

**CDE Notice of Copyright  
Patient-Reported Outcomes Measurement Information System (PROMIS)**

Availability	<p><b>The instrument is freely available here: <a href="#">PROMIS website</a>. See <a href="#">General Page</a> for currently available PROMIS Bank CDE Details.</b></p>
Classification	<p><b>Supplemental - Highly Recommended:</b> Sickle Cell Disease (SCD)</p>
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 (Cella et al., 2010; Garcia et al., 2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance (Bruni et al., 1996, 1994; Spruyt &amp; Gozal 2011), 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: <a href="#">PROMIS Domain Framework</a> for pediatric and adult domains</p> <p><b>Administration:</b> Computer adaptive test (CAT) or short-forms</p> <p><b>Time:</b> Variable but design based on item-response theory algorithms to minimize time. 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. Full range of self-report adult instruments.</p> <p><b>Cost:</b> 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 <a href="#">PROMIS Translations</a> for details.</p> <p><b>Advantages:</b> Brief, yet reliable.</p>

<p>Comments/Special Instructions</p>	<p>N/A</p>
<p>Scoring and Psychometric Properties</p>	<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 for PROMIS measures 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>
<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>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. <i>J Sleep Res</i>. 1996;5(4):251-261.</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) <i>11 Sonno in Italiu 1994</i>. 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 BRM. 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:S3-S11.</p> <p>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</p>

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