

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

Availability:	<p>The instrument is freely available here: PROMIS website.</p> <p>See General Page for currently available PROMIS Bank CDE Details.</p>
Classification:	<p>Supplemental – Highly Recommended: Congenital Muscular Dystrophy (CMD) in studies of psychosocial functioning, quality-of-life, outcome, and long-term adjustment studies.</p> <p>Supplemental: Traumatic Brain Injury (TBI), 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)</p> <p>Exploratory: Cerebral Palsy (CP) Myotonic Muscular Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)</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 & 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. 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: PROMIS Domain Framework for pediatric and adult domains</p> <p>Administration: Computer adaptive test (CAT) or short-forms</p> <p>Time: 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>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>

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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>
References:	<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 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. <i>J Clin Epidemiol</i>. 2010;63(11):1179–1194.</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>Spruyt K, Gozal D. Pediatric sleep questionnaires as diagnostic or epidemiological tools: a review of currently available instruments. <i>Sleep Med Rev</i>. 2011;15(1):19–32.</p>