

**NINDS CDE Notice of Copyright
Spinal Cord Injury - Quality of Life (SCI-QOL)**

Availability:	SCI-QOL Computer Adaptive Tests (CATs) and short forms available at www.assessmentcenter.net (request access through SCI-QOL@udel.edu). Item bank and short form PDFs available through SCI-QOL@udel.edu .
Classification:	Supplemental
Short Description of Instrument:	<p>The SCI-QOL measurement system was developed with funding from the National Institutes of Health (National Institute of Child Health and Human Development /National Center for Medical Rehabilitation Research and the National Institute of Neurological Disorders and Stroke) and the National Institute on Disability and Rehabilitation Research to develop and validate a multifaceted system of measuring patient reported outcomes across a wide variety of functioning specifically targeted for individuals with SCI. Evaluation of the sensitivity and responsiveness is currently underway.</p> <p>The measures were developed following all of the PROMIS standards for patient reported outcomes (PRO) measure development. Twenty-two areas of functioning are measured through Computer Adaptive Tests (CATs) and/or fixed-length short forms (SF). Some scales are unique to the needs of individuals with SCI (e.g., Resilience, Grief/Loss, Independence) while other scales used PROMIS and Neuro-QOL items but recalibrated scores to optimize assessment within an SCI population (e.g., Pain Interference, Depression, Anxiety). These latter scores are linked directly to the PROMIS (PROMIS Instrument Link) or the Neuro-QOL measurement system (Neurological Quality of Life Instrument Link) to allow for direct comparison with PROMIS and Neuro-QOL scores except item administration has been enhanced for individuals with SCI.</p> <p>For more information on linkages between the SCI-QOL, PROMIS, and Neuro-QOL, please see the Guidelines for Use of NIH Resources for Clinical Studies document.</p>

**NINDS CDE Notice of Copyright
Spinal Cord Injury - Quality of Life (SCI-QOL)**

Administration Details:	<p>Administration: Computer adaptive test (CAT) or short forms (SF). Currently, CATs are only available through the Assessment Center platform (www.assessmentcenter.net; contact SCI-QOL@udel.edu for access). SFs may be administered through Assessment Center, by paper and pencil, or may be entered into alternate electronic data capture systems.</p> <p>Time: Variable depending on the number of domains assessed; CATs average 7 items (~2 minutes) each and SFs average 9 items (~3 minutes) each.</p> <p>Ages: SCI-QOL measures were calibrated with adults only (ages 18 and older)</p> <p>Cost: Free to investigators/clinicians who sign a use agreement (available from SCI-QOL@udel.edu). Assessment Center is currently available free of charge, however a fee for use may be implemented in the near future.</p> <p>Languages: SCI-QOL measures are currently available in English only.</p>
Scoring:	<p>Standard scores are provided on a T metric (mean 50, SD 10) for all SCI-QOL CATs and SFs. CATs are scored automatically by Assessment Center. For SFs, raw (sum) scores must be computed and then converted to T-scores using lookup tables available through SCI-QOL@udel.edu.</p> <p>In all cases, higher scores indicate more of the trait being measured (as indicated by the name of the bank). For example, higher scores on SCI-QOL Basic Mobility and SCI-QOL Positive Affect and Well-Being indicate better outcomes whereas higher scores on SCI-QOL Depression and SCI-QOL Fatigue indicate worse outcomes.</p>
References:	<p>Tulsky, D. S., Kisala, P. A., Victorson, D., Tate, D. G., Heinemann, A. W., Charlifue, S., Kirshblum, S. C., Fyffe, D., Gershon, R., Spungen, A. M., Bombardier, C. H., Dyson-Hudson, T. A., Amtmann, D., Kalpakjian, C. Z., Choi, S. W., Jette, A. M., Forchheimer, M., & Cella, D. (2015). Overview of the Spinal Cord Injury – Quality of Life (SCI-QOL) measurement system. <i>The Journal of Spinal Cord Medicine, 38</i>(3), 257-269.</p> <p>Tulsky, D. S., Kisala, P. A., Victorson, D., Choi, S. W., Gershon, R., Heinemann, A. W., & Cella, D. (2015). Methodology for the development and calibration of the SCI-QOL item banks. <i>The Journal of Spinal Cord Medicine, 38</i>(3), 270-287.</p>