items are in a likert-scale format. Eight sub-scales are part of the survey including Physical Functioning, Role Limitations-Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Limitations-Emotional, and Mental Health. A physical component score (PCS) and mental component score (MCS) can be computed.

### PERMISSIBLE VALUES:

T-scores (mean = 50, SD = 10) for the eight subscales and the two composite scores (physical and mental component)

### PROCEDURE:

TheSF-12 is self-administered or can be conducted as an interview. It consists of a series of 12 likert-style questions and can be completed in 2-3 minutes.

### COMMENTS:

This instrument is appropriate for use in adults.

### RATIONALE:

The SF-12 is quick, easy to administer, and has proven validity in numerous applications. It is available in multiple languages. It is not TBI-specific, and thus can allow comparison with other diseases and the general population.

### REFERENCES:

Jenkinson C, Chandola T, Coulter A, Bruster S. An assessment of the construct validity of the SF-12 summary scores across ethnic groups. *Journal of Public Health Medicine* 2001; 23:187-194.

Ware Jr. John, E. (2005). Sf-12 health survey (version 1.0). Retrieved from [University of Wollongong Short Form Health Survey-12 Instrument Review](http://ahsri.uow.edu.au/ahoc/documents/sf12review.pdf)

## Short Form-36 Medical Outcome Study (SF-36 v2)

### DESCRIPTION

The SF-36 is a generic subjective health status measure consisting of eleven items in a three to six-point Likert-scale item format. The eight subscales comprise physical functioning, physical role function, emotional role function, bodily pain, vitality, mental well-being, social functioning, and general health perception. An additional item assesses changes in health status during the last year. Two sum scores can be computed using a freely-available regression-based scoring syntax, the physical component score (PCS) and the mental component score (MCS).

### PERMISSIBLE VALUES

The scoring algorithm provides T-scores (mean = 50, SD = 10) for the eight subscales and the two composite scores (physical and mental component). Higher scores indicate better subjective health.

### PROCEDURES

Self report, face-to-face interview, or telephone interview. Administration time is 5-10 minutes.

### COMMENTS

For use with individuals 14-65 years

### RATIONALE

The SF-36 is the most widely used instrument to assess subjective health. TBI studies show adequate psychometric quality (e.g. Findler et al. (2001)).

### REFERENCES

Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Status Survey (SF-36): 1. Conceptual framework and item selection. Med Care 1992; 30 (6)

 Ware JE, Snow KK, Kosinski M, Gandek B. SF-36 Health Survey manual and interpretation guide. Boston: New England Medical Center, The Health Institute, 1993

Findler M, Cantor J, Haddad L, Cordon L, Ashman T . The reliability and validity of the SF-36 health survey questionnaire for use with individuals with traumatic brain injury. Brain Injury 2001; 15 (8): 715-23.