**NINDS CDE Resource**

**Patient Reported Outcomes Measurement Information System (PROMIS)**

<table>
<thead>
<tr>
<th>Availability:</th>
<th>The instrument is freely available here: PROMIS website. See General Page for currently available PROMIS Bank CDE Details.</th>
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<tr>
<td>Classification:</td>
<td><strong>Supplemental – Highly Recommended:</strong> Congenital Muscular Dystrophy (CMD) in studies of psychosocial functioning, quality-of-life, outcome, and long-term adjustment studies. <strong>Supplemental:</strong> 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, Spinal Cord Injury (SCI), and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) <strong>Exploratory:</strong> Cerebral Palsy (CP) Myotonic Muscular Dystrophy (DM), Facioscapulohumeral Muscular Dystrophy (FSHD), and Sports-Related Concussion (SRC) *Headache specific subtest recommendations: Anxiety (Adult/Pediatric), Depression (Adult/Pediatric), Sleep (Adult)</td>
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<td>Short Description of Instrument:</td>
<td>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. 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. See: PROMIS Domain Framework for pediatric and adult domains <strong>Administration:</strong> Computer adaptive test (CAT) or short-forms <strong>Time:</strong> 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). <strong>Ages:</strong> 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. <strong>Cost:</strong> 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.</td>
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| Available in Spanish and specific domains are available in multiple other languages; see [PROMIS Translations](#) for details.  
**Advantages:** Brief, yet reliable. |
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### Scoring:

- **T** scores for all scales.
- 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.

- **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.
- **Scoring Manuals for PROMIS measures are available at:** [PROMIS Scoring Manuals](#).

### References:

- 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 Jun 9.
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<tr>
<th>Patient Reported</th>
<th>Recommended Instrument for: ALS, CM, CMD, CP, DM, DMD, Epilepsy, FA, FSHD, Headache, HD, Mito, MS, MG, NMD, PD, SAH, SCI, SMA, SRC, Stroke, and TBI</th>
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