

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

Availability:	This instrument is available on the Assessment Center (http://assessmentcenter.net/) website to use as computer adaptive tests and/or shortforms. Interested parties can contact david.tulsky@nyumc.org or pamela.kisala@nyumc.org for more information.
Classification:	Exploratory
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 validated a multifaceted system of measuring patient reported outcomes across a wide variety of functioning specifically targeted for individuals with SCI. Evaluation of the sentivity and responsiveness is currently being studied.</p> <p>The measures were developed following all standards of development advanced by the PROMIS measurement scales. Twenty two areas of functioning are measured through Computer Adaptive Tests and/or short forms. Some scales are unique to the needs of individuals with SCI (e.g., bowel and bladder management, resilience, grief and 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>

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Special instructions: Medical Domains	<p>SCI-QOL Domains and definitions</p> <p>Physical – Medical Domains</p> <p>Domain 1, Bowel Management Difficulties item bank measures a range of difficulties associated with bowel management, ranging from ability to carry out their bowel program, to concerns about incontinence and bowel accidents, concerns about difficulty performing a bowel program, and the impact on everyday living. This bank is an SCI targeted bank.</p> <p>Domain 2, Bladder Management Difficulties item bank measures a range of difficulties associated with bladder management, ranging from ability to carry out their bladder program to worry about bladder accidents, performing their bladder program, and impact on everyday living. This bank is an SCI targeted bank.</p> <p>Domain 3, Bladder Complications items measure a range of difficulties associated with bladder complications such as urinary tract infection (UTI), UTI impact on everyday living, and bladder issues affecting sexual function. The items represent a diverse set of secondary complications and have been aggregated and scored as a short scale composed of 5 items.</p> <p>Domain 4, Skin Pressure Ulcers item bank measures a range of difficulties associated with skin breakdown and pressure ulcers, such as the extent to which pressure ulcers hinder engagement in social, cognitive, emotional, physical, and recreational activities. The bank consists of 12 items and one screener item. Skin breakdown following SCI is referenced as one of the most significant issues affecting the QOL of individuals with SCI. It has been developed as a long (12 item) and short (7 item) fixed battery SCI-QOL scale.</p> <p>Domain 5, Pain Interference item bank measures the self-reported consequences of pain on relevant aspects of one’s life. This includes the extent to which pain hinders engagement with social, cognitive, emotional, physical, and recreational activities. This item bank is made up almost entirely of PROMIS Pain Interference items that have been recalibrated in an SCI population. Scores have been transformed to be equivalent to the PROMIS general population referenced metric to allow direct comparison with the PROMIS scale.</p> <p>Domain 6, Pain Behavior is a small subset of the PROMIS Pain Behavior item bank item bank measures self-reported external manifestations of pain; behavior that typically indicate to others that an individual is experiencing pain. These actions or reactions can be verbal or non-verbal, and involuntary or deliberate. They include observable displays, pain severity behaviors, and verbal reports of pain. The items were recalibrated in an SCI population and only a small set of 7 items were retained in the final SCI-QOL bank and are to be administered as a fixed length scale. The final scores were transformed to represent to be equivalent to the PROMIS general population referenced metric to allow direct comparison with the PROMIS scale.</p>
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Special Instructions:
Emotional Domains
7-9

Emotional Domains:

Domain 7, Depression item bank is made up of several PROMIS items and is characterized by items measuring a profound and persistent feeling of sadness or despair and/or a loss of interest in things that were once pleasurable and feelings of hopelessness, helplessness, and worthlessness. Specifically, the items assess self-reported negative mood (sadness, guilt), views of self (self-criticism, worthlessness), and social cognition (loneliness, interpersonal alienation), as well as decreased positive affect and engagement (loss of interest, meaning, and purpose). Somatic symptoms (changes in appetite, sleeping patterns) are not included, which eliminates consideration for these items' confounding effects when assessing patients with comorbid conditions. Like the Pain Interference item bank, the SCI-QOL Depression items were calibrated in a sample of individuals with SCI and the final scores were transformed to be equivalent to the general population PROMIS metric.

Domain 8, Anxiety item bank measures self-reported fear (fearfulness, panic) anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms to arousal (racing heart, dizziness). Anxiety is best differentiated by symptoms that reflect autonomic arousal and experience of threat. Also, like the SCI-QOL Pain Interference and Depression item banks, the SCI-QOL Anxiety items were calibrated in a sample of individuals with SCI and the final scores were transformed to be equivalent to the general population PROMIS metric.

Domain 9, Resilience. While traditional emotional factors like depression and anxiety were cited as important constructs that impact QOL, a much more frequently cited emotional factor among individuals with SCI was resilience as each focus group discussed the importance of "opening a new book and starting a new life" as a critical prerequisite of psychosocial adjustment following injury (Tulsky et al., 2011). Resilience is defined as one's subjective experience of the process and outcome of successfully adapting to difficult or challenging life experiences, especially highly stressful or traumatic events (O'Leary, 1998; O'Leary & Ickovics, 1995; Rutter, 1987). Being resilient does not mean that life's major hardships are not difficult and upsetting. Instead, it means that these events, though difficult and upsetting, are ultimately surmountable.

Domain 10, Positive Affect and Well-Being. The more generic form of positive emotions is universal to all people and our bank of items related to positive affect and well-being was drawn directly from the Neuro-QOL item bank of the same name which had defined the item bank as those aspects of a person's life that relate to a sense of well-being, life satisfaction or an overall sense of purpose and meaning. The SCI-QOL item bank was calibrated within our SCI sample but scores on this bank were then transformed to the Neuro-QOL metric so that performance is representative of the general population.

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Special Instructions: Emotional Domains 10-14	<p>Emotional Domains</p> <p>Domain 10, Positive Affect and Well-Being. The more generic form of positive emotions is universal to all people and our bank of items related to positive affect and well-being was drawn directly from the Neuro-QOL item bank of the same name which had defined the item bank as those aspects of a person's life that relate to a sense of well-being, life satisfaction or an overall sense of purpose and meaning. The SCI-QOL item bank was calibrated within our SCI sample but scores on this bank were then transformed to the Neuro-QOL metric so that performance is representative of the general population.</p> <p>Domain 11, Grief/Loss is the natural process of reacting to a loss and is an aspect of emotional functioning that is widely experienced by individuals with SCI (Tulsky et al.,2011). For the SCI-QOL measurement system, the grief/loss item bank assesses emotional reactions of grief such as anger, guilt, anxiety, sadness, and despair. The SCI-QOL grief/loss bank was developed based upon feedback from individuals with SCI and the scores reflect emotional functioning within a targeted SCI population.</p> <p>Domain 12, Self-Esteem was another common theme expressed by individuals with SCI and focusses on the self-awareness that individuals experience as they compare themselves to an "ideal self." Such comparisons can result in a negative self-perception and appraisals. For SCI-QOL, we have defined the bank as one's emotional, evaluative, and cognitive perceptions of his/her own competence and worth. This self-evaluation provides a reference by which to compare oneself to relevant others in social and socially competitive situations. The SCI-QOL Self-Esteem bank was developed based upon the input of individuals with SCI and scores are based upon the SCI sample.</p> <p>Domain 13, Stigma is a related, but distinct, construct that was developed as a Neuro-QOL domain. Stigma refers to negative stereotyping that leads to discrimination. The SCI-QOL Stigma item bank assesses perceptions of self and publically enacted negativity, prejudice, and discrimination as a result of SCI manifestations and the item bank includes 12 items that are adapted from Neuro-QOL. Administration order of items is based upon the at large SCI calibration sample; yet the final score has been transformed to the Neuro-QoL metric.</p> <p>Domain 14, Psychological Trauma occurs after an individual experiences exposure to actual or perceived threat(s) to life, bodily integrity or the mind. Psychological trauma often leads to an overwhelming experience of fear, helplessness, or horror and usually renders an individual unable to adequately cope. The psychological trauma bank assesses the individual's experience of psychological trauma and the symptoms that accompany it. The final bank includes 19 items that are targeted to the SCI population and the scores are referenced against the SCI population.</p>
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Special Instructions: Social/Participation Domains	<p>Social / Participation Domains</p> <p>Domain 15, Ability to Participate in Social Roles and Activities is the degree of involvement in one’s usual social roles, activities, and responsibilities, including work, family, friends and leisure. This bank was adopted from Neuro-QOL with 46 Neuro-QOL items being tested and 27 were retained. The item bank was recalibrated with the SCI sample and then transformed back to the Neuro-QOL metric.</p> <p>Domain 16, Satisfaction with Social Roles and Activities is the satisfaction that one has with his/her involvement in one’s usual social roles, activities, and responsibilities, including work, family, friends, and leisure. Items were selected from the Neuro-QOL and PROMIS measures. As above, the items were re-calibrated in individuals with SCI and transformed to the Neuro-QOL metric.</p> <p>Domain 17, Independence/Autonomy is the individual’s sense of independence, or the ability to tell others about the needs and the sense of control over one’s life.</p>
References:	<p>Model Systems Translation Center Evaluating the sensitivity and responsiveness of the SCI-QOL CATs</p> <p>United States Department of Veteran Affairs Journal of Research and Rehabilitation</p> <p>Craig Hospital Evaluating the Sensitivity and Responsiveness of the SCI-QOL CATs</p> <p>Tulsky, D. & Carlozzi, N (chairs) (2009, October). The future of outcomes measurement in rehabilitation medicine: Development of the SCI-CAT, SCI-QOL, and TBI-QOL. Symposium presented at the 2009 ACRM-ASNR Joint Educational Conference, "Building the Evidence Base for Rehabilitation Interventions: From Research to Clinical Care," Denver, CO.</p> <p>Tulsky D, Kisala P, Charlifue S, Heinemann A, Kalpakjian C, Victorson D, Fyffe D, Tate D, Forchheimer M, Cella D.(2013, May). Validation of the SCI-QOL and SCI-FI Measurement Systems for Persons with SCI. A platform presentation presented at the 2013 Annual Meeting of the American Spinal Injury Association, Chicago, IL.</p> <p>Tulsky, D. (2009, October). The future of outcomes measurement in rehabilitation medicine: Part 2 - development of the SCI-CAT, SCI-QOL, and TBI-QOL. Symposium to be presented at the 2009 ACRM-ASNR Joint Educational Conference, "Building the Evidence Base for Rehabilitation Interventions: From Research to Clinical Care," Denver, CO.</p>