

Spinal Cord Injury – Quality of Life (SCI-QOL) Measurement System

All NINDS CDE recommendations include direct links to the NIH quality of life outcomes tools, including the NIH Toolbox, PROMIS, and Neuro-QOL. Users of the NINDS Spinal Cord Injury CDEs are encouraged to consider the Spinal Cord Injury - Quality of Life ([SCI-QOL](#)) measurement system when designing studies with these outcomes in mind.

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. The SCI-QOL is designed as a multifaceted system for measuring patient reported outcomes across a wide variety of functioning. This tool uses the standards of development and links to PROMIS and Neuro-QOL, but it has been revised and is specifically targeted for individuals with SCI.

The SCI-QOL consists of a core set of PROMIS/Neuro-QOL item banks that have been optimized for individuals with SCI so that only the most relevant and discriminating items are administered to individuals with SCI. For these “optimized” PROMIS/Neuro-QOL item banks, scores have been transformed back to the Neuro-QOL or PROMIS metric so that scores reference the original population (i.e., general population or mixed general + neurological population).

Item banks that produce a redundant score with PROMIS (but are optimized for SCI) are as follows:

| | |
|---------------------|------------|
| Pain Behavior Scale | Depression |
| Pain Interference | Anxiety |

Item banks that produce a redundant score with Neuro-QOL (but are optimized for SCI) are as follows:

| | |
|------------------------------|---|
| Positive Affect & Well Being | Satisfaction with Social Roles/Activities |
| Stigma | Ability to Participate in Social Roles/Activities |

The SCI-QOL also includes new, SCI-specific item banks that are not part of the Neuro-QOL or PROMIS systems. These are:

| | |
|----------------------|---------------------------------|
| Independence | Bladder Complications |
| Grief/Loss | Bowel Management Difficulties |
| Psychological Trauma | Bladder Management Difficulties |
| Self Esteem | Pressure Ulcers |
| Resilience | |

These new item banks reference the SCI population. In other words, the mean of 50 on the Pressure Ulcers bank is relative to a sample of individuals with SCI.

When there is a SCI-QOL item bank in an area that is also assessed by PROMIS or Neuro-QOL, the SCI-QOL item bank should be used as it has been optimized for a SCI population. To see the overlap among the three measurement systems, and the corresponding reference population for the SCI-QOL banks, please see the following table:

Linkages among SCI-QOL Short Forms, SCI-QOL Item Banks, PROMIS and Neuro QOL

| | SCI-QOL Subdomain/Bank | SCI-QOL Items | Items in SCI-QOL SF | Scoring Direction | Linked to | PROMIS Items | Neuro-QOL Items | Reference Population |
|----------------------|--------------------------------|---------------|---------------------|-------------------|------------|--------------|-----------------|----------------------|
| Emotional Health | Anxiety | 25 | 9 | Severe | PROMIS | 16 | 20 | General |
| | Depression | 28 | 10 | Severe | PROMIS | 18 | 22 | General |
| | Grief/Loss | 17 | 9 | Severe | -- | 0 | 0 | SCI |
| | Positive Affect and Well Being | 28 | 10 | Better | Neuro-QOL | 0 | 23 | General |
| | Resilience | 21 | 8 | Better | -- | 0 | 0 | SCI |
| | Self-Esteem | 23 | 8 | Better | -- | 0 | 0 | SCI |
| | Stigma | 23 | 10 | Severe | Neuro- QOL | 0 | 23 | Neuro |
| | Psychological Trauma | 18 | 8 | Severe | -- | 0 | 0 | SCI |
| Physical Health | Bladder Complications Scale | 5 | 5 | Severe | -- | 0 | 0 | SCI |
| | Bladder Management Diff. | 15 | 8 | Severe | -- | 0 | 0 | SCI |
| | Bowel Management Diff. | 26 | 9 | Severe | -- | 0 | 0 | SCI |
| | Pain Behavior Scale | 7 | 7 | Severe | PROMIS | 39 | 0 | General |
| | Pain Interference | 25 | 10 | Severe | PROMIS | 40 | 0 | General |
| | Pressure Ulcers | 12 | 7 | Severe | -- | 0 | 0 | SCI |
| Social Participation | Ability to Participate in SRA | 27 | 10 | Better | -- | 0 | 0 | General |
| | Satisfaction with SRA | 35 | 10 | Better | Neuro-QOL | 0 | 43 | General |
| | Independence | 8 | 8 | Better | -- | 0 | 0 | SCI |
| Physical Function* | Basic Mobility | 53 | 11 | Better | PROMIS | 15 | 0 | General |
| | Ambulation | 39 | 11 | Better | -- | 0 | 0 | SCI |
| | Fine Motor Function | 36 | 9 | Better | -- | 0 | 0 | SCI |
| | Self-Care | 90 | 11 | Better | -- | 0 | 0 | SCI |
| | Wheelchair Mobility | 56 | 9/10** | Better | -- | 0 | 0 | SCI |

*Physical Function item banks are also known as the Spinal Cord Injury – Functional Index (SCI-FI)

**Power Wheelchair/Manual Wheelchair short forms

For more information, contact SCI-QOL@udel.edu

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