



# **NINDS Common Data Element (CDE) Project Traumatic Brain Injury Version 3.0 Internal Review / Public Review General Activities of Daily Living Subgroup Materials**

## **Subgroup Summary**

### **Instruments**

- Brief Test of Adult Cognition by Telephone (BTACT)
- Disability Rating Scale (DRS)
- Functional Independence Measure for Children (WeeFIM)
- Pediatric Evaluation of Disability Inventory (PEDI)
- Pediatric Quality of Life Inventory (PedsQL)
- PROMIS Ability to Participate Item Bank and Short Forms
- Short Form 36-Item Health Survey (SF-36)



## **NINDS CDE Project Traumatic Brain Injury Version 3.0 General Activities of Daily Living Subgroup Summary**

The NINDS TBI v3.0 Common Data Element (CDE) General Activities of Daily Living Subgroup reviewed and updated CDEs based on the state of neuroscientific clinical research. General activities of daily living include self-care activities such as body care including bathing, dressing, and grooming, social and community participation, and cognitive functioning.

The General Activities of Daily Living Subgroup focused on instruments that were already reviewed in the TBI v2.0 CDEs and considered additional instruments. General activities of daily living are assessed in TBI to identify how the brain injury has affected their ability to function independently across various aspects of daily life. These instruments are also valuable for evaluating overall functioning and understanding how TBI-related impairments or other comorbid conditions may affect an individual's ability to engage in everyday activities.

The subgroup reassessed 16 validated instruments covering adaptive and daily living skills, behavioral function, cognitive activity limitations, and global outcomes for TBI. These instruments include both objective and subjective assessments, six of which are specific to the pediatric population. The nature of the instruments included self-report questionnaires, performance-based measures, and observational rating scales. The subgroup expanded their review to include additional validated instruments. We used the NINDS CDE Instrument Selection Criteria to evaluate whether to maintain or change the recommendation levels for instruments included in v2.0 of the TBI CDEs, and whether to recommend any new instruments for inclusion.

The subgroup addressed areas of overlap with other subgroups. Specifically, the Functional Independence Measure (FIM) was reviewed by the Performance-based Measures Subgroup. In addition, one instrument that was classified under the Behavioral Function module within General Activities of Daily Living under TBI CDE v2.0, the Frontal Systems Behavior Scale (FrSBe), was reclassified to the Psychosocial Modifiers Subgroup as a result of our initial review. The final evaluation for FrSBe will be completed by that subgroup.



## Summary of Recommendations

Subdomain	Instrument Name	Classification
Adaptive and Daily Living Skills	Functional Independence Measure for Children (WeeFIM)	Pending Classification
	Pediatric Evaluation of Disability Inventory (PEDI)	Supplemental – Highly Recommended
Behavioral Function	PROMIS Ability to Participate Item Bank and Short Forms	Pending Classification
Cognitive Activity Limitations	Brief Test of Adult Cognition by Telephone (BTACT)	Pending Classification
Global Outcome	Disability Rating Scale (DRS)	Supplemental
	Pediatric Quality of Life Inventory (PedsQL)	Pending Classification
	Short Form 36-Item Health Survey (SF-36)	Disease Core

## Instruments Reviewed and Not Recommended for v3.0

Instrument Name	TBI v2.0 Classification	Instrument Selection Criteria Not Met
<del>Adaptive Behavior Assessment Scale (ABAS-II)</del> Adaptive Behavior Assessment Scale (ABAS-3)	Supplemental	Clearly Defined? Broadly validated with demonstrated utility? Specific? Reliable?
Functional Independence Measure - Cognition Subscale (Cog-FIM)	Basic; Supplemental	Reliable? Low burden to participants and investigators?
Glasgow Outcome Scale (GOS)	Supplemental	Reliable? Crosscutting relevance for population groups as well as diseases and conditions? International harmonization (International applicability)?
Glasgow Outcome Scale Extended (GOSE)	Core	Reliable? Crosscutting relevance for population groups as well as diseases and conditions?
Glasgow Outcome Scale Extended (GOSE) Pediatric Revision	Basic; Supplemental	Broadly validated with demonstrated utility? Reliable?
Loewenstein Occupational Therapy Cognitive Assessment (LOTCA)	N/A	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? Specific? Low burden to participants and investigators? Rural vs. Urban (Feasibility of Acquisition)? International harmonization (International applicability)?



Instrument Name	TBI v2.0 Classification	Instrument Selection Criteria Not Met
Mayo-Portland Adaptability Inventory-4 (MPAI-4)	Supplemental	Broadly validated with demonstrated utility? International harmonization (International applicability)?
Neuro-QOL Adult Bank - Ability to Participate in Social Roles and Activities	N/A	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? Specific?
Pediatric Test of Brain Injury (PTBI)	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? Crosscutting relevance for population groups as well as diseases and conditions? International harmonization (International applicability)?
Short Form 12-Item Health Survey (SF-12)	Supplemental	Reliable?
<del>Vineland Adaptive Behavior Scales, Second Edition (Vineland-II)</del> Vineland Adaptive Behavior Scales, Third Edition (Vineland-3)	Supplemental	Well-established, broadly applicable to the intended population (e.g., adult and/or pediatric), and generally accepted by the scientific community? Low burden to participants and investigators?

### Instruments for Future Consideration

<b>ADAPTIVE AND DAILY LIVING SKILLS ASSESSMENTS FOR CONSIDERATION: multiple domains and involve the ability to “adapt” to (e.g., adjust, vary, fit one’s behaviors / actions) and manage one’s surroundings to effectively function in home, school and community life.</b>
Assessment of Life Habits
Canadian Occupational Performance Measure
Care Tool Section GG (ADL domain)
Functional Assessment Standardized Items (FASI) Section GG (Instrumental Activities of Daily Living (IADL) domain)
<b>BEHAVIORAL FUNCTION ASSESSMENTS FOR CONSIDERATION: may contribute to difficulties in return to work/school, personal relationships and social functioning. Common examples are aggression and childlike</b>
.
Neuro-QOL Adult Bank - Satisfaction with Social Roles and Activities
PROMIS v2.0 - Satisfaction with Social Roles and Activities
TBI-QOL Ability to Participate in Social Roles and Activities Item Bank
TBI-QOL Satisfaction with Social Roles and Activities Item Bank



<b>COGNITIVE ACTIVITY ASSESSMENTS FOR CONSIDERATION: describe the impact of neuropsychological impairments on cognitively loaded real-world tasks such as IADLs, functional communication, and health and safety-related behaviors.</b>
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Activity Measure for Post-Acute Care (AM-PAC) 6-Clicks
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Complex Task Performance Assessment
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Executive Function Performance Test
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Neuro-QOL Adult Bank - Cognitive Function
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Performance Assessment of Self-Care Skills
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PROMIS Cognitive Function Item Banks
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TBI-QOL Cognition - General Concerns Item Bank
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### Brief Test of Adult Cognition by Telephone (BTACT)

<b>Availability</b>	Please visit this website for more information about the instrument: <a href="#">Brief Test of Adult Cognition by Telephone</a>
<b>Classification</b> <b>TBI v3.0 Classification</b> <b>Pending</b>	<b>NeuroRehab Supplemental – Highly Recommended</b> Recommendations for Use: Indicated for studies requiring a measure for cognitive assessment that can be administered by phone.  <b>Supplemental:</b> Mitochondrial Disease (Mito) <del>and Traumatic Brain Injury (TBI)</del>
<b>Short Description of Instrument</b>	The Brief Test of Adult Cognition by Telephone (BTACT) is a battery of measures developed by Margie Lachman, PhD of Brandeis University. The battery, which takes about 15-20 minutes to administer, includes measures of episodic memory, working memory, reasoning, executive functions, and speed of information processing. The BTACT was collected as a part of the MIDUS-II (Mid-Life in the United States) study, yielding a normative sample of 7,000 community dwellers aged 32-84.  The test should be completed by trained examiners and is administered by telephone.
<b>Comments/Special Instructions</b>	<b>NeuroRehab-Specific:</b> This test is used as a modular phone assessment. It is widely used including in Midlife in the United States (MIDUS) and Traumatic Brain Injury Model Systems (TBIMS). BTACT currently has one alternate form with others under review.
<b>Scoring and Psychometric Properties</b>	<b>Scoring:</b> <a href="https://www.brandeis.edu/psychology/lachman/pdfs/btact%20forms%20and%20information%204.9.12.pdf">https://www.brandeis.edu/psychology/lachman/pdfs/btact%20forms%20and%20information%204.9.12.pdf</a>  The TBIMS standard operating procedures for administration are located here: <a href="https://www.tbindsc.org/SOP.aspx">https://www.tbindsc.org/SOP.aspx</a>  <b>Psychometric Properties:</b> Psychometric properties have been established for persons with TBI of differing severities as well as aging adults. Studies have suggested that the BTACT can represent a unidimensional construct of cognition as well as a two factor model that is comprised of verbal episodic memory and other cognitive functions (Nelson et al., 2021; Gavett et al., 2013). Test-retest reliability using alternate forms is generally good, however Category Fluency tends to have less stable reliability coefficients suggesting differences between the forms that use animals vs. foods as the categories (Lachman et al., 2014). <b>Cairncross et al., 2022 showed the BTACT to have poor sensitivity to detect subacute cognitive impairment attributable to mild TBI.</b>
<b>Rationale/Justification</b>	<b>Strengths:</b> The brevity and administration by phone allow greater access to participants who may not otherwise be able or willing to participate in a longer and/or in-person

	<p>assessment. The subtests were selected based on sensitivity to change as well as the range of abilities assessed: episodic memory, working memory, executive functioning, reasoning, and reaction time. The subtests are based on well-established neuropsychological measures and the BTACT itself has established psychometric properties. Performance by national samples are available for comparison.</p> <p><b>Weaknesses:</b> Visual, psychomotor, and other non-verbal abilities cannot be assessed. It is challenging to prevent third party interference given the telephone modality. The BTACT is not as comprehensive or reliable as an in-person neuropsychological evaluation.</p>
<p><b>References</b></p>	<p><b>Key References:</b></p> <p>Tun PA, Lachman ME. The Brief Test of Adult Cognition by Telephone (BTACT). Waltham, MA: Brandeis University; 2005.</p> <p>Tun PA, Lachman ME. Telephone assessment of cognitive function in adulthood: the Brief Test of Adult Cognition by Telephone. Age Ageing. 2006 Nov;35(6):629-32.</p> <p>Lachman ME, Tun PA. Cognitive testing in large-scale surveys: Assessment by telephone. In D. Alwin &amp; S. Hofer (Eds.), Handbook on cognitive aging: interdisciplinary perspectives. New York, NY: Sage; 2008. 506-23 p.</p> <p><b>Additional References:</b></p> <p>DiBlasio CA, Sima A, Kumar RG, Kennedy RE, Retnam R, Lachman ME, Novack TA, Dams-O'Connor K. Research Letter: Performance of the Brief Test of Adult Cognition by Telephone in a National Sample. J Head Trauma Rehabil. 2021 Jul-Aug 01;36(4):E233-9.</p> <p>Gavett BE, Crane PK, Dams-O'Connor K. Bi-factor analyses of the Brief Test of Adult Cognition by Telephone. NeuroRehabilitation. 2013;32(2):253-65.</p> <p>Lachman ME, Agrigoroaei S, Tun PA, Weaver SL. Monitoring cognitive functioning: psychometric properties of the brief test of adult cognition by telephone. Assessment. 2014 Aug;21(4):404-17.</p> <p>Nelson LD, Barber JK, Temkin NR, Dams-O'Connor K, Dikmen S, Giacino JT, Kramer MD, Levin HS, McCrea MA, Whyte J, Bodien YG, Yue JK, Manley GT; British Neurosurgical Trainee Research Collaborative (BNTRC). Validity of the Brief Test of Adult Cognition by Telephone in Level 1 Trauma Center Patients Six Months Post-Traumatic Brain Injury: A TRACK-TBI Study. J Neurotrauma. 2021 Apr 15;38(8):1048-59.</p> <p><b>TBI-Specific References:</b></p> <p>Cairncross M, Gindwani H, Rita Egbert A, Torres IJ, Hutchison JS, Dams O'Connor K, Panenka WJ, Brubacher JR, Meddings L, Kwan L, Yeates KO, Green R, Silverberg</p>

ND; National Biobank and Database of Patients with Traumatic Brain Injury (CanTBI) investigators and the Canadian Traumatic Brain Injury Research Consortium (CTRC). Criterion validity of the brief test of adult cognition by telephone (BTACT) for mild traumatic brain injury. Brain Inj. 2022 Sep 19;36(10-11):1228-1236.

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## NINDS CDE Notice of Copyright Disability Rating Scale (DRS)

<b>Availability</b>	<b>Please visit this website for more information about the instrument:</b> <a href="#">Disability Rating Scale</a>
<b>Classification</b>	<b>Supplemental:</b> <del>Traumatic Brain Injury (TBI) Acute Hospitalized, Concussion/Mild TBI, Epidemiology</del>  <b>Basic:</b> <del>Moderate/Severe TBI: Rehabilitation</del>
<b>Short Description of Instrument</b>	<p>The Disability Rating Scale (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.</p> <p>The scale is completed by a clinician and requires some training to administer.</p> <p>Administration time is 10 minutes.</p>
<b>Comments/Special Instructions</b>	
<b>Scoring and Psychometric Properties</b>	<p><b>Scoring:</b> Minimum score is 0 (without disability) and maximum score is 29 (extreme vegetative state).</p> <p><b>Psychometric Properties:</b> The DRS was 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).</p> <p>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.</p>
<b>Rationale/Justification</b>	<p><b>Strengths:</b></p> <p><b>Weaknesses:</b></p>
<b>References</b>	<p><b>Key Reference:</b> Rappaport M, Hall KM, Hopkins K, Belleza T, Cope DN. Disability rating scale for severe head trauma: coma to community. Arch Phys Med Rehabil. 1982 Mar;63(3):118-23.</p> <p><b>Additional Reference(s):</b></p> <p><b>TBI-Specific Reference(s):</b></p> <p><i>Document last updated <del>February 2018</del> December 2025</i></p>

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### Functional Independence Measure for Children (WeeFIM)

<b>Availability</b>	<p><b>Please visit this website for more information about the instrument:</b> <a href="#">Functional Independence Measure for Children (WeeFIM)</a></p> <p>The FIM<del>TM</del> is proprietary. For further information about obtaining the scale, syllabus, and training materials please contact: Uniform Data System for Medical Rehabilitation 270 Northpointe Parkway, Suite 300 Amherst, New York 14228 (716) 817-7800 FAX (716) 568-0037 Email: <a href="mailto:info@udsmr.org">info@udsmr.org</a></p>
<b>Classification</b> <b>TBI v3.0 Classification Pending</b>	<p><b>Supplemental:</b> Cerebral Palsy (CP), Chiari I Malformation (CM), and Spinal Cord Injury (SCI)-Pediatric (age 0 to 7 years)<del>Traumatic Brain Injury (TBI)</del></p>
<b>Short Description of Instrument</b>	<p><b>Purpose:</b> The FIM measures degree of independence in activities of self-care, sphincter control, transfers, locomotion, communication, and cognition.</p> <p><b>Overview:</b> The FIM emerged from a thorough developmental process overseen by a National Task Force of Rehabilitation Research. The National Task force reviewed 36 published and unpublished functional assessment scales before agreeing on an instrument. The FIM is an 18-item ordinal scale, used with all diagnoses within a rehabilitation population. It is viewed as most useful for assessment of progress during inpatient rehabilitation.</p> <p>FIM was originally an acronym for "Functional Independence Measure". It is still often cited as this in the literature. The current owners of the FIM instrument have decided that the acronym FIM no longer stands for anything and should be referred to only as FIM.</p> <p>The WeeFIM builds on the format of the Functional Independence Measure for Adults of the Uniform Data System for Medical Rehabilitation, tracking disability outcomes in children. Specifically, this assessment measures independence in self-care, sphincter control, transfers, locomotion, communication, and social cognition. The WeeFIM consists of 18 items within the six domains.</p> <p><b>Time:</b> Administered through an interview by a trained rater or a telephone interview of caregiver or <b>participant subject</b> by trained rater. The test takes between 20-30 minutes.</p> <p><b>Other Important Notes:</b> The measure is used with children aged 6 months to 7 years. It can be used by children above 7 years if their abilities are below that of 7-year-olds without disabilities.</p> <p><b>SCI-Pediatric-Specific:</b> The WeeFIM instrument may be used with children above the age of 7 years provided their functional abilities, as measured by the WeeFIM instrument, are below those expected of children aged 7 who do not have disabilities.</p>

	To use the FIM and WeeFIM assessors, need to attend training and pass an online exam to become credentialed. Once an assessor has passed the exam, credentialing remains valid for two years, after which time the exam must be sat again. There is a cost to use for research.
<b>Comments/Special Instructions</b>	
<b>Scoring and Psychometric Properties</b>	<p><b>Scoring:</b> A 7-level Likert scale is used to score level of dependence. Scores for the WeeFIM range from 18 (complete dependence in all skills) to 126 (complete independence in all skills).</p> <p><b>Psychometric Properties:</b></p>
<b>Rationale/Justification</b>	<p>“The motor scale (8 self-care, 5 mobility items) was primarily selected ... to assess motor function in the acute recovery phase.” - McCauley et al., 2012.</p> <p><b>Strengths:</b></p> <p><b>Weaknesses:</b></p>
<b>References</b>	<p><b>Key References:</b> Granger C, Hamilton BB, Kayton R. Guide for the Use of the Functional Independence Measure (WeeFIM) of the Uniform Data Set for Medical Rehabilitation. Buffalo NY: Research Foundation of the State University of New York, 1989.</p> <p>Keith RA, Granger CV, Hamilton BB, Sherwin FS. The functional independence measure: a new tool for rehabilitation. Adv Clin Rehabil. 1987;1:6-18.</p> <p><b>Additional References:</b> Chen CC, Bode RK, Granger CV, Heinemann AW. Psychometric properties and developmental differences in children's ADL item hierarchy: a study of the WeeFIM instrument. Am J Phys Med Rehabil. 2005;84(9):671-679.</p> <p>Granger CV. The emerging science of functional assessment: our tool for outcomes analysis. Arch Phys Med Rehabil. 1998;79(3):235-240.</p> <p>Msall ME, DiGaudio K, Duffy LC, LaForest S, Braun S, Granger CV. WeeFIM. Normative sample of an instrument for tracking functional independence in children. Clin Pediatr (Phila). 1994;33(7):431-438.</p> <p>Msall ME, DiGaudio K, Rogers BT, LaForest S, Catanzaro NL, Campbell J, Wilczenski F, Duffy LC. The Functional Independence Measure for Children (WeeFIM). Conceptual basis and pilot use in children with developmental disabilities. Clin Pediatr (Phila). 1994;33(7):421-430.</p> <p>Ottenbacher KJ, Msall ME, Lyon NR, Duffy LC, Granger CV, Braun S. Interrater agreement and stability of the Functional Independence Measure for Children (WeeFIM): use in children with developmental disabilities. Arch Phys Med Rehabil.</p>

1997;78(12):1309-1315.

Ottenbacher KJ, Msall ME, Lyon N, Duffy LC, Ziviani J, Granger CV, Braun S, Feidler RC. The WeeFIM instrument: its utility in detecting change in children with developmental disabilities. Arch Phys Med Rehabil. 2000;81(10):1317-1326.

Ottenbacher KJ, Taylor ET, Msall ME, Braun S, Lane SJ, Granger CV, Lyons N, Duffy LC. The stability and equivalence reliability of the functional independence measure for children (WeeFIM). Dev Med Child Neurol. 1996;38(10):907-916.

Swaine BR, Pless IB, Friedman DS, Montes JL. Effectiveness of a head injury program for children: a preliminary investigation. Am J Phys Med Rehabil. 2000;79(5):412-420.

Ziviani J, Ottenbacher KJ, Shephard K, Foreman S, Astbury W, Ireland P. Concurrent validity of the Functional Independence Measure for Children (WeeFIM) and the Pediatric Evaluation of Disabilities Inventory in children with developmental disabilities and acquired brain injuries. Phys Occup Ther Pediatr. 2001;21(2-3):91-101.

#### **SCI Pediatric-Specific References:**

Garcia RA, Gaebler-Spira D, Sisung C, Heinemann AW. Functional improvement after pediatric spinal cord injury. Am J Phys Med Rehabil. 2002;81(6):458-463.

Prosser LA. Locomotor training within an inpatient rehabilitation program after pediatric incomplete spinal cord injury. Phys Ther. 2007;87(9):1224-1232.

#### **TBI-Specific References:**

Fuentes MM, Jimenez N, Apkon SD, Rivara FP. Functional outcomes during inpatient rehabilitation for American Indian and Alaska Native children with traumatic brain injury. J Pediatr Rehabil Med. 2016;9(2):133-141.

Massagli TL, Michaud LJ, Rivara FP. Association between injury indices and outcome after severe traumatic brain injury in children. Arch Phys Med Rehabil. 1996;77(2):125-132.

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;29(4):678-705.

Rice SA, Blackman JA, Braun S, Linn RT, Granger CV, Wagner DP. Rehabilitation of children with traumatic brain injury: descriptive analysis of a nationwide sample using the WeeFIM. Arch Phys Med Rehabil. 2005;86(4), 834-836.

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## NINDS CDE Notice of Copyright Pediatric Evaluation of Disability Inventory (PEDI)

<b>Availability</b>	<p>Please visit this website for more information about the instrument:  <a href="#">Pediatric Evaluation of Disability Inventory (PEDI)</a>  <a href="#">Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT)</a></p>
<b>Classification</b>	<p><b>Supplemental – Highly Recommended:</b> Traumatic Brain Injury (TBI)  Recommendations for use: Indicated for studies of pediatric TBI for children.</p> <p><del><b>Supplemental/Basic:</b> Traumatic Brain Injury (TBI)</del>  <del>–Basic: Acute Hospitalized and Moderate/ Severe TBI</del>  <del>–Supplemental: Epidemiology and Concussion/ Mild TBI</del></p> <p><b>Supplemental:</b> Cerebral Palsy (CP), Neuromuscular Disease (NMD), Spinal Cord Injury (SCI)-Pediatric (ages 6 months to 7 years) and Spinal Muscular Atrophy (SMA)</p> <p><b>Supplemental:</b> Congenital Muscular Dystrophy (CMD)  Particularly appropriate in assessing functional capabilities in CMD children in terms of both present status and change over time.</p> <p><b>Exploratory:</b> Duchenne Muscular Dystrophy (DMD)</p>
<b>Short Description of Instrument</b>	<p>Published in 1992, the Pediatric Evaluation of Disability Inventory (PEDI) is a descriptive measure of a child’s current functional capabilities performance and tracks changes over time (Haley et al., 1992a; Haley et al., 1992b; Haley et al., 2010). The PEDI has been developed into a CAT and Short Form. The PEDI-CAT™ is a computerized adaptive test version (Haley et al., 2012).</p> <p>The PEDI measures both capability and performance of functional activities in three content areas: Self-care, Mobility and Social Function (Haley et al., n.d.). The PEDI-CAT™ also measures abilities across three functional domains of Daily Activities, Mobility and Social/Cognitive and “can be used across all clinical diagnoses and community settings” (CRE Care, 2018). It also includes a Responsibility domain that measures the extent that a caregiver or child takes “responsibility for managing complex, multi-step life tasks” (Dumas &amp; Fragala-Pinkham, 2013; CRE Care, 2018).</p>
<b>Comments/Special Instructions</b>	<p>Type: The original PEDI™ paper-and-pencil, parent interview; and the computer administered version PEDI-CAT™</p> <p>Time: 45-60 minutes; PEDI-CAT™ uses algorithms to choose next items to reduce administration time.</p> <p>Age Range: The original PEDI™ is limited to the functional age range of 6 months - 7.5 years (Haley et al., 1992; Dumas &amp; Fragala-Pinkham, 2013); can be used to evaluate children older than 7 years whose functional capabilities are less than that of a typically developing 7-year-old. The PEDI-CAT™ is intended for use with children from birth through 20 years of age and can be used across all diagnoses, conditions and settings.</p>
<b>Scoring and Psychometric Properties</b>	<p><b>Scoring:</b> Scoring/Norms: Manual scoring</p> <p>Scores for the PEDI™ range between 0-100, with higher scores indicating less degree of disability (higher functional level).</p>

	<p>Scores in each content area can be converted to Scaled Scores and a Standard Score obtained compared to norms from typically-developing individuals.</p> <p>Skills commensurate with at least a master's degree level in psychology, education, or related field are recommended for interpretation. The computerized PEDI-CAT™ provides normative standard scores for 21 age groups (CRE Care, 2018). The normative standard scores are reported as age percentiles and T scores can be used to interpret a child's functioning relative to others of the same age. Scaled scores are available for all ages which provide the child's current level of function (CRE Care, 2018).</p> <p><b>Psychometric Properties:</b> Vos-Vromans et al. (2005) found that the PEDI was responsive to change over time in children with cerebral palsy with the most responsiveness to change in children younger than 4 years of age.</p>
<b>Rationale/Justification</b>	<p><b>Strengths:</b> The PEDI allows calculation of Change Scores to monitor changes in the child's status over time. PEDI is widely used with children with a range of physical disabilities particularly cerebral palsy (Vargus-Adams et al., 2011). Vos-Vromans and colleagues (2005) found that the PEDI is responsive to changes in motor functioning in children with CP.</p> <p>Choksi et al. (2010) used the PEDI to examine the functional recovery of children with spinal cord injury. They found that children with SCI showed improved functional skills as measured by the PEDI. Other researchers have used the PEDI to measure functional outcome in children with critical illness (Coster et al., 2008; Choong et al., 2015), because it can assess key functional capabilities, and is sensitive to change (Choong et al., 2015).</p> <p><b>Weaknesses:</b> Internationally there is mixed data regarding validity of PEDI use in other countries, though overall supports usefulness (Nordmark et al., 1999; Sršen et al., 2005; Berg et al. 2008; Elad et al., 2012).</p>
<b>References</b>	<p><b>Key References:</b> Haley SM, Coster WJ, Ludlow LH, Haltiwanger JT, Andrellos PA (1992a). Pediatric Evaluation of Disability Inventory: Development, Standardization and Administration Manual. Boston, MA, Trustees of Boston University.</p> <p>Haley S, Coster W, Ludlow LH, Haltiwanger JT (1992b). Pediatric evaluation of disability inventory: development, standardization, and administration manual, version 1.0. Boston, MA, Trustees of Boston University, Health and Disability Research Institute. Retrieved 13 February 2024. Available from: <a href="https://eprovide.mapi-trust.org/instruments/pediatric-evaluation-of-disability-inventory">https://eprovide.mapi-trust.org/instruments/pediatric-evaluation-of-disability-inventory</a>.</p> <p>CRE Care. (2018). Pediatric Evaluation of Disability Inventory Computer Adaptive Test. Retrieved 05Jan2026, from <a href="https://www.pedicat.com/">https://www.pedicat.com/</a></p> <p>Haley SM, Coster WI, Kao YC, Dumas HM, Fragala-Pinkham MA, Kramer JM, Ludlow LH, Moed R. Lessons from use of the Pediatric Evaluation of Disability Inventory: where do we go from here? Pediatr Phys Ther. 2010 Spring;22(1):69-75.</p>

Haley SM, Coster WJ, Dumas HM, Fragala-Pinkham MA, Kramer J, Ni P, Tian F, Kao YC, Moed R, Ludlow LH. Accuracy and precision of the Pediatric Evaluation of Disability Inventory computer-adaptive tests (PEDI-CAT). *Dev Med Child Neurol*. 2011 Dec;53(12):1100-6.

Haley SM, Coster WJ, Dumas HM, Fragala-Pinkham MA. (2012). Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT), Version 1.3.6, Development, Standardization and Administration Manual., CRE Care, LLC. Retrieved 11 January, 2016, from <http://www.pearsonclinical.com/psychology/products/100000505/pediatric-evaluation-of-disability-inventory-pedi.html>.

Haley SM, Coster WJ, Ludlow LH, Haltiwanger JT, Andrellos PJ. Pediatric Evaluation of Disability Inventory. Retrieved 05Jan2026, from <https://www.pearsonassessments.com/en-us/Store/Professional-Assessments/Developmental-Early-Childhood/Pediatric-Evaluation-of-Disability-Inventory/p/100000505>

**Additional References:**

Berg M, Aamodt G, Stanghelle J, Krumlinde-Sundholm L, Hussain A. Cross-cultural validation of the Pediatric Evaluation of Disability Inventory (PEDI) norms in a randomized Norwegian population. *Scand J Occup Ther*. 2008 Sep;15(3):143-52.

Cavallina I, D'Alessandro R, Brusa C, Panero E, Rolle E, Rossi F, Mongini T, Ricci FS. Motor Outcome Measures in Pediatric Patients with Congenital Muscular Dystrophies: A Scoping Review. *Applied Sciences*. 2023 Jan 16;13(2):1204.

Cordeiro L, Villagomez A, Swain D, Deklotz S, Tartaglia N. Adaptive Skills in FXS: A Review of the Literature and Evaluation of the PEDI-Computer Adaptive Test (PEDI-CAT) to Measure Adaptive Skills. *Brain Sci*. 2020 Jun 6;10(6):351.

Dumas HM & Fragala-Pinkham MA. (2013). Making Advances in Pediatric Outcomes: Using the Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT). Retrieved 13 February 2024. Available from: <https://educationresourcesinc.com/pedi-cat/>.

Dumas HM, Fragala-Pinkham MA, Rosen EL, Ni P. A content validity evaluation of the PEDI-CAT Speedy Mobility domain. *Physiother Theory Pract*. 2021 Apr;37(4):517-526.

Dumas HM, Fragala-Pinkham MA, Rosen EL, O'Brien JE. Construct validity of the pediatric evaluation of disability inventory computer adaptive test (PEDI-CAT) in children with medical complexity. *Disabil Rehabil*. 2017 Nov;39(23):2446-2451.

Dumas HM, Haley SM, Boyce ME, Peters CY, Mulcahey MJ. Self-report measures of physical function for children with spinal cord injury: a review of current tools and an option for the future. *Dev Neurorehabil*. 2009 Apr;12(2):113-8.

Elad D, Barak S, Eisenstein E, Bar O, Herzberg O, Brezner A. Reliability and validity of Hebrew Pediatric Evaluation of Disability Inventory (PEDI)

in children with cerebral palsy -- health care professionals vs. mothers. *J Pediatr Rehabil Med.* 2012;5(2):107-15.

Feldman AB, Haley SM, Coryell J. Concurrent and construct validity of the Pediatric Evaluation of Disability Inventory. *Phys Ther.* 1990 Oct;70(10):602-10.

Fragala-Pinkham MA, Dumas HM, Lombard KA, O'Brien JE. Responsiveness of the Pediatric Evaluation of Disability Inventory-Computer Adaptive Test in measuring functional outcomes for inpatient pediatric rehabilitation. *J Pediatr Rehabil Med.* 2016 Sep 2;9(3):215-22.

Fragala-Pinkham M, Pasternak A, McDermott MP, Mirek E, Glanzman AM, Montes J, Dunaway Young S, Salazar R, Quigley J, Riley SO, Chiriboga CA, Finkel RS, Tennekoon G, Martens WB, De Vivo DC, Darras BT. Psychometric properties of the PEDI-CAT for children and youth with spinal muscular atrophy. *J Pediatr Rehabil Med.* 2021;14(3):451-461.

Iyer LV, Haley SM, Watkins MP, Dumas HM. Establishing minimal clinically important differences for scores on the pediatric evaluation of disability inventory for inpatient rehabilitation. *Phys Ther.* 2003 Oct;83(10):888-98.

McCarthy ML, Silberstein CE, Atkins EA, Harryman SE, Sponseller PD, Hadley-Miller NA. Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Dev Med Child Neurol.* 2002 Jul;44(7):468-76.

Nichols DS & Case-Smith. Reliability and Validity of the Pediatric Evaluation of Disability Inventory. *Pediatr Phys Ther.* Spring 1996;8(1):15-24.

Nordmark E, Orban K, Hägglund G, Jarnlo GB. The American Paediatric Evaluation of Disability Inventory (PEDI). Applicability of PEDI in Sweden for children aged 2.0-6.9 years. *Scand J Rehabil Med.* 1999 Jun;31(2):95-100.

Ogonowski J, Kronk R, Rice C, Feldman H. Inter-rater reliability in assigning ICF codes to children with disabilities. *Disabil Rehabil.* 2004 Mar 18;26(6):353-61.

Østensjø S, Bjorbaekmo W, Carlberg EB, Vøllestad NK. Assessment of everyday functioning in young children with disabilities: an ICF-based analysis of concepts and content of the Pediatric Evaluation of Disability Inventory (PEDI). *Disabil Rehabil.* 2006 Apr 30;28(8):489-504.

Pasternak A, Sideridis G, Fragala-Pinkham M, Glanzman AM, Montes J, Dunaway S, Salazar R, Quigley J, Pandya S, O'Riley S, Greenwood J, Chiriboga C, Finkel R, Tennekoon G, Martens WB, McDermott MP, Fournier HS, Madabusi L, Harrington T, Cruz RE, LaMarca NM, Videon NM, Vivo DC, Darras BT; Muscle Study Group (MSG) and the Pediatric Neuromuscular Clinical Research Network for Spinal Muscular Atrophy (PNCRN). Rasch analysis of the Pediatric Evaluation of Disability Inventory-computer adaptive test (PEDI-CAT) item bank for children and

young adults with spinal muscular atrophy. *Muscle Nerve*. 2016 Dec;54(6):1097-1107.

Reid DT, Boschen K & Wright V. Critique of the Pediatric Evaluation of Disability Inventory (PEDI). *Phys Occup Ther Pediatr*. 1994;13(4):57-93.

Shirely Ryan Ability Lab. (2017). Pediatric Evaluation of Disability Inventory. Retrieved 10Oct2023, from:  
<https://www.sralab.org/rehabilitation-measures/pediatric-evaluation-disability-inventory>.

Sršen KG, Vidmar G, Zupan A. Applicability of the pediatric evaluation of disability inventory in Slovenia. *J Child Neurol*. 2005 May;20(5):411-6.

Tsai PY, Yang TF, Chan RC, Huang PH, Wong TT. Functional investigation in children with spina bifida -- measured by the Pediatric Evaluation of Disability Inventory (PEDI). *Childs Nerv Syst*. 2002 Feb;18(1-2):48-53.

Vargus-Adams JN, Martin LK, Maignan SH, Klein AC, Salisbury S. The GMFM, PEDI, and CP-QOL and perspectives on functioning from children with CP, parents, and medical professionals. *J Pediatr Rehabil Med*. 2011;4(1):3-12.

Vos-Vromans DC, Ketelaar M, Gorter JW. Responsiveness of evaluative measures for children with cerebral palsy: the Gross Motor Function Measure and the Pediatric Evaluation of Disability Inventory. *Disabil Rehabil*. 2005 Oct 30;27(20):1245-52.

**SCI-Pediatric-Specific References:**

Choksi A, Townsend EL, Dumas HM, Haley SM. Functional recovery in children and adolescents with spinal cord injury. *Pediatr Phys Ther*. 2010 Summer;22(2):214-21.

Choong K, Al-Harbi S, Siu K, Wong K, Cheng J, Baird B, Pogorzelski D, Timmons B, Gorter JW, Thabane L, Khetani M; Canadian Critical Care Trials Group. Functional recovery following critical illness in children: the "wee-cover" pilot study. *Pediatr Crit Care Med*. 2015 May;16(4):310-8.

Coster WJ, Haley SM, Ni P, Dumas HM, Fragala-Pinkham MA. Assessing self-care and social function using a computer adaptive testing version of the pediatric evaluation of disability inventory. *Arch Phys Med Rehabil*. 2008 Apr;89(4):622-9.

Dumas H. Clinical review of the pediatric evaluation of disability inventory. *Pediatr Phys Ther*. 2001 Spring;13(1):47-8.

Dumas HM, Fragala-Pinkham MA. Concurrent validity and reliability of the pediatric evaluation of disability inventory-computer adaptive test mobility domain. *Pediatr Phys Ther*. 2012 Summer;24(2):171-6; discussion 176.

Dumas HM, Fragala-Pinkham MA, Haley SM, Ni P, Coster W, Kramer JM, Kao YC, Moed R, Ludlow LH. Computer adaptive test performance in children with and without disabilities: prospective field study of the PEDI-CAT. *Disabil Rehabil*. 2012;34(5):393-401.

Dumas HM, Fragala-Pinkham MA, Rosen EL, O'Brien JE. Construct validity of the pediatric evaluation of disability inventory computer adaptive test (PEDI-CAT) in children with medical complexity. *Disabil Rehabil*. 2017 Nov;39(23):2446-2451.

Shore BJ, Allar BG, Miller PE, Matheney TH, Snyder BD, Fragala-Pinkham M. Measuring the Reliability and Construct Validity of the Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT) in Children With Cerebral Palsy. *Arch Phys Med Rehabil*. 2019 Jan;100(1):45-51.

**TBI-Specific Reference(s):**

Bedell GM. Functional outcomes of school-age children with acquired brain injuries at discharge from inpatient rehabilitation. *Brain Inj*. 2008 Apr;22(4):313-24.

Coster WJ, Haley S, Baryza MJ. Functional performance of young children after traumatic brain injury: a 6-month follow-up study. *Am J Occup Ther*. 1994 Mar;48(3):211-8.

Dumas HM, Haley SM, Bedell GM, Hull EM. Social function changes in children and adolescents with acquired brain injury during inpatient rehabilitation. *Pediatr Rehabil*. 2001 Oct-Dec;4(4):177-85.

Dumas HM, Haley SM, Fragala MA, Steva BJ. Self-care recovery of children with brain injury: descriptive analysis using the Pediatric Evaluation of Disability Inventory (PEDI) functional classification levels. *Phys Occup Ther Pediatr*. 2001;21(2-3):7-27.

Dumas HM, Haley SM, Ludlow LH, Carey TM. Recovery of ambulation during inpatient rehabilitation: physical therapist prognosis for children and adolescents with traumatic brain injury. *Phys Ther*. 2004 Mar;84(3):232-42.

Fragala MA, Haley SM, Dumas HM, Rabin JP. Classifying mobility recovery in children and youth with brain injury during hospital-based rehabilitation. *Brain Inj*. 2002 Feb;16(2):149-60.

Haley SM, Dumas HM, Rabin JP, Ni P. Early recovery of walking in children and youths after traumatic brain injury. *Dev Med Child Neurol*. 2003 Oct;45(10):671-5.

Kissane AL, Eldridge BJ, Kelly S, Vidmar S, Galea MP, Williams GP. High-level mobility skills in children and adolescents with traumatic brain injury. *Brain Inj*. 2015;29(13-14):1711-6.

Kothari DH, Haley SM, Gill-Body KM, Dumas HM. Measuring functional change in children with acquired brain injury (ABI): comparison of generic and ABI-specific scales using the Pediatric Evaluation of Disability Inventory (PEDI). *Phys Ther*. 2003 Sep;83(9):776-85.

Tokcan G, Haley SM, Gill-Body KM, Dumas HM. Item-specific functional recovery in children and youth with acquired brain injury. *Pediatr Phys Ther*. 2003 Spring;15(1):16-22.

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## NINDS CDE Notice of Copyright Pediatric Quality of Life Inventory (PedsQL)

<b>Availability</b>	<b>Please visit these websites for more information about the instrument:</b> <a href="#">Pediatric Quality of Life Inventory</a> or <a href="#">ePROVIDE</a>
<b>Classification</b> <b>TBI v3.0 Classification Pending</b>	<p><b>NeuroRehab Core:</b> Pediatric (ages 2-18)</p> <p><b>Supplemental - Highly Recommended:</b> Mitochondrial Disease (Mito) and Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months)</p> <p><b>Supplemental:</b> Cerebral Palsy (CP), Duchenne Muscular Dystrophy (DMD), Friedreich's Ataxia (FA), Headache, Spinal Muscular Atrophy (SMA), Sport-Related Concussion (SRC) Acute (time of injury until 72 hours) and Persistent/Chronic (3 months and greater post concussion), and Stroke <del>Acute, Moderate and Mild Traumatic Brain Injury (TBI), and Epidemiology TBI</del></p> <p><b>Exploratory:</b> Myotonic Dystrophy (DM)</p>
<b>Short Description of Instrument</b>	<p><b>Description:</b> Developed 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>
<b>Comments/Special Instructions</b>	<p>PedsQL Disease-Specific Modules are available for asthma, arthritis, cancer, cardiac disease, and diabetes.</p> <p><b>NeuroRehab Specific:</b> The PedsQL covers a wide age range, it has been well used and has reasonable psychometrics. It captures something that the NINDS CDE NeuroRehab Infant Pediatrics subgroup agrees is important for almost all NeuroRehab scientific studies, especially clinical trials.</p> <p>There is an infant version for children 1-24 months. The infant scales include two age-appropriate versions for ages 1-12 months and 13-24 months and assess parents' perceptions of their</p>

	<p>infant's generic HRQOL. The 36-item PedsQL™ Infant Scales 1-12 months Version encompasses 5 scales: (1) Physical Functioning (6 items), (2) Physical Symptoms (10 items), (3) Emotional Functioning (12 items), (4) Social Functioning (4 items), and (5) Cognitive Functioning (4 items). The 45-item PedsQL™ Infant Scales 13-24 months Version contains the same 5 scales and the same 36 items as the 1-12 months Version with 9 additional age-appropriate items: (1) Physical Functioning (9 items), (2) Physical Symptoms (10 items), (3) Emotional Functioning (12 items), (4) Social Functioning (5 items), and (5) Cognitive Functioning (9 items). For the infant scales, the total score internal consistency reliability was <math>\alpha=.92</math>.</p>
<b>Scoring and Psychometric Properties</b>	<p><b>Scoring:</b> The generic core contains 23 items encompassing four areas: physical, emotional, social, and school. Participants respond on a Likert scale from 0 to 4. Items are reverse scored and linearly transformed to a 0 to 100 scale, with higher converted scores indicating better HRQOL. The instrument provides four domain scores, two summary scores (physical and psychosocial functioning), and a total HRQOL score.</p> <p>The scale ranges from 0-100 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><b>Psychometric Properties:</b> Well-standardized and validated, good reliability and sensitivity to change, good correlations with other standardized measures of disease severity in disease-specific modules.</p> <p><b>Reliability:</b> For the generic core, over all 23 multi-item scales had internal consistency reliabilities averaging 0.80; The total scale score had <math>\alpha=0.88</math> for child and <math>\alpha=0.90</math> for parent report.</p> <p><b>Validity of scales:</b> Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition.</p> <p>Headache specific data is also supportive of the reliability (internal consistency and test-retest) and validity (criterion related, convergent, known-groups, and responsiveness to intervention) of the PedsQL 4.0 within a pediatric headache sample.</p>
<b>Rationale/Justification</b>	<p><b>Strengths:</b> PedsQL is short, easy to complete, and is widely used and validated in US. It also has many translations. Lastly, it is a broad measurement of function collected in under 4 minutes. <b>It has been used in pediatric TBI and has been translated into over 48 languages including Spanish (McCauley et al., 2012).</b></p> <p><b>Weaknesses:</b> 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</p>

	<p>childhood and adolescence with adequate psychometric properties for application in clinical research (NINDS Headache CDEs). It is an overall quality of life tool that does not focus on either epilepsy or its treatment.</p>
<b>References</b>	<p><b>Key Reference:</b> 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. Med Care. 2001;38(8):800-812.</p> <p>List of PedsQL references: <a href="https://www.mapistrust.org/ePROVIDE-Online-Support-for-Clinical-Outcome-Assessments">ePROVIDE™ - Online Support for Clinical Outcome Assessments (mapi-trust.org)</a></p> <p><b>Additional References:</b> Varni JW, Burwinkle TM, 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. Pediatr Clin North Am. 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;14(4):611-622.</p> <p>Varni JW, Limbers CA, Neighbors K, Schulz K, Lieu JE, Heffer RW, Tuzinkiewicz K, Mangione-Smith R, Zimmerman JJ, Alonso EM. The PedsQL™ Infant Scales: feasibility, internal consistency reliability, and validity in healthy and ill infants. Qual Life Res. 2011;20(1):45-55.</p> <p>Varni JW, Seid M, Knight TS, Uzark K, Szer IS. The PedsQL™ 4.0 Generic Core Scales: Sensitivity, responsiveness, and impact on clinical decision-making. J Behav Med. 2002;25(2):175-193.</p> <p>Varni JW, Seid M, Rode CA. The PedsQL™: measurement model for the pediatric quality of life inventory. Med Care. 1999;37(2):126-139.</p> <p><b>Headache-Specific Reference:</b> Connelly M, Rapoff MA. Assessing health-related quality of life in children with recurrent headache: reliability and validity of the PedsQL™ 4.0 in a pediatric headache sample. J Pediatr Psychol. 2006;31(7):698-702.</p> <p><b>Mitochondrial Disease-Specific Reference:</b> Martinelli D, Catteruccia M, Piemonte F, Pastore A, Tozzi G, Dionisi-Vici C, Pontrelli G, Corsetti T, Livadiotti S, Kheifets V, Hinman A, Shrader WD, Thoolen M, Klein MB, Bertini E, Miller G. EPI-743 reverses the progression of the pediatric mitochondrial disease--genetically defined Leigh Syndrome. Mol Genet Metab. 2012 Nov;107(3):383-8.</p>

**Stroke-Specific References:**

Abecassis IJ, Nerva JD, Barber J, Rockhill J, Ellenbogen RG, Kim LJ, Sekhar LN. Toward a comprehensive assessment of functional outcomes in pediatric patients with brain arteriovenous malformations: the Pediatric Quality of Life Inventory. *J Neurosurg Pediatr*. 2016 Nov;18(5):611-622.

Friefeld S, Yeboah O, Jones JE, deVeber G. Health-related quality of life and its relationship to neurological outcome in child survivors of stroke. *CNS Spectr*. 2004 Jun;9(6):465-475.

Ghotra SK, Johnson JA, Qiu W, Newton AS, Rasmussen C, Yager JY. Health-related quality of life and its determinants in paediatric arterial ischaemic stroke survivors. *Arch Dis Child*. 2018 Oct;103(10):930-936.

Smith SE, Vargas G, Cucchiara AJ, Zelonis SJ, Beslow LA. Hemiparesis and epilepsy are associated with worse reported health status following unilateral stroke in children. *Pediatr Neurol*. 2015 Apr;52(4):428-434.

**TBI-Specific References:**

McCarthy ML, MacKenzie EJ, Durbin DR, Aitken ME, Jaffe KM, Paidas CN, Slomine BS, Dorsch AM, Berk RA, Christensen JR, Ding R; CHAT Study Group. The Pediatric Quality of Life Inventory: an evaluation of its reliability and validity for children with traumatic brain injury. *Arch Phys Med Rehabil*. 2005;86(10):1901-1909.

McCarthy ML, MacKenzie EJ, Durbin DR, Aitken ME, Jaffe KM, Paidas CN, Slomine BS, Dorsch AM, Christensen JR, Ding R, Children's Health After Trauma Study Group. Health-related quality of life during the first year after traumatic brain injury. *Arch Pediatr Adolesc Med*. 2006;160(3):252-260.

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;29(4):678-705.

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### PROMIS Ability to Participate Item Bank and Short Forms

<b>Availability</b>	<p><b>Please visit this website for more information about the instrument:</b> <a href="#">PROMIS Ability to Participate Item Bank</a></p> <p>PROMIS Item Bank v2.0 – Ability to Participate in Social Roles and Activities PROMIS Short Form v2.0 - Ability to Participate in Social Roles and Activities 4a PROMIS Short Form v2.0 – Ability to Participate in Social Roles and Activities 6a PROMIS Short Form v2.0 - Ability to Participate in Social Roles and Activities 8a</p> <p>Find all measures by selecting ‘Ability to Participate’ as the domain criteria or a specific item bank or short form by entering the name in the Measure Name search field.</p>
<b>Classification</b> <b>TBI v3.0 Classification</b> <b>Pending</b>	<p><b><i>Disorder-specific classifications were assigned with respect to the overall collection of PROMIS measures. Use of individual item banks or short forms depends upon the study design or type of research involved unless additional guidance is noted.</i></b></p> <p><b><i>The item bank is included in the General CDE recommendations and the item bank and short forms are recommended for NeuroRehab.</i></b></p> <p><b>NeuroRehab Supplemental – Highly Recommended</b> Recommendations for Use: Indicated for studies requiring a measure of participation. Intended for use in community settings since participation takes place in the community.</p> <p><b>Supplemental – Highly Recommended:</b> Stroke, Congenital Muscular Dystrophy (CMD) in studies of psychosocial functioning, quality-of-life, outcome, and long-term adjustment studies.</p> <p><b>Supplemental:</b> <del>Traumatic Brain Injury (TBI)</del>, Amyotrophic Lateral Sclerosis (ALS), Chiari I Malformation (CM), Epilepsy, Friedreich’s Ataxia (FA), Headache, Huntington’s Disease (HD), Mitochondrial Disease (Mito), Multiple Sclerosis (MS), Myasthenia Gravis (MG), Neuromuscular Diseases (NMD), Duchenne/Becker Muscular Dystrophy (DMD/BMD), Spinal Muscular Atrophy (SMA), Parkinson’s Disease (PD), Stroke, and Spinal Cord Injury (SCI), and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)</p> <p><b>Exploratory:</b> Cerebral Palsy (CP), Myotonic Muscular Dystrophy (DM), Facioscapulohumeral Muscular Dystrophy (FSHD), and Sport-Related Concussion (SRC)</p> <p>*Headache specific subtest recommendations: Anxiety (Adult/Pediatric), Depression (Adult/Pediatric), Sleep (Adult)</p>
<b>Short Description of Instrument</b>	<p>The Patient Reported Outcomes Measurement Information System (PROMIS) Ability to Participate in Social Roles and Activities Adult Item Bank and Short Forms (4a, 6a, 8a) assess the perceived ability to perform one’s usual social roles and activities. Items are worded negatively in terms of perceived limitations, but responses are reverse-coded so that higher scores represent fewer limitations (better abilities). The item bank does not use a time frame (e.g., over the past seven days) when assessing ability to participate in social roles and activities. See <a href="#">List of Adult Measures</a> for details.</p> <p>PROMIS contains calibrated item banks with Likert style items for approximately 70 domains (e.g., anger, anxiety, depression, fatigue (Cella et al., 2010; Garcia et al.,</p>

	<p>2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance, and global health). It is part of the NIH goal to develop systems to support NIH-funded research supported by all its institutes and centers. PROMIS measures cover physical, mental, and social health and can be used across chronic conditions.</p> <p>The instrument is domain-focused (domains listed above) rather than specific to a particular disease; however, a disease-customized measurement approach can be utilized by choosing the PROMIS measures most relevant to the specific disease. For example, there would be extra time up front (compared to a standardized single measure) to select and agree upon appropriate CMD-specific items but would be worthwhile in the long term if other researchers studying CMD agree to use the CMD specific items identified.</p> <p>See: <a href="#">PROMIS Domain Framework</a> for pediatric and adult domains</p> <p><b>Administration:</b> There are two administration options for assessing Ability to Participate in Social Roles and Activities: short forms (4a, 6a, 8a) and computerized adaptive test (CAT). With CAT, participant responses guide the system's choice of subsequent items from the full item bank (35 items in total). Although items differ across respondents taking CAT, scores are comparable across participants and over time. PROMIS measures can be administered in three ways: on paper (short forms and profiles only); by computer; with an app.</p> <p><b>Time:</b> For CAT version, variable but design based on item-response theory algorithms to minimize time. For short forms, the administration time is 1-3 minutes.</p> <p><b>Ages:</b> Adult ages 18+.</p> <p><b>Cost:</b> No licensing or royalty fees for English and Spanish PROMIS measures used in individual research, clinical practice, educational assessment, or other application. Translations in other languages are subject to a distribution fee. Permission is required for commercial use or integration into proprietary technology; see <a href="#">PROMIS Terms and Conditions of Use</a> for details.</p> <p>Available in Spanish and specific domains are available in multiple other languages; see <a href="#">PROMIS Translations</a> for details.</p>
<b>Comments/Special Instructions</b>	<p><b>NeuroRehab Specific:</b> The PROMIS Ability to Participate in Social Roles and Activities item bank and short forms (4a, 6a, 8a) are self-reported measures of participation.</p>
<b>Scoring and Psychometric Properties</b>	<p><b>Scoring:</b> T scores for all scales.</p> <p>In all cases, a high score means more of domain. For example, higher scores on the fatigue measures indicate poorer health whereas higher scores on physical functioning measure indicate better health.</p> <p>Standardization Population: For most domains, T-scores relate to the US General Population. See <a href="#">PROMIS Calibrations Testing</a> for further details regarding sample for specific ages and domains.</p> <p>Scoring Manuals are available at: <a href="#">PROMIS Scoring Manuals</a></p>

	<p><b>Psychometric Properties:</b> Substantial qualitative and quantitative evidence has been gathered that supports the validity of PROMIS measures. More information about validation is available at: <a href="#">PROMIS Validation</a></p>
<b>Rationale/Justification</b>	<p><b>Strengths:</b> PROMIS Ability to Participate in Social Roles and Activities Short Forms (4a, 6a, 8a) are brief, yet reliable.</p> <p><b>Weaknesses:</b> Coverage of all aspects of participation is not comprehensive. Use of the item bank requires CAT software.</p>
<b>References</b>	<p><b>Key References:</b>            Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Amtmann D, Bode R, Buysse D, Choi S, Cook K, Devellis R, DeWalt D, Fries JF, Gershon R, Hahn EA, Lai JS, Pilkonis P, Revicki D, Rose M, Weinfurt K, Hays R; PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. J Clin Epidemiol. 2010 Nov;63(11):1179-94.</p> <p>See a list of primary citations for PROMIS measures here: <a href="#">Primary Citations for PROMIS Measures</a></p> <p><b>Item Bank and Short Form-Specific Primary Reference:</b>            Hahn EA, DeWalt DA, Bode RK, Garcia SF, DeVellis RF, Correia H, Cella D, PROMIS Cooperative Group. New English and Spanish social health measures will facilitate evaluating health determinants. Health Psychol. 2014 May;33(5):490-499.</p> <p><b>Additional References:</b>            Amtmann D, Cook KF, Jensen MP, Chen WH, Choi S, Revicki D, Cella D, Rothrock N, Keefe F, Callahan L, Lai JS. Development of a PROMIS item bank to measure pain interference. Pain. 2010 Jul;150(1):173-182.</p> <p>Bruni O, Ottaviano S, Guidetti V, Romoli M, Innocenzi M, Cortesi F, Giannotti F. The Sleep Disturbance Scale for Children (SDSC). Construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. J Sleep Res. 1996 Dec;5(4):251-61.</p> <p>Bruni O, Romoli M., Innocenzi M, Giannotti F, Cortesi F and Ottaviano S. Prevalenza dei disturbi del sonno in eth scolare. In: Di Perri R., Raffaele M., Silvestri R. and Smirne S. (Eds) 11 Sonno in Italiu 1994. Poletto Ed., Milano, 1994 163-171.</p> <p>Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, Ader D, Fries JF, Bruce B, Rose M; PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. Med Care. 2007 May;45(5 Suppl 1):S3-S11.</p> <p>Garcia SF, Cella D, Clauser SB, Flynn KE, Lad T, Lai JS, Reeve BB, Smith AW, Stone AA, Weinfurt K. Standardizing patient-reported outcomes assessment in cancer clinical trials: a patient-reported outcomes measurement information system initiative. J Clin Oncol. 2007 Nov 10;25(32):5106-12. Erratum in: J Clin Oncol. 2008 Feb 20;26(6):1018. Lad, Thomas [added].</p> <p>Katzan IL, Thompson N, Uchino K. Innovations in Stroke: The Use of PROMIS and NeuroQoL Scales in Clinical Stroke Trials. Stroke. 2016 Feb;47(2):e27-30.</p>

Kobau R, Cui W, Zack MM. Adults with an epilepsy history fare significantly worse on positive mental and physical health than adults with other common chronic conditions-Estimates from the 2010 National Health Interview Survey and Patient Reported Outcome Measurement System (PROMIS) Global Health Scale. *Epilepsy Behav.* 2017 Jul;72:182-184.

Spruyt K, Gozal D. Pediatric sleep questionnaires as diagnostic or epidemiological tools: a review of currently available instruments. *Sleep Med Rev.* 2011 Feb;15(1):19-32.

**NeuroRehab-Specific References:**

Hahn EA, Kallen MA, Jensen RE, Potosky AL, Moinpour CM, Ramirez M, Cella D, Teresi JA. Measuring social function in diverse cancer populations: Evaluation of measurement equivalence of the Patient Reported Outcomes Measurement Information System® (PROMIS®) Ability to Participate in Social Roles and Activities short form. *Psychol Test Assess Model.* 2016 Jun 27;58(2):403-421.

Tamminga SJ, van Vree FM, Volker G, Roorda LD, Terwee CB, Goossens PH, Vliet Vlieland, TPM. Changes in the ability to participate in and satisfaction with social roles and activities in patients in outpatient rehabilitation. *J Patient Rep Outcomes.* 2020 4(1):73.

van Leeuwen LM, Tamminga SJ, Ravinskaya M, de Wind A, Hahn EA, Terwee CB, Beckerman H, Boezeman EJ, Hoving JL, Huysmans MA, Nieuwenhuijsen K, de Boer AGEM, van der Beek AJ. Proposal to extend the PROMIS® item bank v2.0 'Ability to Participate in Social Roles and Activities': item generation and content validity. *Qual Life Res.* 2020 Oct;29(10):2851-2861.

**TBI-Specific Reference(s):**

*Document last updated ~~May 2024~~ January 2026*

## NINDS CDE Notice of Copyright Short Form 36-Item Health Survey (SF-36v2)

Availability	<p><b>Please visit this website for more information about the instrument:</b> <a href="#">Short Form 36 Item Health Survey</a></p> <p><b>Copyright holder:</b> RAND Corporation - Please read <a href="#">Terms and Conditions for Using the 36-Item Short Form Health Survey</a></p> <p><b>Please note:</b> <del>The original SF-36 (i.e., SF-36 v1) is freely available in public domain.</del> The SF-36-version 2 is separately validated and copyrighted from SF-36v1. CDEs are not posted for the SF-36v2 since the NINDS does not have permission to post the content of this version of the instrument. Please contact the copyright holders for permissions for use.</p> <p>The Medical Outcomes Trust (MOT), Health Assessment Lab (HAL) and Quality Metric Health Outcomes Solutions, co-copyright holders of all SF-36v2®, SF-12v2® and SF-8™ Health Surveys, have merged their licensing and user registration programs, with the objectives of simplifying licensing and user registration and better meeting the needs of the many new academic, commercial, and other licensees. Use of SF-36 v2 and other SF Health Surveys versions require a signed license agreement.</p> <p><b>Licensing agreement information for the SF-36v2®, SF-12v2® and SF-8™ Health Surveys can be found on the Quality Metric website:</b> <a href="#">Quality Metric PRO Health Surveys</a></p>
Classification	<p><b>Core:</b> Traumatic Brain Injury (TBI)</p> <p><b>NeuroRehab Supplemental – Highly Recommended</b> Recommendations for Use: Indicated for studies requiring a Generic Health-Related Quality of Life measure.</p> <p><b>Supplemental - Highly Recommended:</b> Parkinson's Disease (PD) Recommendations for use: Indicated for studies as a Generic Health-Related Quality of Life measure.</p> <p><b>Supplemental:</b> Amyotrophic Lateral Sclerosis (ALS), Chiari Malformation (CM), Facioscapulohumeral Muscular Dystrophy (FSHD), Friedreich's Ataxia (FA), Headache, Huntington's Disease (HD), Mitochondrial Disease (Mito), Multiple Sclerosis (MS), Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS), Myasthenia Gravis (MG), Myotonic Muscular Dystrophy (DM), Neuromuscular Diseases (NMD), Spinal Muscular Atrophy (SMA), Sport-Related Concussion (SRC) Persistent/Chronic (3 months and greater post-concussion), and Stroke <del>and Traumatic Brain Injury (TBI)</del></p> <p><b>Exploratory:</b> Cerebral Palsy (CP), Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH), Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months), and Spinal Cord Injury (SCI)-Pediatric</p>
Short Description of Instrument	<p><b>Construct measured:</b> Health-related quality of life</p> <p><b>Generic vs. disease specific:</b> Generic</p> <p><b>Means of administration:</b> Interview or Self-Administered</p>

	<p><b>Intended respondent:</b> <del>Patient-Participant</del></p> <p><b># of items:</b> 36</p> <p><b># of subscales and names of sub-scales:</b> 8 <del>subscales</del>: Physical Functioning, Role-Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional, Mental Health</p> <p><b># of items per sub-scale:</b> Varies</p>
<p><b>Comments/Special Instructions</b></p>	<p><del>The CDEs posted with this version of the SF-36 are specific to the Multiple Sclerosis Quality of Life Inventory (MSQLI). The National Institute of Health Neurological Disorder and Stroke (NINDS) received permission to post only the SF-36 version 1 questions that are used on the MSQLI.</del></p> <p><b>Background:</b> The Short Form-36 was derived from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988). It is one of the most widely used generic measures of health-related quality of life and has been shown to discriminate between <del>subjects-participants</del> with different chronic conditions and between <del>subjects participants</del> with different severity levels of the same disease. This instrument addresses health concepts that are relevant to <del>patients-participants</del> from the <del>patient participant's</del> perspective.</p> <p>A 12-item version, the Short Form-12 (SF-12) is also widely used. It was created by the developer of the SF-36 and found to have good reliability and validity (Ware et al., 1996). <del>However, it does not fully represent the SF-36. An 8-item version, the Short Form-8 (SF-8) fully represents the SF-36.</del></p>
<p><b>Scoring and Psychometric Properties</b></p>	<p><b>Scoring:</b> There are 36 items and measures of health across three domains - functional status, well-being and overall perceptions of health. The scoring system for the SF-36 is relatively complex and generates subscale scores for physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, and mental health.</p> <p>There is no single overall score for the SF-36, instead, it generates two summary scores (physical health and mental health) and 8 subscales. There are weighted sums of the questions in their section. Each scale is transformed into a 0-100 scale. The lower the score the worse the <del>participant's disability</del> generic health-related QoL has been rated. Scores are also converted to z scores for comparison with the general population.</p> <p>For SF-36 v1, scoring instructions are publicly available from the Rand Corporation. (<a href="#">Medical Outcomes Study: 36-Item Short Form Survey Scoring Instructions</a>)</p> <p><b>Psychometric Properties:</b> The SF-36 is highly validated. The SF-36 has been widely used to assess <del>patients-participants</del> with PD. It showed good reliability and discriminative validity. The SF-36 was partially responsive to change over time and intervention. In one study, it was more responsive than <del>Parkinson's Disease Questionnaire (PDQ-39)</del> and <del>Parkinson's Disease Quality of Life (PDQUALIF)</del>. The minimal detectable change has been determined.</p> <p>To date the properties of the SF-36 have not been evaluated in the mitochondrial disease population. In a multiple sclerosis (MS) population, the</p>

	<p>Cronbach's alphas for the various subscales of the SF-36 range from 0.67 to 0.94. There is considerable evidence for the validity of the SF-36 in a variety of populations including MS. (Vickrey et al., 1995) In this study, the physical functioning and role limitations due to physical problems subscales were the ones that best discriminated between MS <del>patients</del> <b>participants</b> and the normative US population.</p>
<p><b>Rationale/Justification</b></p>	<p><b>Strengths:</b> The SF-36 is easy to administer, covers a broad range of domains of health-related quality of life, and is among the most widely used of such measures. It is available in multiple languages. Availability of population-based normative data makes the SF-36 useful for comparative purposes. The availability of <del>several</del> <b>eight</b> subscales may be useful to investigators interested in testing hypotheses concerning these different areas of function. The SF-36 is the most extensively evaluated health status survey, it is brief, and data can be compared to the US normative population and across disease states. To keep the instrument brief, some health status concepts are missing, e.g., family functioning, sexual functioning, cognitive functioning, and sleep disorders. It is suitable for self-administration, computerized administration or administration by a trained interviewer in person or by telephone.</p> <p>It has been previously used in multiple myotonic dystrophy clinical trials; however, its responsiveness to change and relevance to this population is still unknown. The response rate for the population over age 65 is low.</p> <p><b>Administration:</b> Administration time is approximately 10 minutes. The SF-36 is a structured, self-report questionnaire that the <del>patient</del> <b>participant</b> can generally complete with little or no intervention from an interviewer. However, <del>patients</del> <b>participants</b> with visual or upper extremity impairments may need to have the SF-36 administered by a trained interviewer.</p> <p><b>Sport-Related Concussion-Specific:</b>  <b>Strengths:</b> Generic 36-item quality of life measure that include subscales for physical function, role limitations due to physical and emotional health, energy, emotional well- being, social functioning, pain and general health. Publicly available through RAND corp. Subscales are reliable. Intuitive 100 point based scoring system for each subscale.</p> <p><b>Weaknesses:</b> Measure is lengthy- 36 items (12 item scale may be more appropriate for sport concussion). Scoring conversion is challenging for the administrator and complicated. Lack of overall score. Clinical cut-off scores unavailable at this time. Subpopulations: Intended for adult <del>patients</del> <b>participants</b>.</p> <p><b>ME/CFS-Specific:</b>  As a generalized questionnaire, it does a good job of characterizing differences in ME/CFS reported measures compared to healthy individuals and other pathological or fatiguing conditions. Consider the DePaul Symptom Questionnaire for better evaluation between and among ME/CFS <del>patients</del> <b>participants</b>.</p> <p><b>Strengths:</b> Clearly separates mental issues from physical issues - the SF-36 shows that the pain, loss of vitality, physical functioning and fatigue are not accompanied by mental problems. Provides objective measures for reduced functional status, bodily pain, functional impairment, and fatigue severity that are characteristic of ME/CFS. There are enough published studies available to compare results - given the heterogeneity of the illness/comorbidities such</p>

	<p>as fibromyalgia syndrome (FMS) - it's nice to be able to have a relative abundance of studies to compare measures.</p> <p><b>Weaknesses:</b> Not designed to capture the post-exertional malaise (PEM) characteristic of the illness. May have a "floor effect" that makes it hard to determine when there is a symptom flare that reduces dimensions of health over a shorter period of time. Doesn't describe the full range of symptoms ME/CFS <del>patients</del> <b>participants</b> experience such as cognitive, fatigability, PEM and sleep problems.</p> <p><b>TBI-Specific:</b></p> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Convergent and discriminant validity of the Generalized Anxiety Disorder (GAD-7), Patient Health Questionnaire-9 (PHQ-9), PTSD Checklist for the DSM-5 (PCL-5), Rivermead Post-Concussion Symptom Questionnaire (RPQ), Quality of Life after Brain Injury (QOLIBRI), and Quality of Life after Brain Injury – Overall Scale (QOLIBRI-OS) with the SF-12v2 shows minimal, less good results compared with the SF-36.v2 (von Steinbuechel et al., 2021a)</li> <li>• Translation and linguistic validation in 20 languages (von Steinbuechel et al., 2021b)</li> </ul> <p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>• No TBI studies yet on psychometric properties of the English version (von Steinbuechel et al., 2021a)</li> <li>• SF-12v2 is a generic questionnaire on health-related quality of life and lacks TBI-specific questions</li> </ul>
<p><b>References</b></p>	<p><b>Key References:</b></p> <p>Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992 Jun;30(6):473-83.</p> <p>Hays RD. (1994). The Medical Outcomes Study (MOS) Measures of Patient Adherence. Santa Monica, CA: RAND Corporation Retrieved from <a href="https://www.rand.org/content/dam/rand/www/external/health/surveys_tools/mos/mos_adherence_survey.pdf">https://www.rand.org/content/dam/rand/www/external/health/surveys_tools/mos/mos_adherence_survey.pdf</a></p> <p>Hays RD, Sherbourne CD, Mazel R. (1995). User's Manual for the Medical Outcomes Study (MOS) Core Measures of Health-Related Quality of Life. Santa Monica, CA: RAND corporation.</p> <p>McHorney CA, Ware JE Jr, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993 Mar;31(3):247-63.</p> <p>Stewart AL, Hays RD, Ware JE Jr. The MOS short-form general health survey. Reliability and validity in a patient population. Med Care. 1988 Jul;26(7):724-35.</p> <p>Ware JE Jr. (2001). SF-36 Physical and Mental Health Summary Scales: A Manual for Users of Version 1 (2nd Edition ed.). Lincoln, RI: Quality Metric Inc.</p>

Ware JE Jr, Kosinski M, Dewey JE. (2000). How to Score Version 2 of the SF-36® Health Survey. Retrieved from Lincoln, RI: Quality Metric Inc.

Ware JE Jr, Kosinski M, Keller SD. (1994). SF-36® Physical and Mental Health Summary Scales: A Users' Manual. Boston, MA: The Health Institute.

Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care. 1996 Mar;34(3):220-33.

Ware JE Jr, Snow KK, Kosinski M, Gandek B. (1993). SF-36 Health Survey: Manual and Interpretation Guide. Boston, MA: The Health Institute.

**Additional References:**

Andresen EM, Gravitt GW, Aydelotte ME, Podgorski CA. Limitations of the SF-36 in a sample of nursing home residents. Age Ageing. 1999 Oct;28(6):562-6.

Hayes V, Morris J, Wolfe C, Morgan M. The SF-36 health survey questionnaire: is it suitable for use with older adults? Age Ageing. 1995 Mar;24(2):120-5.

Heartbeat Medical. (2021, 21 Aug). Short Form 36 (SF-36). Retrieved 05Jan2026, from <https://heartbeat-med.com/resources/short-form-36-sf-36/>

Score Range for the SF-36®v2 Health Survey & SF-12®v2 Health Surveys. Retrieved 10Dec2025, from <https://www.qualitymetric.com/score-range-data-sheet/>

Ruta DA, Hurst NP, Kind P, Hunter M, Stubbings A. Measuring health status in British patients with rheumatoid arthritis: reliability, validity and responsiveness of the short form 36-item health survey (SF-36). Br J Rheumatol. 1998 Apr;37(4):425-36.

Vickrey BG, Hays RD, Harooni R, Myers LW, Ellison GW. A health-related quality of life measure for multiple sclerosis. Qual Life Res. 1995 Jun;4(3):187-206.

**ME/CFS-Specific References:**

Buchwald D, Pearlman T, Umali J, Schmaling K, Katon W. Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. Am J Med. 1996 Oct;101(4):364-70.

Haywood KL, Staniszevska S, Chapman S. Quality and acceptability of patient-reported outcome measures used in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review. Qual Life Res. 2012 Feb;21(1):35-52.

Jason L, Brown M, Evans M, Anderson V, Lerch A, Brown A, Hunnell J, Porter N. Measuring substantial reductions in functioning in patients with chronic fatigue syndrome. Disabil Rehabil. 2011;33(7):589-98.

Komaroff AL, Fagioli LR, Doolittle TH, Gandek B, Gleit MA, Guerriero RT, Kornish RJ 2nd, Ware NC, Ware JE Jr, Bates DW. Health status in patients with chronic fatigue syndrome and in general population and disease comparison groups. Am J Med. 1996 Sep;101(3):281-90.

**Myotonic Dystrophy-Specific References:**

Antonini G, Soscia F, Giubilei F, De Carolis A, Gragnani F, Morino S, Ruberto A, Tatarelli R. Health-related quality of life in myotonic dystrophy type 1 and its relationship with cognitive and emotional functioning. *J Rehabil Med*. 2006 May;38(3):181-5.

Laberge L, Mathieu J, Auclair J, Gagnon É, Noreau L, Gagnon C. Clinical, psychosocial, and central correlates of quality of life in myotonic dystrophy type 1 patients. *Eur Neurol*. 2013;70(5-6):308-15.

Peric S, Nisic T, Milicev M, Basta I, Marjanovic I, Peric M, Lavrnjic D, Rakocevic Stojanovic V. Hypogonadism and erectile dysfunction in myotonic dystrophy type 1. *Acta Myol*. 2013 Oct;32(2):106-9.

Peric S, Rakocevic-Stojanovic V, Stevic Z, Basta I, Pavlovic S, Vujanac V, Marjanovic L, Lavrnjic D. Health-related quality of life in patients with myotonic dystrophy type 1 and amyotrophic lateral sclerosis. *Acta Neurol Belg*. 2010 Mar;110(1):71-7.

Peric S, Stojanovic VR, Basta I, Peric M, Milicev M, Pavlovic S, Lavrnjic D. Influence of multisystemic affection on health-related quality of life in patients with myotonic dystrophy type 1. *Clin Neurol Neurosurg*. 2013 Mar;115(3):270-5.

Tieleman AA, Jenks KM, Kalkman JS, Borm G, van Engelen BG. High disease impact of myotonic dystrophy type 2 on physical and mental functioning. *J Neurol*. 2011 Oct;258(10):1820-6.

**Parkinson's Disease-Specific References:**

Banks P, Martin CR. The factor structure of the SF-36 in Parkinson's disease. *J Eval Clin Pract*. 2009 Jun;15(3):460-3.

Brown CA, Cheng EM, Hays RD, Vassar SD, Vickrey BG. SF-36 includes less Parkinson Disease (PD)-targeted content but is more responsive to change than two PD-targeted health-related quality of life measures. *Qual Life Res*. 2009 Nov;18(9):1219-37.

Chrischilles EA, Rubenstein LM, Voelker MD, Wallace RB, Rodnitzky RL. The health burdens of Parkinson's disease. *Mov Disord*. 1998 May;13(3):406-13.

Den Ouden BL, Van Heck GL, De Vries J. The suitability of patient-based measures in the field of Parkinson's disease: a systematic review. *Mov Disord*. 2007 Jul 30;22(10):1390-1401.

Hagell P, Törnqvist AL, Hobart J. Testing the SF-36 in Parkinson's disease. Implications for reporting rating scale data. *J Neurol*. 2008 Feb;255(2):246-54.

Hobson P, Meara J. Self-reported functioning and well-being in patients with Parkinson's disease: comparison of the Short-Form 36 and the Parkinson's Disease Questionnaire. *Age Ageing*. 1996 Jul;25(4):334-5.

Jenkinson C, Peto V, Fitzpatrick R, Greenhall R, Hyman N. Self-reported functioning and well-being in patients with Parkinson's disease: comparison

of the short-form health survey (SF-36) and the Parkinson's Disease Questionnaire (PDQ-39). Age Ageing. 1995 Nov;24(6):505-9.

Kuopio AM, Marttila RJ, Helenius H, Toivonen M, Rinne UK. The quality of life in Parkinson's disease. Mov Disord. 2000 Mar;15(2):216-23.

Rubenstein LM, Voelker MD, Chrischilles EA, Glenn DC, Wallace RB, Rodnitzky RL. The usefulness of the Functional Status Questionnaire and Medical Outcomes Study Short Form in Parkinson's disease research. Qual Life Res. 1998 May;7(4):279-90.

Schrag A, Spottke A, Quinn NP, Dodel R. Comparative responsiveness of Parkinson's disease scales to change over time. Mov Disord. 2009 Apr 30;24(6):813-8.

Siderowf A, Jaggi JL, Xie SX, Loveland-Jones C, Leng L, Hurtig H, Colcher A, Stern M, Chou KL, Liang G, Maccarone H, Simuni T, Baltuch G. Long-term effects of bilateral subthalamic nucleus stimulation on health-related quality of life in advanced Parkinson's disease. Mov Disord. 2006 Jun;21(6):746-53.

Steffen T, Seney M. Test-retest reliability and minimal detectable change on balance and ambulation tests, the 36-item short-form health survey, and the unified Parkinson disease rating scale in people with parkinsonism. Phys Ther. 2008 Jun;88(6):733-46. Erratum in: Phys Ther. 2010 Mar;90(3):462.

#### **Stroke-Specific References:**

Anderson C, Laubscher S, Burns R. Validation of the Short Form 36 (SF-36) health survey questionnaire among stroke patients. Stroke. 1996 Oct;27(10):1812-6.

Hobart JC, Williams LS, Moran K, Thompson AJ. Quality of life measurement after stroke: uses and abuses of the SF-36. Stroke. 2002 May;33(5):1348-56.

Lai SM, Perera S, Duncan PW, Bode R. Physical and social functioning after stroke: comparison of the Stroke Impact Scale and Short Form-36. Stroke. 2003 Feb;34(2):488-93.

O'Mahony PG, Rodgers H, Thomson RG, Dobson R, James OF. Is the SF-36 suitable for assessing health status of older stroke patients? Age Ageing. 1998 Jan;27(1):19-22.

Williams LS. Health-related quality of life outcomes in stroke. Neuroepidemiology. 1998;17(3):116-20.

#### **Huntington's Disease-Specific References:**

Ho AK, Gilbert AS, Mason SL, Goodman AO, Barker RA. Health-related quality of life in Huntington's disease: Which factors matter most? Mov Disord. 2009 Mar 15;24(4):574-8.

Ho AK, Robbins AO, Walters SJ, Kaptoge S, Sahakian BJ, Barker RA. Health-related quality of life in Huntington's disease: a comparison of two generic instruments, SF-36 and SIP. Mov Disord. 2004 Nov;19(11):1341-8.

Tabrizi SJ, Langbehn DR, Leavitt BR, Roos RA, Durr A, Craufurd D, Kennard C, Hicks SL, Fox NC, Scahill RI, Borowsky B, Tobin AJ, Rosas HD, Johnson H, Reilmann R, Landwehrmeyer B, Stout JC; TRACK-HD investigators.

Biological and clinical manifestations of Huntington's disease in the longitudinal TRACK-HD study: cross-sectional analysis of baseline data. *Lancet Neurol.* 2009 Sep;8(9):791-801.

Tabrizi SJ, Scahill RI, Durr A, Roos RA, Leavitt BR, Jones R, Landwehrmeyer GB, Fox NC, Johnson H, Hicks SL, Kennard C, Craufurd D, Frost C, Langbehn DR, Reilmann R, Stout JC; TRACK-HD Investigators. Biological and clinical changes in premanifest and early stage Huntington's disease in the TRACK-HD study: the 12-month longitudinal analysis. *Lancet Neurol.* 2011 Jan;10(1):31-42.

**Subarachnoid Hemorrhage-Specific References:**

Anderson C, Rubenach S, Mhurchu CN, Clark M, Spencer C, Winsor A. Home or hospital for stroke rehabilitation? Results of a randomized controlled trial : I: health outcomes at 6 months. *Stroke.* 2000 May;31(5):1024-31.

de Haan R, Aaronson N, Limburg M, Hewer RL, van Crevel H. Measuring quality of life in stroke. *Stroke.* 1993 Feb;24(2):320-7.

McDowell I. (2006) *Measuring Health: A Guide to Rating Scales and Questionnaires.* 3rd Edition. New York: Oxford University Press.

**Sport-Related Concussion-Specific References:**

Chiang CC, Guo SE, Huang KC, Lee BO, Fan JY. Trajectories and associated factors of quality of life, global outcome, and post-concussion symptoms in the first year following mild traumatic brain injury. *Qual Life Res.* 2016 Aug;25(8):2009-19.

Kuehl MD, Snyder AR, Erickson SE, McLeod TC. Impact of prior concussions on health-related quality of life in collegiate athletes. *Clin J Sport Med.* 2010 Mar;20(2):86-91.

Valier AR, Welch Bacon CE, Bay RC, Houston MN, Valovich McLeod TC. Validity of Single-Item Patient-Rated Outcomes in Adolescent Football Athletes With Concussion. *Arch Phys Med Rehabil.* 2016 Jul;97(7):1202-5.

**TBI-Specific References:**

von Steinbuechel N, Rauen K, Bockhop F, Covic A, Krenz U, Plass AM, Cunitz K, Polinder S, Wilson L, Steyerberg EW, Maas AIR, Menon D, Wu YJ, Zeldovich M, The Center-Tbi Participants And Investigators. Psychometric Characteristics of the Patient-Reported Outcome Measures Applied in the CENTER-TBI Study. *J Clin Med.* 2021 May 28;10(11):2396.

von Steinbuechel N, Rauen K, Krenz U, Wu YJ, Covic A, Plass AM, Cunitz K, Mueller I, Bockhop F, Polinder S, Wilson L, Steyerberg EW, Maas AIR, Menon D, Zeldovich M, The Linguistic Validation Group Of Center-Tbi. Translation and Linguistic Validation of Outcome Instruments for Traumatic Brain Injury Research and Clinical Practice: A Step-by-Step Approach within the Observational CENTER-TBI Study. *J Clin Med.* 2021 Jun 28;10(13):2863

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