

NINDS CDE Resource
Patient Reported Outcomes Measurement Information System (PROMIS) – Pediatric

Availability:	Please click here for more information: PROMIS website .
Classification:	Exploratory: Chiari I Malformation (CM) and Spinal Cord Injury (SCI)-Pediatric
Short Description of Instrument:	<p>The Patient Reported Outcomes Measurement Information System (PROMIS) Version 1.0 contains 12 calibrated item banks with likert style items (e.g., anger, anxiety, depression, fatigue, pain, 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 of 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.</p> <p>See: PROMIS Domain Framework for pediatric domains</p> <p>Administration: Computer adaptive test or short-forms</p> <p>Time: Variable but design based on item-response theory algorithms to minimize time. Also, the basic PROMIS instrument is available in multiple versions (10-, 29-, and 57-item versions).</p> <p>Ages: Pediatric self-report instruments are available for children ages 8–17 and parent proxy reports are available for children ages 5–17.</p> <p>Cost: Free access to investigators who register and describe their study on the Assessment Center website. Currently, free use with a cooperative agreement. The goal is to grant free access in the public domain to the scientific community including the data repository, CAT, and supporting documents. This is in process.</p> <p>Available in Spanish and specific domains are available in multiple other languages; see PROMIS Translations for details.</p> <p>Advantages: Brief, yet reliable.</p>
Scoring:	<p>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 PROMIS Calibrations Testing for further details regarding sample for specific ages and domains.</p> <p>Scoring Manuals for PROMIS measures are available at: PROMIS Scoring Manuals.</p>

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<p>Comments / Special Instructions</p>	<p>The PROMIS measures were developed and calibrated on the general pediatric population with inclusion of some children with chronic conditions (asthma, primarily). There have been no studies on how the item banks work in children, such as those with SCI. Some items may show DIF or may not be relevant to all children with SCI, as has been described when used with Children with CP (Kratz et al., 2013; Mulcahey, et al., 2015; Coster et al., 2016). Research on PROMIS measures with children with SCI is needed.</p>
<p>References:</p>	<p>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. <i>Pain</i>. 2010;150(1):173–182.</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. <i>Med Care</i>. 2007;45(5 Suppl 1):S3–S11.</p> <p>Coster WJ, Ni P, Slavin MD, Kisala PA, Nandakumar R, Mulcahey MJ, Tulskey DS, Jette AM. Differential item functioning in the Patient Reported Outcomes Measurement Information System Pediatric Short Forms in a sample of children and adolescents with cerebral palsy. <i>Dev Med Child Neurol</i>. 2016: In Press.</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. <i>J Clin Oncol</i>. 2007;25(32):5106–5112.</p> <p>Kratz AL, Slavin MD, Mulcahey MJ, Jette AM, Tulskey DS, Haley SM. An examination of the PROMIS(®) pediatric instruments to assess mobility in children with cerebral palsy. <i>Qual Life Res</i>. 2013;22(10):2865–2876.</p> <p>Mulcahey MJ, Haley SM, Slavin MD, Kisala PA, Ni P, Tulskey DS, Jette AM. Ability of PROMIS Pediatric Measures to Detect Change in Children With Cerebral Palsy Undergoing Musculoskeletal Surgery. <i>J Pediatr Orthop</i>. 2016;36(7):749–756.</p>