

Traumatic Brain Injury – Quality of Life (TBI-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 Traumatic Brain Injury CDEs are encouraged to consider the Traumatic Brain Injury - Quality of Life ([TBI-QOL](#)) measurement system when designing studies with these outcomes in mind.

The TBI-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 TBI-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 TBI.

The TBI-QOL consists of a core set of PROMIS/Neuro-QOL item banks that have been optimized for individuals with TBI so that only the most relevant and discriminating items are administered to individuals with TBI. 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). The TBI-QOL also includes new, TBI-specific item banks that are not part of the Neuro-QOL or PROMIS systems. These are:

Grief/Loss	Resilience
Headache Pain	Self-Esteem
Independence	Communication/Comprehension

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

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

Fatigue	Anger
Pain Interference	Anxiety
	Depression

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

Mobility	Emotional & Behavioral Dyscontrol
Upper Extremity Function	Positive Affect & Well-being
Cognition – General Concerns	Stigma
Cognition – Executive Function	Ability to Participate in Social Roles/Activities
	Satisfaction with Social Roles/Activities

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

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

	TBI-QOL Subdomain/Bank	TBI-QOL Items	Items in TBI-QOL SF	Higher scores are ...	Linked to	PROMIS Items	Neuro-QOL Items	Reference Population
Physical Health	Fatigue	73	10	Worse (symptoms)	PROMIS	67	6	General
	Headache Pain	13	10	Worse (symptoms)	--	0	0	TBI
	Mobility	32	9	Better (function)	Neuro-QOL	9	19	General + Neuro
	Pain Interference	40	10	Worse (symptoms)	PROMIS	40	0	General
	Upper Extremity	33	9	Better (function)	Neuro-QOL	17	16	General + Neuro
Emotional Health	Anger	35	10	Worse (symptoms)	PROMIS	29	0	General
	Anxiety	28	10	Worse (symptoms)	PROMIS	16	20	General
	Depression	28	8	Worse (symptoms)	PROMIS	18	22	General
	Emotional & Behavioral Dyscontrol	26	10	Worse (symptoms)	Neuro-QOL	2	16	Neuro
	Grief/Loss	17	9	Worse (symptoms)	--	0	0	TBI
	Positive Affect & Well-Being	32	9	Better (function)	Neuro-QOL	0	23	General
	Resilience	27	10	Better (function)	--	0	0	TBI
	Self-Esteem	13	10	Better (function)	--	0	0	TBI
	Stigma	28	7	Worse (symptoms)	Neuro-QOL*	0	23	Neuro
Cognition	Cognition – General Concerns	39	10	Better (function)	Neuro-QOL	0	12	General + Neuro
	Communication/Comprehension	31	9	Better (function)	--	0	5	TBI
	Executive Function	37	10	Better (function)	Neuro-QOL	0	11	General + Neuro
Social Participation	Ability to Participate in Social Roles & Activities	45	10	Better (function)	Neuro-QOL	0	43	General
	Independence	13	8	Better (function)	--	0	0	TBI
	Satisfaction with Social Roles & Activities	41	10	Better (function)	Neuro-QOL	19	39	General

Note: Bold text indicates number of items that are statistically linked.

Note: Neuro-QOL and PROMIS items are not mutually exclusive – many items are in both PROMIS and Neuro-QOL.

*The term “injury” has replaced “illness” in all Neuro-QOL Stigma items

Abbreviation: Neuro=mixed neurological population consisting of individuals with stroke, epilepsy, Parkinson’s, multiple sclerosis, and amyotrophic lateral sclerosis, SF=Short Form, CAT=Computer Adaptive Test.

If you have questions or need more information, contact TBI-QOL@udel.edu.