



NINDS Common Data Element (CDE) Project

Traumatic Brain Injury Version 3.0

Internal Review / Public Review

Outcomes and Endpoints Subgroup Materials

Subgroup Summary

Instruments

- EuroQoL-5 Dimension Questionnaire (EQ-5D)
- Health and Behavior Inventory (HBI) Child Version
- Health and Behavior Inventory (HBI) Parent Current Version
- Health and Behavior Inventory (HBI) Parent Retrospective Version
- Neurobehavioral Symptom Inventory (NSI)
- Pediatric Quality of Life Inventory Generic Core Scale (PEDIQL Generic Core Scale)
- Post-Concussion Symptom Inventory (PCSI) Self-Report Assessment Form Pre and Post-Injury Report Ages 13-18
- Post-Concussion Symptom Inventory (PCSI-P) Parent Assessment Form Pre and Post-Injury Report
- Post-Concussion Symptom Scale
- Quality of Life After Brain Injury (QOLIBRI)
- Rivermead Post-Concussion Symptoms Questionnaire (RPQ)
- Satisfaction with Life Scale



NINDS CDE Project Traumatic Brain Injury Version 3.0 Outcomes and Endpoints Subgroup Summary

The NINDS TBI v3.0 Common Data Element (CDE) Outcomes and Endpoints Subgroup reviewed and updated CDEs based on the current state of neuroscientific clinical research.

The Outcomes and Endpoints Subgroup focused on patient- and informant-reported outcome measures assessing symptoms, life function, and quality of life after TBI. Outcomes and Endpoints in these domains are used widely in TBI clinical research to measure effects of injury, as well as postinjury recovery and outcome.

In its review, the Outcomes and Endpoints Subgroup used the NINDS CDE Instrument Selection Criteria to evaluate screening tools, surveys, and tests used to assess post-concussive/TBI-related symptoms, patient- and informant-reported outcomes, and perceived quality of life after brain injury. This included review of previously-published studies on relevant psychometric properties of each candidate measure, and actual case report forms.

Review of performance-based measures is being led by a separate TBI CDE v3.0 Subgroup and not included in the scope of the Outcomes and Endpoints Subgroup.



Summary of Recommendations

Subdomain	Instrument Name	Classification
Health-Economic Measures	EuroQoL-5 Dimension Questionnaire (EQ-5D)	Pending Classification
Perceived Generic and Disease-Specific Health-Related Quality of Life	Pediatric Quality of Life Inventory Generic Core Scale (PedsQL Generic Core Scale)	Pending Classification
	Quality of Life After Brain Injury (QOLIBRI)	Supplemental – Highly Recommended
	Satisfaction with Life Scale	Supplemental – Highly Recommended
Post-concussive/TBI-Related Symptoms	Health and Behavior Inventory (HBI) Child Version	Supplemental
	Health and Behavior Inventory (HBI) Parent Current Version	Supplemental
	Health and Behavior Inventory (HBI) Parent Retrospective Version	Supplemental
	Neurobehavioral Symptom Inventory (NSI)	Pending Classification
	Post-Concussion Symptom Inventory (PCSI) Self-Report Assessment Form Pre and Post-Injury Report Ages 13-18	Pending Classification
	Post-Concussion Symptom Inventory (PCSI-P) Parent Assessment Form Pre and Post-Injury Report	Pending Classification
	Post-Concussion Symptom Scale	Pending Classification
	Rivermead Post-Concussion Symptoms Questionnaire (RPQ)	Pending Classification

Instruments Reviewed and Not Recommended for v3.0

Instrument Name	TBI v2.0 Classification	Instrument Selection Criteria Not Met
Immediate Post-Concussion Assessment and Cognitive Testing (imPACT)	Supplemental	Specific? Reliable? Low burden to participants and investigators? Crosscutting relevance for population groups as well as diseases and conditions?
Patient-Reported Outcomes Measurement Information System (PROMIS)	Supplemental	Broadly validated with demonstrated utility? Specific? Reliable?



Instrument Name	TBI v2.0 Classification	Instrument Selection Criteria Not Met
Quality of Life in Neurological Disorders (Neuro-QOL)	Supplemental	Well-established, broadly applicable to the intended population (e.g., adult and/or pediatric), and generally accepted by the scientific community? Broadly validated with demonstrated utility? Reliable? International harmonization (International applicability)?
Traumatic Brain Injury - Quality of Life (TBI-QOL)	Exploratory	Reliable? Standard measurement protocols exist? Low burden to participants and investigators? Crosscutting relevance for population groups as well as diseases and conditions? Rural vs. Urban (Feasibility of Acquisition)? International harmonization (International applicability)?

Guidance Documents Reviewed and Not Recommended for v3.0

Guidance Document Name	TBI v2.0 Classification
NIH Resources TBI Guidelines	N/A

NINDS CDE Notice of Copyright EuroQoL-5 Dimension Questionnaire (EQ-5D)

Availability	<p>Please visit this website for more information about the instrument: EuroQol-5 Dimension Questionnaire</p> <p>Users must register the study in which EQ-5D is to be used by completing the EQ-5D registration form (visit EuroQol-5 Dimension Questionnaire website). The EuroQol Executive Office will then contact by e-mail to inform about the terms and conditions which apply to use of the EQ-5D, including licensing fees (if applicable). Please allow three working days to receive this reply. The EuroQol Executive Office determines licensing fees based on user-provided information. The amount is dependent upon the type of study, size and/or number of users and requested languages. Without the prior written consent of the EuroQol Executive Office, you are not permitted to use, reproduce, alter, amend, convert, translate, publish or make available in whatever way (digital, hard-copy etc.) the EQ-5D and related proprietary materials. All copyrights in the EQ-5D, its (digital) representations, and its translations exclusively vest in the EuroQol Group. EQ-5D™ is a trademark of the EuroQol Group.</p>
Classification TBI v3.0 Classification Pending	<p>Supplemental – Highly Recommended: *Mitochondrial Disease (Mito), **Parkinson’s Disease (PD), and Stroke (based on study type, disease stage and disease type)</p> <p>*Recommendations for use: 5L version is indicated for interventional studies requiring a measure of quality of life. Either the EuroQoL-5D-5L or SF-36/SF-12 is recommended.</p> <p>**Recommendations for use: Indicated for studies as a Generic Health-Related Quality of Life measure.</p> <p>Supplemental: Amyotrophic Lateral Sclerosis (ALS), Headache, Multiple Sclerosis (MS), Neuromuscular Disease (NMD), Spinal Cord Injury (SCI), and Traumatic Brain Injury (TBI)</p> <p>Exploratory: Huntington’s Disease (HD), Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS), and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)</p>
Short Description of Instrument	<p>Construct measured: Quality of Life / Self-reported Patient Satisfaction</p> <p>Generic vs. disease-specific: Generic</p> <p>Means of administration: Self-Administered EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics, and in face-to-face interviews. It is cognitively undemanding, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire. It is currently available in 102 languages.</p> <p>Intended respondent: Patient</p>

	<p># of items: 5</p> <p># of subscales and names of sub-scales: Each question, from which the summary index is derived, can also be presented individually. There is an additional Visual Analog Scale (VAS) of general health.</p> <p># of items per sub-scale: 1</p> <p>EQ-5D, the adult version, can be used for youth over 16.</p> <p>For children aged 4 -7 a proxy version can be used. Two proxy versions: Proxy 1: The proxy rates the health of the child. Proxy 2: The proxy rates how they think the child would rate their own state if they were asked directly and could communicate it.</p> <p>It is recommended to use Proxy 1 (if applicable) and can be applied to children from 4 -7 years and to children over 8 years who are not able to complete the EQ-5DY themselves.</p> <p>EQ-5D is specific to teenagers and adults, but there is an EQ-5D-Y (EQ-5D-Youth version) which is an EQ-5D-3L self-complete version for children and adolescents aged 7 -12. The EQ-5D consists of two parts: the EQ-5D section and the EQ VAS section. These sections provide a composite picture of the respondent's health status. The EQ-5D consists of 5 questions (representing 5 dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) each with a single digit response option. The EQ VAS generates a self-rating of health-related quality of life.</p> <p>Studies have found moderate agreement between responses from patients and those from their proxies for some of the domains of the EQ-5D and the agreement between patient and proxy is the best when assessed at six months, rather than two to three weeks, after stroke. Reproducibility is better when patients completed the instrument instead of their proxies. The relationship between the EQ-5D and the Barthel Index and mapping the modified Rankin Scale to the EQ-5D have been explored. Except for the SF-36 mental health domain, EQ-5D and SF-36 measure similar domains with similar test-retest reliability.</p>
<p>Comments/Special Instructions</p>	<p>Background: EQ-5D is a standardized measure of health status developed by the EuroQol Group to provide a simple, generic measure of health for clinical and economic appraisal. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care as well as in population health surveys.</p> <p>The EQ-5D self-report questionnaire essentially consists of two pages comprising the EQ-5D descriptive system (page 2) and the EQ VAS (page 3). There is also an optional page of demographic questions. There is also an extended version of EQ-5D that incorporates the valuation task but this is only used for valuation studies and is not relevant for clinical users.</p>

	<p>The EQ-5DY is the child-friendly version of the EQ-5D, with language modifications, such as changing the word “depression” to “sad”. (Burstrom et al., 2011) The main differences between the EQ-5D and the EQ-5D-Y are revisions to domain definitions, introduction of age-appropriate wording and adaptations to layout. The purpose of the adaptation was to clarify the meaning of dimensions for younger respondents and to establish that items referred exclusively to health-related impairment and not to age-related difficulties. For example, “self-care” was modified to “looking after myself” and the usual activities domain listed going to school, hobbies, sports, playing, and doing things with family or friends as the examples of activities. (Burstrom et al., 2014; Wille et al., 2010)</p>
Scoring and Psychometric Properties	<p>Scoring: Each of the 5 EQ-5D descriptive dimensions has 3 levels: no problems, some problems, severe problems. A 5-level version has also been developed (EQ-5D-5L) and validated. The respondent indicates their health state by ticking in the box against the most appropriate statement in each of the 5 dimensions. This decision results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health state. It should be noted that the numerals 1-3 have no arithmetic properties and should not be used as a cardinal score. Missing values should be coded as '999'. Ambiguous values (e.g., the line crosses the VAS twice) should be treated as missing values.</p> <p>Psychometric Properties: Test-retest reliability: ICC = .81 (Canadian study population); Construct validity: Spearman correlation with other utility measures: SF-6D, $r=.70$; HUI- III, $r=0.80$; Correlates with EDSS: Spearman $r= -.66$ in a Canadian study population, Pearson $r= -.54$ in a German study population; 9HPT: $r= -.056$; timed 25-foot walk: $r= -.63$; ambulation index: $r= -.68$; Ceiling effects may be evident in patients with less marked disability. The scale is widely used in European countries for the assessment of health-related quality of life but also as a health-economic measures that allows calculation of Quality-Adjusted Life Years (QALYs). In PD, it has been used in numerous studies and acceptable sensitivity to change, but it has been criticized for missing disease-specific domains.</p> <p>Feasibility/validity: Feasibility and discriminative validity of the EQ-5D-Y was supported in a Swedish patient sample with children and adolescents with functional disability, but additional studies with more participants are necessary (Burstrom et al., 2014).</p>
Rationale/Justification	<p>Mitochondrial Disease-Specific:</p> <p>Strengths: This is a simple and well validated scale with no recall bias as it asks for status "right now". It also has visual analog scale which can be used for longitudinal assessments of mitochondrial patients. It is a good "quick" questionnaire, translated in many languages and although non-specific to mitochondrial disease, it is deemed helpful in capturing data in the pediatric group as a supplement to a more elaborate</p>

	<p>questionnaire. This scale can be used to estimate the cost of illness at introduction and in post-market studies.</p> <p>Weaknesses: Generic, non-disease specific. Might not capture all the nuances of the intricate mitochondrial patients' limitations. No instrument for children under the age of 7.</p> <p>ME/CFS-Specific: Strengths: This scale has the advantage of prior use in ME/CFS and importantly, comparison data with general population and specific illness population. It is not at all burdensome to complete. There is a great deal of comparison data, as shown in Hvidberg et al., 2015.</p> <p>Weaknesses: The scale is very brief and focuses only on the current day. It is a helpful snapshot of exacerbations on a particular day, but does not capture disability, QoL impact and changes over time or multiple dimensions of QoL. It asks about ADLs on the one hand, and asks about work/school on the other.</p> <p>TBI-Specific: Strengths:</p> <p>Weaknesses:</p>
<p>References</p>	<p>Key References: EuroQol Group. EuroQol--a new facility for the measurement of health-related quality of life. Health Policy. 1990 Dec;16(3):199-208.</p> <p>Burstrom K, Bartonek A, Brostrom EW, Sun S, Egmar AC. EQ-5D-Y as a health-related quality of life measure in children and adolescents with functional disability in Sweden: testing feasibility and validity. Acta Paediatr. 2014 Apr;103(4):426-35.</p> <p>Burstrom K, Egmar AC, Lugner A, Eriksson M, Svartengren M. A Swedish child-friendly pilot version of the EQ-5D instrument--the development process. Eur J Public Health. 2011 Apr;21(2):171-7.</p> <p>Dolan P. Modeling valuations for EuroQol health states. Med Care. 1997 Nov;35(11):1095-108.</p> <p>Noyes J, Edwards RT. EQ-5D for the assessment of health-related quality of life and resource allocation in children: a systematic methodological review. Value Health. 2011 Dec;14(8):1117-29.</p> <p>Wille N, Badia X, Bonsel G, Burstrom K, Cavrini G, Devlin N, Egmar AC, Greiner W, Gusi N, Herdman M, Jelsma J, Kind P, Scalone L, Ravens-Sieberer U. Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. Qual Life Res. 2010 Aug;19(6):875-86.</p> <p>Headache-Specific References: Stafford MR, Hareendran A, Ng-Mak DS, Insinga RP, Xu R, Stull DE. EQ-5D™-derived utility values for different levels of migraine</p>

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Parkinson's Disease-Specific References:

Alvarado-Bolanos A, Cervantes-Arriaga A, Rodriguez-Violante M, Llorens-Arenas R, Calderon-Fajardo H, Millan-Cepeda R, Leal-Ortega R, Estrada-Bellmann I, Zuniga-Ramirez C. Convergent validation of EQ-5D-5L in patients with Parkinson's disease. J Neurol Sci. 2015 Nov 15;358(1-2):53-7.

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Schrag A, Selai C, Jahanshahi M, Quinn NP. The EQ-5D--a generic quality of life measure-is a useful instrument to measure quality of life in patients with Parkinson's disease. J Neurol Neurosurg Psychiatry. 2000 Jul;69(1):67-73.

Stroke-Specific References:

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Dorman P, Slattery J, Farrell B, Dennis M, Sandercock P. Qualitative comparison of the reliability of health status assessments with the EuroQol and SF-36 questionnaires after stroke. United Kingdom Collaborators in the International Stroke Trial. Stroke. 1998 Jan;29(1):63-8.

Dorman PJ, Waddell F, Slattery J, Dennis M, Sandercock P. Are proxy assessments of health status after stroke with the EuroQol questionnaire feasible, accurate, and unbiased? Stroke. 1997b Oct;28(10):1883-7.

Dorman PJ, Waddell F, Slattery J, Dennis M, Sandercock P. Is the EuroQol a valid measure of health-related quality of life after stroke? Stroke. 1997a Oct;28(10):1876-82.

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TBI-Specific Reference(s):

Document last updated ~~March 2024~~ December 2025

NINDS CDE Notice of Copyright Health and Behavior Inventory (HBI) Child Version

Availability	<p>Please visit this website for more information about the instrument: Health and Behavior Inventory (HBI) Child Version</p> <p>Please note: The HBI Child Version is embedded in the Child Sport Concussion Office Assessment Tool 6 (SCOAT6). Please email the authors for information about obtaining the instrument: Dr. Keith Yeates, kyeates@ucalgary.ca</p>
Classification	<p>Core: Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion)</p> <p>Basic: Concussion/Mild TBI</p> <p>Supplemental – Highly Recommended: Sport-Related Concussion (SRC) Acute (time of injury until 72 hours)</p> <p>Supplemental: Acute Hospitalized TBI, Moderate/Severe TBI, and Epidemiology Traumatic Brain Injury (TBI)</p>
Short Description of Instrument	<p>The Health and Behavior Inventory (HBI) consists of 20 items that measure the frequency of common post-concussive symptoms. There are three versions of the inventory – Child, Parent Current Version and Parent Retrospective Version. The Parent Retrospective Version is used for rating pre-injury symptoms retrospectively. Completion time is estimated to be less than 10 minutes.</p>
Comments/Special Instructions	<p>The HBI has been used primarily with 8 to 15-year-old children, although the current and retrospective parent versions have been utilized for younger children. All versions can be used for older adolescents.</p>
Scoring and Psychometric Properties	<p>Scoring: Symptoms are rated on a 4-point Likert scale from 1=never to 4=often based on frequency over the past week. Scores are summed for a total score, with higher scores indicating more positive health behavior.</p> <p>Psychometric Properties:</p>
Rationale/Justification	<p>Sport-Related Concussion-Specific: Strengths: Simple to use and developed specifically for pediatric mild traumatic brain injury. It has been used with increased frequency in the literature.</p> <p>Weaknesses: It does not measure pre-injury symptoms by participants themselves.</p> <p>TBI-Specific: The scale has been used to investigate the outcomes of mild to severe TBI and is sensitive to various markers of injury severity (McCauley et al., 2012).</p>
References	<p>Key Reference(s):</p>

Ayr LK, Yeates KO, Taylor HG, Browne M. Dimensions of postconcussive symptoms in children with mild traumatic brain injuries. *J Int Neuropsychol Soc.* 2009;15(1):19–30.

Davis GA, Patricios JS, Purcell LK, Anderson V, Gioia GA, Giza CC, Yeates KO, Ahmed OH, Blauwet C, Corwin D, Master CL, Schneider GM, van Ierssel J, Echemendia RJ, Fremont P, Fuller GW, Herring S, Harmon KG, Holte K, Loosemore M, Makdissi M, McCrea M, Meehan WP 3rd, O'Halloran P, Premji Z, Putukian M, Shill IJ, Turner M, Vaandering K, Webbhorn N, Schneider KJ. Introducing the Child Sport Concussion Office Assessment Tool 6 (Child SCOAT6). *Br J Sports Med.* 2023 Jun;57(11):668-671.

Additional References:

Fay TB, Yeates KO, Taylor HG, Bangert B, Dietrich A, Nuss KE, Rusin J, Wright M. Cognitive reserve as a moderator of postconcussive symptoms in children with complicated and uncomplicated mild traumatic brain injury. *J Int Neuropsychol Soc.* 2010;16(1):94–105.

Hajek CA, Yeates KO, Taylor HG, Bangert B, Dietrich A, Nuss KE, Rusin J, Wright M. Agreement between parents and children on ratings of post-concussive symptoms following mild traumatic brain injury. *Child Neuropsychol.* 2011;17(1):17–33.

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; Pediatric TBI Outcomes Workgroup. Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. *J Neurotrauma.* 2012 Mar 1;29(4):678-705.

Moran LM, Taylor HG, Rusin J, Bangert B, Dietrich A, Nuss KE, Wright M, Yeates KO. Do postconcussive symptoms discriminate injury severity in pediatric mild traumatic brain injury? *J Head Trauma Rehabil.* 2011;26(5):348–354.

O'Brien H, Minich NM, Langevin LM, Taylor HG, Bigler ED, Cohen DM, Beauchamp MH, Craig WR, Doan Q, Zemek R, Bacevice A, Mihalov LK, Yeates KO. Normative and Psychometric Characteristics of the Health and Behavior Inventory Among Children With Mild Orthopedic Injury Presenting to the Emergency Department: Implications for Assessing Postconcussive Symptoms Using the Child Sport Concussion Assessment Tool 5th Edition (Child SCAT5). *Clin J Sport Med.* 2021 Sep 1;31(5):e221-e228.

Taylor HG, Dietrich A, Nuss K, Wright M, Rusin J, Bangert B, Minich N, Yeates KO. Post-concussive symptoms in children with mild traumatic brain injury. *Neuropsychology.* 2010;24(2):148–159.

Zhang C, Tang K, Zemek R, Beauchamp MH, Craig W, Doan Q, Yeates KO; Pediatric Emergency Research Canada A-CAP Study Team. Factor structure and measurement invariance of post-

concussion symptom ratings on the Health and Behaviour Inventory across time, raters, and groups: An A-CAP study. J Int Neuropsychol Soc. 2023 May;29(4):346-359.

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NINDS CDE Notice of Copyright Health and Behavior Inventory (HBI) Parent Current Version

Availability	<p>Please visit this website for more information about the instrument: Health and Behavior Inventory (HBI) Parent Current Version</p> <p>Please note: The HBI Parent Current Version is embedded in the Child Sport Concussion Office Assessment Tool 6 (SCOAT6). Please email the authors for information about obtaining the instrument: Dr. Keith Yeates, kyeates@ucalgary.ca</p>
Classification	<p>Supplemental – Highly Recommended: Sport-Related Concussion (SRC)</p> <p>Basic: Concussion/Mild TBI</p> <p>Supplemental: Acute Hospitalized TBI, Moderate/Severe TBI, and Epidemiology Traumatic Brain Injury (TBI)</p>
Short Description of Instrument	<p>The Health and Behavior Inventory (HBI) consists of 20 items that measure the frequency of common post-concussive symptoms. There are three versions of the inventory – Child, Parent Current Version and Parent Retrospective Version. The Parent Retrospective Version is used for rating pre-injury symptoms retrospectively. Completion time is estimated to be less than 10 minutes.</p>
Comments/Special Instructions	<p>The HBI has been used primarily with 8 to 15-year-old children, although the current and retrospective parent versions have been utilized for younger children. All versions can be used for older adolescents.</p>
Scoring and Psychometric Properties	<p>Scoring: Symptoms are rated on a 4-point Likert scale from 1=never to 4=often based on frequency over the past week. Scores are summed for a total score, with higher scores indicating more positive health behavior.</p> <p>Psychometric Properties:</p>
Rationale/Justification	<p>Sport-Related Concussion-Specific: Strengths: Simple to use and developed specifically for pediatric mild traumatic brain injury. It has been used with increased frequency in the literature. Weaknesses: It does not measure pre-injury symptoms by participants themselves.</p> <p>TBI-Specific: The scale has been used to investigate the outcomes of mild to severe TBI and is sensitive to various markers of injury severity (McCauley et al., 2012).</p>
References	<p>Key Reference(s): Ayr LK, Yeates KO, Taylor HG, Browne M. Dimensions of postconcussive symptoms in children with mild traumatic brain injuries. J Int Neuropsychol Soc. 2009;15(1):19–30.</p> <p>Davis GA, Patricios JS, Purcell LK, Anderson V, Gioia GA, Giza CC, Yeates KO, Ahmed OH, Blauwet C, Corwin D, Master CL,</p>

Schneider GM, van Iersel J, Echemendia RJ, Fremont P, Fuller GW, Herring S, Harmon KG, Holte K, Loosemore M, Makdissi M, McCrea M, Meehan WP 3rd, O'Halloran P, Premji Z, Putukian M, Shill IJ, Turner M, Vaandering K, Webbhorn N, Schneider KJ. Introducing the Child Sport Concussion Office Assessment Tool 6 (Child SCOAT6). Br J Sports Med. 2023 Jun;57(11):668-671.

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NINDS CDE Notice of Copyright Health and Behavior Inventory (HBI) Parent Retrospective Version

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Classification	<p>Supplemental – Highly Recommended: Sport-Related Concussion (SRC)</p> <p>Basic: Concussion/Mild TBI</p> <p>Supplemental: Acute Hospitalized TBI, Moderate/Severe TBI, and Epidemiology Traumatic Brain Injury (TBI)</p>
Short Description of Instrument	<p>The Health and Behavior Inventory (HBI) consists of 20 items that measure the frequency of common post-concussive symptoms. There are three versions of the inventory – Child, Parent Current Version and Parent Retrospective Version. The Parent Retrospective Version is used for rating pre-injury symptoms retrospectively. Completion time is estimated to be less than 10 minutes.</p>
Comments/Special Instructions	<p>The HBI has been used primarily with 8 to 15-year-old children, although the current and retrospective parent versions have been utilized for younger children. All versions can be used for older adolescents.</p>
Scoring and Psychometric Properties	<p>Scoring: Symptoms are rated on a 4-point Likert scale from 1=never to 4=often based on frequency over the past week. Scores are summed for a total score, with higher scores indicating more positive health behavior.</p> <p>Psychometric Properties:</p>
Rationale/Justification	<p>Sport-Related Concussion-Specific:</p> <p>Strengths: Simple to use and developed specifically for pediatric mild traumatic brain injury. It has been used with increased frequency in the literature.</p> <p>Weaknesses: It does not measure pre-injury symptoms by participants themselves.</p> <p>TBI-Specific: The scale has been used to investigate the outcomes of mild to severe TBI and is sensitive to various markers of injury severity (McCauley et al., 2012).</p>
References	<p>Key Reference(s): Ayr LK, Yeates KO, Taylor HG, Browne M. Dimensions of postconcussive symptoms in children with mild traumatic brain injuries. J Int Neuropsychol Soc. 2009;15(1):19–30.</p>

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	<i>Document last updated March 2018 November 2025</i>
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NINDS CDE Notice of Copyright Neurobehavioral Symptom Inventory (NSI)

Availability	Please visit this website for more information about the instrument: Neurobehavioral Symptom Inventory
Classification TBI v3.0 Classification Pending	Supplemental: Stroke, Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) and Traumatic Brain Injury (TBI)
Short Description of Instrument	The severity of each symptom on the Neurobehavioral Symptom Inventory (NSI) is measured using a 5-item scale (0-none to 4-very severe) across cognitive, affective, somatic and sensory domains that asks patients to indicate the extent to which each symptom has disturbed them in the previous 2 weeks. The NSI total score is the sum of severity ratings of the 22 symptoms.
Comments/Special Instructions	<p>Patient-self-report either through 1) written completion of the questionnaire, or 2) in-person or telephone interview with clinician or research associate.</p> <p>Validated for symptom burden measurement and symptom tracking in adults. Not validated as a TBI diagnostic tool as symptoms overlap extensively with other conditions.</p> <p>Administration time is 5-10 minutes.</p>
Scoring and Psychometric Properties	<p>Scoring: Raw scores can be calculated for the four domains (Physical, Cognitive, Affective and Sensory) and for the total score.</p> <p>Psychometric Properties: See Meterko et al., 2012 and King et al., 2012 for psychometric properties information.</p>
Rationale/Justification	<p>Strengths:</p> <ol style="list-style-type: none"> 1. Standardized measures 2. Validated in adults with good cutoff points for clinically relevant burden/improvement 3. Patient centered (often self-administered) making it scalable 4. Low cost 5. Invariance across sex (shown in VA population) 6. Embedded validity scales to mitigate exaggeration of reported symptoms <p>Weaknesses:</p> <ol style="list-style-type: none"> 1. Similar to other TBI symptom measures, symptoms overlap with other neuro- and psychiatric conditions) 2. Self-report makes it susceptible to bias (although see strength #6 – embedded validity scales mitigate)
References	<p>Key Reference(s): Cicerone KD & Kalmar K. Persistent Post Concussion Syndrome: The structure of subjective complaints after mild traumatic brain injury. J Head Trauma Rehabil. 1995;10(3):1-17.</p> <p>Additional Reference(s):</p>

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NINDS CDE Notice of Copyright

Pediatric Quality of Life Inventory Generic Core Scale (PEDSQL Generic Core Scale)

Availability	Please visit this website for more information about the instrument: Pediatric Quality of Life Inventory Generic Core Scale
Classification TBI v3.0 Classification Pending	Basic: Acute, Moderate and Mild Traumatic Brain Injury (TBI) Supplemental: TBI
Short Description of Instrument	<p>Description: Developed in the US in 1998. The PedsQL 4.0 Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model covers 4 domains: physical (8 items), emotional (5 items), social (5 items) and school (5 items). It provides a total scales score from 23 items, of which 8 are for physical health summary score and 15 are for psychosocial health summary score.</p> <p>The instrument takes 4 minutes to complete and is translated in multiple international languages including broadcast Spanish. It is usable for parents/guardians of children between the ages of 2 to 18 years (in 4 age groups) and child versions are available for all age groups except the 2–4 years old.</p> <p>Administration mode: Interviewer-administered, proxy-rated, self-administered</p> <p>Data Collection mode: Paper and pen. Self-administered self-report ages 8 and older. Interviewer-administered self-report ages 5–7. Self-administered proxy report ages 2 and older.</p>
Comments/Special Instructions	Particular Features: PedsQL Disease-Specific Modules are available for asthma, arthritis, cancer, cardiac disease, and diabetes. There is no module at this time for epilepsy.
Scoring and Psychometric Properties	<p>Scoring: 0-100 scale with scores near 0 representing lower QOL and scores near 100 representing higher QOL. Individual subscale scores can also be calculated for each of the four areas of functioning: physical, emotional, social, and school. To score, items are transferred to a 0-100 scale, i.e., 0=100, 1=75, 2=50, 3=25, 4=0. Scores are then averaged to obtain a final score between 0-100.</p> <p>Psychometric Properties: Reliability: Over all 23 multi-item scales had internal consistency reliabilities averaging 0.80. The total scale score had $\alpha=0.88$ for child and $\alpha=0.90$ for parent report.</p> <p>Sensitivity to Change: One article showed that children with epilepsy had impairments in HRQOL but there were no differences in the parent proxy scorings between a single seizure</p>

	<p>population and a newly diagnosed untreated population. Therefore it is likely that the PedsQL will not be sensitive to change as a result of treatment of epilepsy.</p> <p>Validity of scales: Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition.</p> <p>Relationships to other variables: One article showed that HRQOL in siblings of children with intractable epilepsy may also be lower than average.</p>
Rationale/Justification	<p>Strengths: Short and easy to complete. Widely used and validated in US. Has many translations. Broad measurement of function collected in under 4 minutes.</p> <p>Weaknesses: Nothing specific noted in publications on the studies listed above, although a reliable mitochondrial disease-specific module does not exist. PedsQL 4.0 has been described as one of the three available general measures of QOL in childhood and adolescence with adequate psychometric properties for application in clinical research. (NINDS Headache CDEs)</p>
References	<p>Key Reference(s): Varni JW, Seid M, Kurtin PD. PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory Version 4.0 generic core scales in healthy and patient populations. Medical Care. 2001; 38(8):800–812.</p> <p>Additional References: Felder-Puig R, Frey E, Proksch K, Varni JW, Gadner H, Topf R. Validation of the German version of the Pediatric Quality of Life Inventory (PedsQL) in childhood cancer patients off treatment and children with epilepsy. Quality of Life Research. 2004; 13(1):223–234.</p> <p>Modi AC, King AS, Monahan SR, Koumoutsos JE, Morita JA, Glauser TA. Even a single seizure negatively impacts pediatric health-related quality of life. Epilepsia. 2009;50(9):2110–16.</p> <p>Varni J, Burwinkle T, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr. 2003;3(6):329–341.</p> <p>Varni JW, Limbers CA. The pediatric quality of life inventory: Measuring pediatric health-related quality of life from the perspective of children and their parents. Pediatric Clinics of North America. 2009; 56(4): 843–863.</p> <p>Varni JW, Limbers CA. The PedsQL™ 4.0 Generic Core Scales Young Adult Version: feasibility, reliability and validity in a university student population. J Health Psychol. 2009 May;14(4):611–622.</p> <p>Varni JW, Seid M, Knight TS, Uzark K & Szer IS. The PedsQL™ 4.0 Generic Core Scales: Sensitivity, responsiveness, and impact</p>

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TBI-Specific References:

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NINDS CDE Notice of Copyright

Post-Concussion Symptom Inventory (PCSI) Self-Report Assessment Form Pre and Post-Injury Report Ages 13-18

Availability	Please visit this website for more information about the instrument: Post-Concussion Symptom Inventory
Classification TBI v3.0 Classification Pending	<p>Core: Sport-Related Concussion (SRC)</p> <ul style="list-style-type: none"> Core: <u>One</u> of Core Symptoms Checklists should be collected: Automated Neuropsychological Assessment Metrics (ANAM), Axon Sports Computerized Cognitive Assessment Tool (CCAT), CNS Vital Signs, Child Sport Concussion Assessment Tool (Child-SCAT), Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT), Post Concussion Symptom Inventory (PCSI), Post Concussion Symptoms Scale (PCS-S), Sport Concussion Assessment Tool (SCAT-3) or (SCAT-5), Standardized Symptoms Questionnaire (RPQ), or Post Concussion Symptom Inventory (PCSI)
Short Description of Instrument	<p>The Post Concussion Symptom Inventory (PCSI) is a standardized questionnaire that consists of 26 symptoms and provides an overall rating of symptoms based on parent report. The scale covers 6 domains: affective, amnesia, cognitive, fatigue, physical, and sleep.</p> <p>Sport-Related Concussion-Specific: Similar to the Rivermead Post-Concussion Symptoms Questionnaire.</p> <p>Age Range: 13–18</p>
Comments/Special Instructions	
Scoring and Psychometric Properties	<p>Scoring: Each item is scaled from 0-4 with a total symptom score ranging from 0-104.</p> <p>Psychometric Properties:</p>
Rationale/Justification	<p>Strengths: The PCSI has 4 forms, 3 developmentally validated child forms (5–7, 8–12, 13–18) and a companion parent form. Sady et al. (2014) provides the psychometric analyses with multiple lines of evidence for reliability and validity. Factor analysis indicates a 4-factor structure: physical, cognitive, emotional, and sleep-related. It has been used in a large Canadian pediatric study (5P) and demonstrated validity in predicting persistent PCS. PCSI has also been found to predict high versus low perceived school problems. A retrospective pre-injury form is available to adjust for pre-injury symptoms.</p> <p>Weaknesses: Study samples have been a mixture of injury mechanisms, including sport concussion, but other injury types as well.</p>
References	Key Reference(s):

Sady MD, Vaughan CG, Gioia GA. Psychometric characteristics of the postconcussion symptom inventory in children and adolescents. Arch Clin Neuropsychol. 2014;29(4):348–363.

Additional References:

Barlow KM, Crawford S, Stevenson A, Sandhu SS, Belanger F, Dewey D. Epidemiology of postconcussion syndrome in pediatric mild traumatic brain injury. Pediatrics. 2010;126(2):e374–e381.

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Kontos AP, McAllister-Deitrick J, Sufrinko AM. Predicting Post-Concussion Symptom Risk in the ED. Pediatr Neurol Briefs. 2016;30(3):19.

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Ransom DM, Vaughan CG, Pratson L, Sady MD, McGill CA, Gioia GA. Academic Effects of Concussion in Children and Adolescents. Pediatrics. 2015;135(6):1043–1050.

Terwilliger VK, Pratson L, Vaughan CG, Gioia GA. Additional Post-Concussion Impact Exposure May Affect Recovery in Adolescent Athletes. J Neurotrauma. 2016;33(8):761–765.

Zemek R, Barrowman N, Freedman SB, Gravel J, Gagnon I, McGahern C, Aglipay M, Sangha G, Boutis K, Beer D, Craig W, Burns E, Farion KJ, Mikrogianakis A, Barlow K, Dubrovsky AS, Meeuwisse W, Gioia G, Meehan WP 3rd, Beauchamp MH, Kamil Y, Grool AM, Hoshizaki B, Anderson P, Brooks BL, Yeates KO, Vassilyadi M, Klassen T, Keightley M, Richer L, DeMatteo C, Osmond MH; Pediatric Emergency Research Canada (PERC) Concussion Team. Clinical Risk Score for Persistent Postconcussion Symptoms Among Children With Acute Concussion in the ED. JAMA. 2016;315(10):1014–1025.

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NINDS CDE Notice of Copyright

Post-Concussion Symptom Inventory (PCSI-P) Parent Assessment Form Pre and Post-Injury Report

Availability	Please visit this website for more information about the instrument: Post-Concussion Symptom Inventory
Classification TBI v3.0 Classification Pending	Core: Sport-Related Concussion (SRC) <ul style="list-style-type: none"> Core: <u>One</u> of Core Symptoms Checklists should be collected: Automated Neuropsychological Assessment Metrics (ANAM), Axon Sports Computerized Cognitive Assessment Tool (CCAT), CNS Vital Signs, Child Sport Concussion Assessment Tool (Child-SCAT), Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT), Post Concussion Symptom Inventory (PCSI), Post Concussion Symptoms Scale (PCS-S), Sport Concussion Assessment Tool (SCAT-3) or (SCAT-5), Standardized Symptoms Questionnaire (RPQ), or Post Concussion Symptom Inventory (PCSI)
Short Description of Instrument	The Post Concussion Symptom Inventory (PCSI) is a standardized questionnaire that consists of 26 symptoms and provides an overall rating of symptoms based on parent report. The scale covers 6 domains: affective, amnesia, cognitive, fatigue, physical, and sleep. Sport-Related Concussion-Specific: Similar to the Rivermead Post-Concussion Symptoms Questionnaire; only for pediatric and completed by parents. Age Range: 5–18
Comments/Special Instructions	
Scoring and Psychometric Properties	Scoring: Each item is scaled from 0-4 with a total symptom score ranging from 0-104. Psychometric Properties:
Rationale/Justification	Strengths: The PCSI has 4 forms, 3 developmentally validated child forms (5–7, 8–12, 13–18) and a companion parent form. Sady et al. (2014) provides the psychometric analyses with multiple lines of evidence for reliability and validity. Factor analysis indicates a 4-factor structure: physical, cognitive, emotional, and sleep-related. It has been used in a large Canadian pediatric study (5P) and demonstrated validity in predicting persistent PCS. PCSI has also been found to predict high versus low perceived school problems. A retrospective pre-injury form is available to adjust for pre-injury symptoms. Weaknesses: Study samples have been a mixture of injury mechanisms, including sport concussion, but other injury types as well.
References	Key Reference(s):

Sady MD, Vaughan CG, Gioia GA. Psychometric characteristics of the postconcussion symptom inventory in children and adolescents. Arch Clin Neuropsychol. 2014;29(4):348–363.

Additional References:

Barlow KM, Crawford S, Stevenson A, Sandhu SS, Belanger F, Dewey D. Epidemiology of postconcussion syndrome in pediatric mild traumatic brain injury. Pediatrics. 2010;126(2):e374–e381.

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Ransom DM, Vaughan CG, Pratson L, Sady MD, McGill CA, Gioia GA. Academic Effects of Concussion in Children and Adolescents. Pediatrics. 2015;135(6):1043–1050.

Terwilliger VK, Pratson L, Vaughan CG, Gioia GA. Additional Post-Concussion Impact Exposure May Affect Recovery in Adolescent Athletes. J Neurotrauma. 2016;33(8):761–765.

Zemek R, Barrowman N, Freedman SB, Gravel J, Gagnon I, McGahern C, Aglipay M, Sangha G, Boutis K, Beer D, Craig W, Burns E, Farion KJ, Mikrogianakis A, Barlow K, Dubrovsky AS, Meeuwisse W, Gioia G, Meehan WP 3rd, Beauchamp MH, Kamil Y, Grool AM, Hoshizaki B, Anderson P, Brooks BL, Yeates KO, Vassilyadi M, Klassen T, Keightley M, Richer L, DeMatteo C, Osmond MH; Pediatric Emergency Research Canada (PERC) Concussion Team. Clinical Risk Score for Persistent Postconcussion Symptoms Among Children With Acute Concussion in the ED. JAMA. 2016;315(10):1014–1025.

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NINDS CDE Notice of Copyright Post-Concussion Symptom Scale (New for TBI)

Availability	Please visit this website for more information about the instrument: Post-Concussion Symptom Scale
Classification TBI v3.0 Classification Pending	<p>NeuroRehab Sport-Related Concussion Core</p> <p>Core: Sport-Related Concussion (SRC) Core: One of Core Symptoms Checklists should be collected: Automated Neuropsychological Assessment Metrics (ANAM), Axon Sports Computerized Cognitive Assessment Tool (CCAT), CNS Vital Signs, Child Sport Concussion Assessment Tool (Child-SCAT), Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT), Post Concussion Symptom Inventory (PCSI), Post Concussion Symptoms Scale (PCS-S), Sport Concussion Assessment Tool (SCAT-3) or (SCAT-5), Standardized Symptoms Questionnaire (RPQ), or Post Concussion Symptom Inventory (PCSI).</p>
Short Description of Instrument	The Post-Concussion Symptom Scale (PCSS) is a 22-item computerized symptom scale embedded into the ImPACT cognitive test that is designed to measure the presence and severity of post-concussion symptoms over a 72-hour period.
Comments/Special Instructions	
Scoring and Psychometric Properties	<p>Scoring: Participants are asked to rate the severity of 22 common post-concussion symptoms (e.g., headache, dizziness, nausea) on a 7 point Likert-type scale from 0-none to 6-severe. A total symptom severity score of 0–132 is then calculated. Symptoms factor scores that are dependent on time since injury are also used to assess symptoms factors (see Kontos et al., 2012).</p> <p>Psychometric Properties:</p>
Rationale/Justification	<p>Strengths: Brief administration time- 5 min. Validated in numerous studies. Factor scores can be used to track factor specific symptoms and recovery.</p> <p>Weaknesses: Self-report bias. Baseline symptoms can vary considerably and may influence post-concussion scores on PCSS. Reading level restrictions. Not usable in pediatric population without using parent report. Some symptoms overlap with other illnesses, disorder, etc.</p>

References	<p>Key Reference: Lovell MR, Collins MW. Neuropsychological assessment of the college football player. J Head Trauma Rehabil. 1998 Apr;13(2):9-26.</p> <p>Additional References: Joyce AS, Labella CR, Carl RL, Lai JS, Zelko FA. The Postconcussion Symptom Scale: utility of a three-factor structure. Med Sci Sports Exerc. 2015;47(6):1119–1123.</p> <p>Kontos AP, Elbin RJ, Schatz P, Covassin T, Henry L, Pardini J, Collins MW. A revised factor structure for the Post Concussion Symptom Scale (PCSS): Baseline and post-concussion factors. Am J Sports Med. 2012;40(10):2375–2384.</p> <p>TBI-Specific Reference(s):</p> <p><i>Document last updated January 2022 December 2025</i></p>
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NINDS CDE Notice of Copyright Quality of Life After Brain Injury (QOLIBRI)

Availability	Please visit this website for more information about the instrument: Quality of Life After Brain Injury
Classification	Supplemental – Highly Recommended: Traumatic Brain Injury (TBI)
Short Description of Instrument	<p>The Quality of Life After Brain Injury (QOLIBRI) is a TBI disease-specific self-report questionnaire instrument used to measure Health Related Quality of Life (HRQOL) after TBI in adults ≥ 18 years old. Items address the respondent's perspective on their health condition, functioning and wellbeing. Its multidimensional structure contains 37 items on 4 Satisfaction scales: "Cognition", "Self", "Daily Life & Autonomy", and "Social Relationships. Part A comprises items measuring satisfaction with various aspects of HRQOL and Part B assesses "feeling bothered" and is composed of 2 subscales: "Emotions" and "Physical Problems". 2 "Bothered" scales "Emotions" and "Physical Problems" and a total score. The 6-item QOLIBRI Overall Scale (QOLIBRI-OS) was developed in 2012 to index the respondent's overall judgment of different aspects of HRQOL. The 35-item QOLIBRI in Children and Adolescents (QOLIBRI-KID/ADO) is a TBI-specific HRQOL designed for children and adolescents aged 8-17 years. For screening purposes there is an additional overall scale available with 6 items.</p> <p>Completion time: 5-10 minutes.</p> <p>Translations available in Chinese, Spanish, English, Finnish, French, Italian, German, Dutch, Polish, etc.).</p>
Comments/Special Instructions	<p>Level of Evidence: More than two studies demonstrate construct validity based on TBI CDE v3.0 criteria and thresholds.</p> <p>Applicable to all study designs.</p> <p>Applicable to some TBI domains (not neuroimaging, biomarker studies).</p>
Scoring and Psychometric Properties	<p>Scoring: 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. Responses to the "satisfaction" items (i.e., items on the Cognition, Self, Daily Life & Autonomy, and Social Relationship subscales) are coded on a 1 to 5 scale, where 1 = "Not at all", and 5 = "Very". Responses to the "bothered" items (i.e., items on the Emotions and Physical Problem subscales) are reverse scored to correspond with the satisfaction items, where 1 = "Very" and 5 = "Not at all". Responses on each scale are summed to give a total and then divided by the number of responses to give a scale mean. Scale means have a maximum possible range of 1 to 5. The mean can be computed when there are some missing responses but should not be calculated if more than one third of responses on the scale are missing. The QOLIBRI total score is calculated by summing all the responses and then dividing by the actual number of responses. A total score should not be calculated if more than one third of responses are missing. Scale means are converted to the 0-100 scale</p>

by subtracting 1 from the mean and then multiplying by 25. This produces scaled scores with a lowest possible value of 0 (worst possible quality of life) and a maximum value of 100 (best possible quality of life).

~~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.~~

Psychometric Properties: Rasch analysis performed on an international TBI sample found moderate support (38% of variance explained) for a unidimensional model of HRQOL, primarily based on the items in the first three scales (cognitive function, self-perception, independent living). Loadings on the first component of the single-factor solution indicate that items in the first three scales generally have good fit (loadings>0.6) while those in the last three scales have weaker fit, and two items (“partner” and “see/hear”) have poor fit (loading<.45). Results of single-factor principal component analysis (PCA) were consistent with the Rasch analysis conducted on all items combined, further supporting unidimensionality as a measure of HRQOL (von Steinbuchel et al., J Neurotrauma 2010a). The QOLIBRI scales also met standard psychometric criteria for reliability (internal consistency, α = 0.75–0.89, test-retest reliability, r_{tt} = 0.78–0.85). A second construct validity study performed by the same group found strong Pearson and Spearman’s correlations with SF-36 PCS (QOLIBRI Physical Problems scale=.63; Comorbid health conditions=.60), HADS Anxiety Scale (QOLIBRI Emotions scale= .64), HADS Depression (QOLIBRI Self scale= .62), SF-36 MCS (QOLIBRI Emotions= .62); Self=.56), Help needed with activities (QOLIBRI Daily Life= .53; Physical Problems=.47) and GOSE (QOLIBRI Daily Life=.43; Physical Problems=.40) (von Steinbuchel et al, J Neurotrauma 2010b).

A study using 4509 CENTER-TBI participants found moderate to high correlations between QOLIBRI-OS and total scores on the QOLIBRI (0.59 to 0.83) and between the QOLIBRI-OS and SF-36v2 PCS domain (0.49-0.65) across all languages. There was also good discriminant validity with GCS (-0.08-0.25) across all languages except Swedish (0.40). Factorial validity analyses showed acceptable goodness of fit indices for the English version (Chi square= 15.22, df=9, p=.085; RMSEA=0.05 [0.00-0.10], SRMR=0.04. Factor loadings ranged from 0.73 to 0.92 indicating unidimensionality of the TBI-specific HRQOL construct across translations (von Steinbuchel, et al., J Clin Med, 2021).

Comparative analyses between the QOLIBRI and the Satisfaction with Life Scale (SWLS) revealed greater reductions in QoL on the QOLIBRI relative to the SWLS for participants with TBI at all time points, and with orthopedic trauma controls at 2 weeks and 3 months post-injury. The QOLIBRI-OS better captured expected improvements in QoL during the injury recovery course in injured groups than the SWLS, which demonstrated smaller changes over time. TBI severity was not consistently or robustly associated with self-reported QoL. These findings imply that the QOLIBRI-OS appears to identify QoL issues more specifically relevant to traumatically injured patients and may be a more appropriate primary QoL outcome measure for

	<p>research focused on the sequelae of traumatic injuries. In contrast, the SWLS asks about general satisfaction with life and does not anchor ratings to a concrete time point (such as an injury event) or cover specific domains (e.g., cognition and psychological and social functioning) of life that are commonly impacted by TBI (Kreitzer, et al., J Neurotrauma 2021).</p> <p>A second study compared the QOLIBRI and SWLS at 3 months post-injury and found that the QOLIBRI Cognition and Physical subscales successfully differentiated TBI patients from orthopedic trauma controls, providing further support that the QOLIBRI captures issues important to brain-injured patients better than the SWLS (Harfman, et al., J Neurotrauma, 2020).</p> <p>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 924 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).</p>
Rationale/ Justification	<p>Strengths: Strong construct validity as a disease-specific measure of HRQOL); Available in many different languages.</p> <p>Weaknesses: Some evidence that three of the six satisfaction subscales show overfit, suggesting some redundancy in the information provided.</p>
References	<p>Key Reference(s): von Steinbüchel N, Wilson L, Gibbons H, Hawthorne G, Höfer S, Schmidt S, Bullinger M, Maas A, Neugebauer E, Powell J, von Wild K, Zitnay G, Bakx W, Christensen AL, Koskinen S, Sarajuuri J, Formisano R, Sasse N, Truelle JL; QOLIBRI Task Force. Quality of Life after Brain Injury (QOLIBRI): scale development and metric properties. J Neurotrauma. 2010;27(7):1167–1185.</p> <p>Additional References: von Steinbüchel N, Real RGL, Sasse N, Wilson L, Otto C, Mullins R, Behr R, Deinsberger W, Martinez Olivera R, Puschendorf W, Peterleit W, Rohde V, Schmidt H, Schmisch S, Stürmer KM, von Wild K, Gibbons H. German validation of Quality of Life after Brain Injury (QOLIBRI) assessment and associated factors. PLoS One. 2017;12(5):e0176668. Harfmann EJ, deRoos-Cassini TA, McCrea MA, Nader AM, Nelson LD. Comparison of Four Quality of Life Inventories for Patients with Traumatic Brain Injuries and Orthopedic Injuries. J Neurotrauma. 2020 Jun 15;37(12):1408-1417.</p>

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Rivermead Post-~~Concussive~~-Concussion Symptoms Questionnaire (RPQ)

Availability	Please visit this website for more information about the instrument: Rivermead Post-Concussive-Concussion Symptoms Questionnaire
Classification TBI v3.0 Classification Pending	<p>NeuroRehab Supplemental – Highly Recommended: Recommendations for Use: Indicated for studies requiring a measure of other clinical data. Recommended for Sport-Related Concussion (SRC), Concussion/Mild TBI studies.</p> <p>Core: Sport-Related Concussion (SRC)</p> <p>Core: One of Core Symptoms Checklists should be collected: Automated Neuropsychological Assessment Metrics (ANAM), Axon Sports Computerized Cognitive Assessment Tool (CCAT), Child Sport Concussion Assessment Tool (Child-SCAT), Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT), Post Concussion Symptom Inventory (PCSI), Post Concussion Symptoms Scale (PCSS), Sport Concussion Assessment Tool (SCAT-3) or (SCAT-5), Standardized Assessment of Concussion (SAC), or Rivermead Post-Concussive Concussion Symptoms Questionnaire (RPQ)</p> <p>Supplemental – Highly Recommended: Traumatic Brain Injury (TBI) Basic: Concussion/Mild TBI - Supplemental: Acute/Hospitalized, Moderate/Severe TBI and Epidemiology TBI</p>
Short Description of Instrument	<p>The Rivermead Post-Concussive-Concussion Symptoms Questionnaire (RPQ) is a 16-item self-report measure of the presence and severity of the 16 most commonly reported post-concussive post-concussion symptoms (PCS) commonly found in the literature. The questionnaire scale compares any current symptoms to pre-injury symptom levels to account for potential identify symptom exacerbation due to TBI.</p> <p>Sport-Related Concussion-Specific: This test-assessment can be delivered soon after mild traumatic brain injury (ED) and is well tolerated due to its simplicity.</p>
Comments/Special Instructions	
Scoring and Psychometric Properties	<p>Scoring: The range of scores is 0–64. Values for each of the 16 items include 0 (not experienced at all), 1 (no more of a problem than before the injury), 2 (mild problem), 3 (moderate problem), 4 (severe problem). The total score is a summation of symptoms rated as > 2 indicating post-concussion symptoms that represent new onset symptoms onset or an exacerbation of a symptoms present pre-injury.</p> <p>Psychometric Properties: The RPQ provides a brief assessment of post-concussive symptoms. It can be used for prognosis</p>

	<p>diagnostic and severity of symptoms purposes, and can be used to monitor change in response to treatment. The RPQ would be most useful in was developed to assess post-concussion symptoms in persons with mild to moderate TBI. ,but has also been used with more severely injured participantspatients.</p>
Rationale/Justification	<p>Sport-Related Concussion-Specific:</p> <p>Strengths: The RPQ is an established longstanding measure used in studies of mild TBI. It allows for separate analysis of emotional and somatic symptoms, therefore and it may be used to monitor changes longitudinally. The scale can be used to account for assess potential exacerbation of symptoms due to return to activity.</p> <p>Weaknesses: none found if administered in the acute phase. Some questions have been posed about its psychometric characteristics. It does not have a parent/ proxy companion measure. It does not include younger children. It has not commonly been used in sport concussion research. On account of its brevity, the RPQ lacks comprehensiveness and detail.</p> <p>Highly Recommended for adult and pediatric concussed athletes, in the first 72 hrs and repeat after return to play. Age Range: 8-18</p>
References	<p>Key Reference(s): King NS, Crawford S, Wenden FJ, Moss NE, Wade DT. The Rivermead Post Concussion Symptoms Questionnaire: a measure of symptoms commonly experienced after head injury and its reliability. J Neurol. 1995;242(9):587–592.</p> <p>Additional References: Kristman VL, Brison RJ, Bédard M, Reguly P, Chisholm S. Prognostic Markers for Poor Recovery After Mild Traumatic Brain Injury in Older Adults: A Pilot Cohort Study. J Head Trauma Rehabil. 2016;31(6):E33–E43.</p> <p>Potter S, Leigh E, Wade D, Fleminger S. The Rivermead Post Concussion Symptoms Questionnaire: a confirmatory factor analysis. J Neurol. 2006;253(12):1603–1614.</p> <p><i>Document last updated January 2022 November 2025</i></p>

NINDS CDE Notice of Copyright Satisfaction with Life Scale

Availability	Please visit this website for more information about the instrument: Satisfaction with Life Scale
Classification	<p>Basic Moderate/Severe Rehabilitation and Concussion/Mild Traumatic Brain Injury (TBI)</p> <p>Supplemental – Highly Recommended: Traumatic Brain Injury (TBI)</p> <p>Supplemental: Spinal Cord Injury (SCI), and Sport-Related Concussion (SRC) Acute (time of injury until 72 hours) and Acute Hospitalized and Epidemiology (TBI)</p>
Short Description of Instrument	The Satisfaction with Life Scale (SWLS) measures the respondents' overall satisfaction with life. The SWLS consists of 5 questions answered on a 7-point Likert scale ranging from 1=strongly disagree to 7=strongly agree. Administration time is brief and is rarely more than 2-3 minutes.
Comments/Special Instructions	
Scoring and Psychometric Properties	<p>Scoring: Total score ranges from 7-35. Higher scores indicate better satisfaction with life.</p> <p>Psychometric Properties: See Corrigan, 2000 for psychometric properties information.</p>
Rationale/Justification	<p>SCI-Specific:</p> <p>Strengths: The measure has been widely used with SCI samples across the US including Spinal Cord Injury Model Systems (SCIMS) centers. In general, the outcome measure has good psychometric properties and reasonably good clinical utility. It is easy to administer and score. Life satisfaction after SCI can be reliably measured by means of the SWLS. Correlates of subjective well-being parallel those suggested by earlier studies and those for the population at large.</p> <p>Weaknesses: The effects of life satisfaction on social participation, health, and other aspects of life need further study (Dijkers, 1999).</p> <p>Sport-Related Concussion-Specific:</p> <p>Strengths: Specific to sport concussion, includes acute timeframe (time of injury until 72 hours). Short measure consists of 5 questions answered on a 7-point Likert scale which takes <4 minutes to administer. It is widely used across the US. The measure has good psychometric properties and reasonably good clinical utility. It is easy to administer and score.</p> <p>Weaknesses: Age range of scale not mentioned but may not be relevant for pediatric patients either.</p> <p>TBI-Specific:</p> <p>Strengths:</p>

	Weaknesses:
References	<p>Key Reference(s): Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. J Pers Assess. 1985 Feb;49(1):71-75.</p> <p>Additional References: Corrigan, J. (2000). Satisfaction With Life Scale. The Center for Outcome Measurement in Brain Injury. Retrieved 14Jun2024 from http://www.tbims.org/combi/swls</p> <p>Dijkers MP. Correlates of life satisfaction among persons with spinal cord injury. Arch Phys Med Rehabil. 1999 Aug;80(8):867-876.</p> <p>Fuhrer MJ. Subjectifying quality of life as a medical rehabilitation outcome. Disabil Rehabil. 2000 Jul 20;22(11):481-489.</p> <p>Fuhrer MJ. Subjective well-being: implications for medical rehabilitation outcomes and models of disablement. Am J Phys Med Rehabil. 1994;73(5):358-364.</p> <p>Richards JS, Bombardier CH, Tate D, Dijkers M, Gordon W, Shewchuk R, DeVivo MJ. Access to the environment and life satisfaction after spinal cord injury. Arch Phys Med Rehabil. 1999 Nov;80(11):1501-1506.</p> <p>TBI-Specific Reference(s): Ritchie L, Wright-St Clair VA, Keogh J, Gray M. Community integration after traumatic brain injury: a systematic review of the clinical implications of measurement and service provision for older adults. Arch Phys Med Rehabil. 2014;95(1):163-174.</p> <p><i>Document last updated April 2020 December 2025</i></p>