

NINDS User Manual

Quality of Life in Neurological Disorders (Neuro-QOL) Measures

Version 1.0

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1.0- What is Neuro-QOL?

Neuro-QOL is a set of self-report measures that assesses the health-related quality of life (HRQOL) of adults and children with neurological disorders. Neuro-QOL instruments were developed through a collaborative, multisite NINDS-sponsored research initiative (Contract HHSN 2652004236-01C – David Cella, Principal Investigator) to construct a psychometrically-sound and clinically-relevant health-related quality of life measurement tools for individuals with neurological conditions (e.g. stroke, multiple sclerosis [MS], amyotrophic lateral sclerosis [ALS], Parkinson’s disease [PD], epilepsy, and muscular dystrophy [MD]). Neuro-QOL is comprised of item banks and scales that evaluate symptoms, concerns, and issues that are relevant across disorders (generic measures) along with instruments that assess areas most relevant for specific patient populations (targeted). The Neuro-QOL instruments enable within-disease as well as cross-disease comparisons and are intended for use in both neurology clinical trials and clinical practice.

1.1- Overview of Development

The HRQOL domains included in Neuro-QOL were identified through several sources, including an extensive literature review, an on-line Request for Information (RFI), two phases of in-depth expert interviews (n=44 and n=89, respectively), patient and caregiver focus groups (N =11 groups) and individual interviews with patients and proxies (N = 63). On the basis of this input, 17 HRQOL domains and sub-domains were chosen for adults and 11 for children, organized within the framework below (see Figures below).

Table 1: Adult Domain Framework

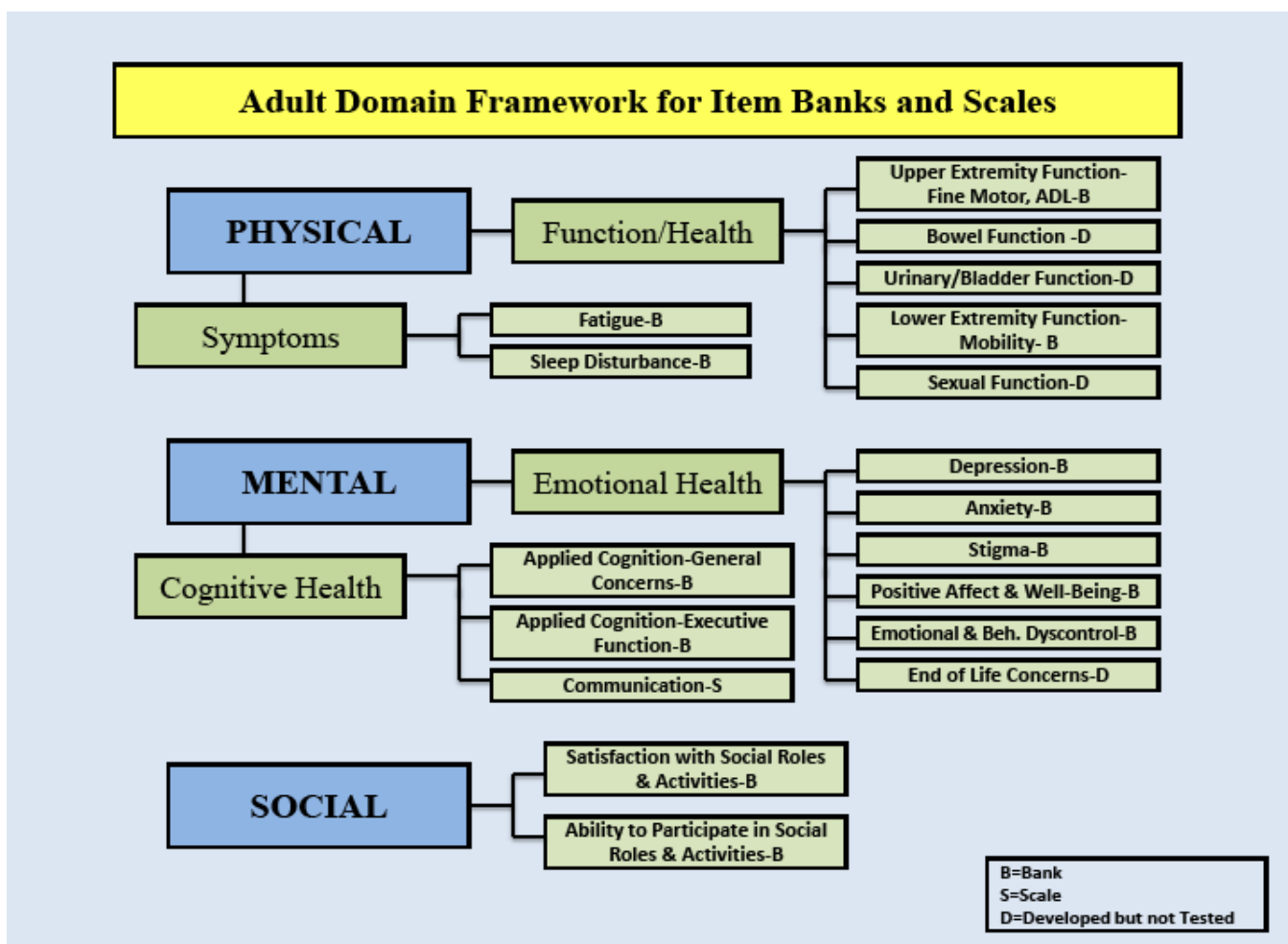
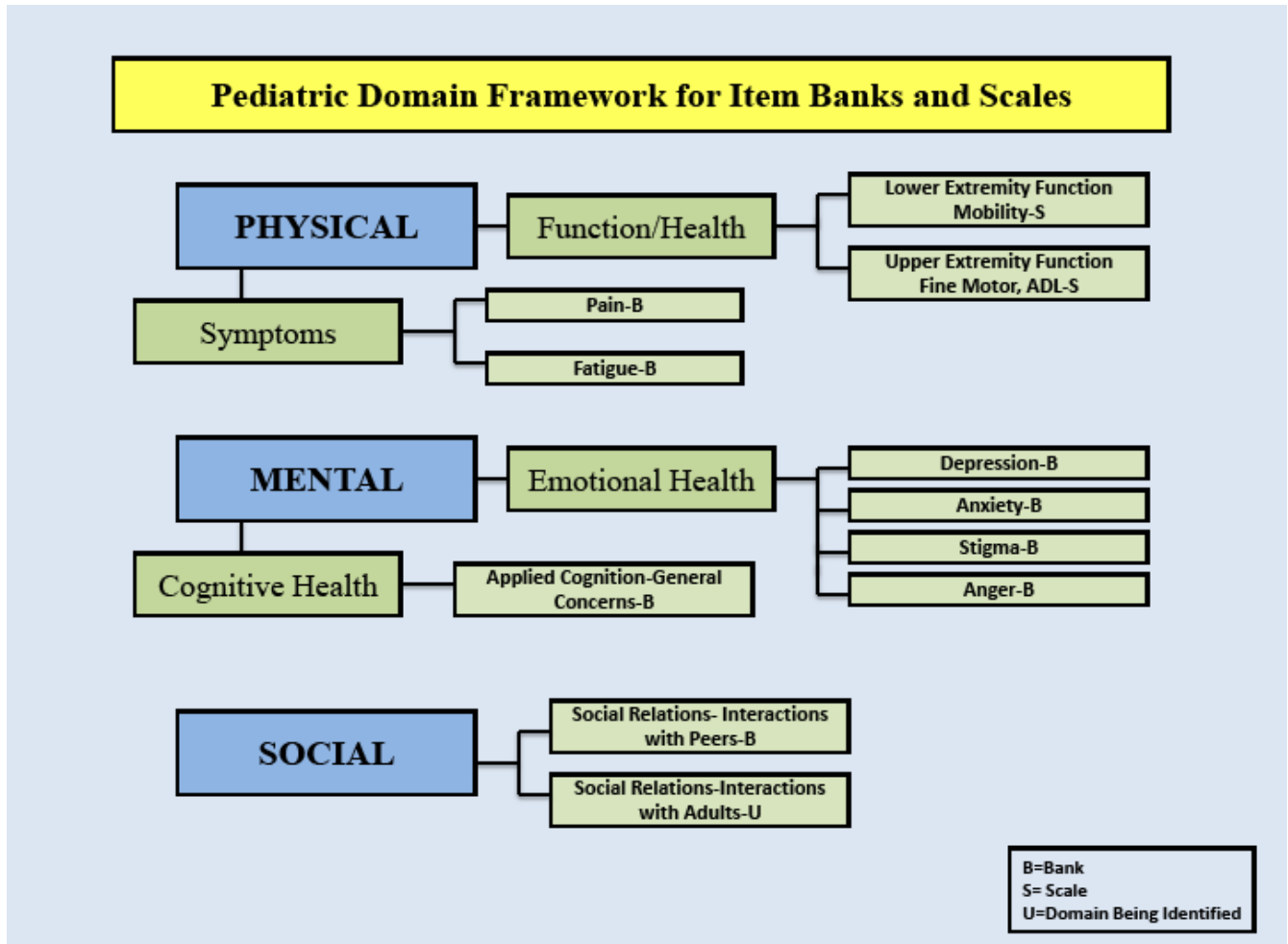


Table 2: Pediatric Domain Framework



Items were selected for inclusion in each domain through a multi-step, iterative process whereby candidate items were reviewed to ensure relevance, translatability, clarity and comprehensive content coverage. The resultant sets of items (item pools) underwent calibration using Item Response Theory (IRT) analyses to form the final item banks and scales. The scales and short forms (8-10 items) from each bank were subsequently validated in adult and pediatric clinical samples. Details of the calibration and validation studies can be found in Appendix 1 (“Neuro-QOL Technical Report”).

2.0- Available Neuro-QOL Instruments

2.1- Domain Definitions

Components of self-reported health as measured in Neuro-QOL are organized in the above domain framework. Domain definitions associated with the components of the framework are provided below.

Table 3: Adult Domain Definitions

Adult Domain	Definition
Anxiety	Unpleasant thoughts and/or feelings related to fear (e.g., fearfulness, feelings of panic), helplessness, worry and hyperarousal (e.g., tension, nervousness, restlessness).
Depression	Experience of loss and feelings of hopelessness, negative mood (e.g., sadness, guilt), decrease in positive affect (e.g., loss of interest), information-processing deficits (e.g., problems in decision-making), negative views of the self (e.g., self-criticism, worthlessness), and negative social cognition (e.g., loneliness).
Fatigue	Sensations ranging from tiredness to an overwhelming, debilitating and sustained sense of exhaustion that decreases one's capacity for physical, functional, social and mental activities.
Upper Extremity Function - Fine Motor, ADL	One's ability to carry out various activities involving digital, manual and reach-related functions, ranging from fine motor to self-care (activities of daily living)
Lower Extremity Function - Mobility	One's ability to carry out various activities involving the trunk region and increasing degrees of bodily movement, ambulation, balance or endurance.
Applied Cognition- Executive Function	Perceived difficulties in applications of mental function related to planning, organizing, calculating, working with memory and learning.
Applied Cognition- General Concerns	Perceived difficulties in everyday cognitive abilities such as memory, attention, and decision making.
Emotional and Behavioral Dyscontrol	A set of disease and/or treatment related manifestations including disinhibition, emotional lability, irritability, impatience, and impulsiveness.
Positive Affect and Well-Being	Aspects of a person's life that relate to a sense of well-being, life satisfaction or an overall sense of purpose and meaning.
Sleep Disturbance	Perceptions of sleep quality, sleep depth, and restoration associated with sleep; perceived difficulties with getting to sleep or staying asleep; and perceptions of the adequacy of and satisfaction with sleep.
Ability to Participate in Social Roles and Activities	Degree of involvement in one's usual social roles, activities and responsibilities, including work, family, friends and leisure

Adult Domain	Definition
Satisfaction with Social Roles and Activities	Satisfaction with involvement in one's usual social roles, activities and responsibilities, including work, family, friends and leisure
Stigma	Perceptions of self and publically enacted negativity, prejudice and discrimination as a result disease-related manifestations.
Communication	Perceived difficulties related to oral expression, language production, articulation, comprehension and organization.
End of Life Concerns	Issues and concerns that emerge at the end of one's life (including basic functioning across physical, social, emotional, cognitive and existential domains, as well as overall satisfaction with care and symptom palliation)
Bowel Function	Functional problems related to storage and emptying, such as incontinence or constipation, urgency, leakage or discomfort.
Urinary/Bladder Function	Functional problems related to storage and emptying, such as incontinence, urgency, leakage or discomfort.
Sexual Function	A person's overall evaluation of, satisfaction with and quality of sexual activities, including interest, discomfort, functioning and ability to achieve orgasm.

Table 4: Pediatric Domain Definitions

Pediatric Domain	Definitions
Anxiety	Unpleasant thoughts and/or feelings related to fear (e.g., fearfulness, feelings of panic), helplessness, worry and hyperarousal (e.g., tension, nervousness, restlessness).
Depression	Experience of loss and feelings of hopelessness, negative mood (e.g., sadness, guilt), decrease in positive affect (e.g., loss of interest), information-processing deficits (e.g., problems in decision-making), negative views of the self (e.g., self-criticism, worthlessness), and negative social cognition (e.g., loneliness).
Anger	Angry mood (e.g., irritability, frustration), verbal aggression, and efforts to control anger.
Fatigue	Sensations ranging from tiredness to an overwhelming, debilitating and sustained sense of exhaustion that decreases one's capacity for physical, functional, social and mental activities.
Upper Extremity - Fine Motor, ADL	One's ability to carry out various activities involving digital, manual and reach-related functions, ranging from fine motor to self-care (activities of daily living)
Lower Extremity - Mobility	One's ability to carry out various activities involving the trunk region and increasing degrees of bodily movement, ambulation, balance or endurance.

Pediatric Domain	Definitions
Applied Cognition - General Concerns	Perceived difficulties in everyday cognitive abilities such as memory, attention, concentration, processing speed and organization skill
Social Relations - Interaction with Peers	Degree of involvement with one's peers in usual social roles, activities and responsibilities
Social Relations - Interaction with Adults	Degree of involvement with adults in one's usual social roles, activities and responsibilities
Stigma	Perceptions of self and publically enacted negativity, prejudice and discrimination as a result of disease-related manifestations.
Pain	An unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Conceptually divided into components of quality (e.g. the nature, characteristics, intensity, frequency, and duration of pain), behaviors (e.g. verbal and nonverbal actions that communicate pain to others) and interference (e.g. impact of pain on physical, mental, and social activities).

2.2- Instrument Formats

Most Neuro-QOL instruments are calibrated item banks that can be administered as a computerized adaptive test (CAT) or as fixed-length short forms. The remaining are uncalibrated scales. The following instruments are available as of September 30, 2010.

Table 5: Neuro-QOL Instruments

Domain	Format Adult/Pediatric	Adult		Pediatric	
		# of Items in Bank or Scale	# of Items in Short Form	# of Items in Bank or Scale	# of Items in Short Form
Anxiety	Bank/Bank	21	8	19	8
Depression	Bank/Bank	24	8	17	8
Anger	NA/Bank	NA	NA	8	NA
Fatigue	Bank/Bank	19	8	13	8
Upper Extremity Function - Fine Motor, ADL	Bank/Scale	20	8	20	NA
Lower Extremity Function – Mobility	Bank/Scale	19	8	20	NA
Applied Cognition- Executive Function	Bank/NA	13	8	NA	NA
Applied Cognition- General Concerns	Bank/Bank	18	8	14	8
Emotional and Behavioral Dyscontrol	Bank/NA	18	8	NA	NA
Positive Affect and Well- Being	Bank/NA	23	9	NA	NA
Sleep Disturbance	Bank/NA	8	NA	NA	NA
Ability to Participate in Social Roles and Activities	Bank/NA	45	8	NA	NA
Satisfaction with Social Roles and Activities	Bank/NA	45	8	NA	NA
Social Relations - Interaction with Peers	NA/Bank	NA	NA	16	8
Social Relations - Interaction with Adults	NA/Domain Being Identified	NA	NA	9	NA
Stigma	Bank/Bank	24	8	18	8
Pain	NA/Bank	NA	NA	10	NA
Communication	Scale/NA	5	NA	NA	NA
End of Life Concerns*	Item Pool**	79		NA	NA
Bowel Function*	Item Pool**	58		NA	NA
Urinary/Bladder Function*	Item Pool**	136		NA	NA
Sexual Function*	Item Pool**	61		NA	NA

NA = not applicable

* Available in English only. All other instruments are available in English and Spanish

** These item pools are not yet available as scored instruments

2.3- Languages

Neuro-QOL instruments are available in English. Most instruments are also available in Spanish except as indicated in Table 3. Until separate calibrations are obtained on Spanish language items, instruments administered in Spanish will be scored based upon English language calibrations. Spanish instruments can utilize calibrations created in English.

2.4- Terms of Use

Neuro-QOL instruments were developed and validated by investigators under a contract to the National Institute of Neurological Disorders and Stroke (NINDS). As such, they are intended to be freely available for research purposes. There is no charge to use any of the Neuro-QOL instruments. If a user needs assistance in set-up, design, analysis or interpretation of Neuro-QOL data, appropriate charges for such help may be incurred.

All Neuro-QOL instruments are copyrighted and should not be reproduced or modified in any way without permission. If any improvements or modifications are made to these instruments, the developers and NINDS reserve the right to designate such improvements or modifications as continuing to carry the name of Neuro-QOL.

3.0- Instrument Properties

3.1- Recall Period

“The past 7 days” is the reference period for all items in the adult Anxiety, Depression, Fatigue, Applied Cognition – General Concerns, Emotional and Behavioral Dyscontrol, Sleep Disturbance, Ability to Participate in Social Roles and Activities, Satisfaction with Social Roles and Activities, and Communication Difficulty domains. Physical function items emphasize current capabilities and therefore do not employ a recall period. Item stems begin with phrases such as “Are you able to..” and “How much difficulty do you currently have.” Applied Cognition – Executive Function also implies current functioning by utilizing item stems beginning with “How much difficulty do you currently have...” Stigma and Positive Affect and Well-Being items begin with “Lately...”

For Pediatric domains, a 7-day recall period is used for Anxiety, Depression, Anger, Social Relations – Interaction with Peers, Social Relations – Interaction with Adults, Fatigue, Pain, Lower Extremity (Mobility) and Upper Extremity (Fine Motor, ADL). As with adults, the pediatric Stigma bank items begin with “Lately...” No recall period is specified for Applied Cognition – General Concerns.

3.2- Response Options

The term “response options” refers to the set of answers a respondent can choose from when responding to a question or statement. All Neuro-QOL items employ five response options (e.g., 1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much).

To the extent possible, the wording of response categories was kept consistent within banks, and a limited degree of variation in response options was used across banks. This was done to ease patient burden. Some flexibility in response choices within banks was considered important, however, to capture the range of patient experience in a domain (e.g., intensity, frequency, duration). Therefore, for example, most banks employed a common set of response options for intensity (i.e., “Not at all” to “Very much”) and frequency (i.e., “Never” to “Always”). The final response categories were pre-tested with cognitive interviews to confirm patient

comprehension, prior to field testing for item calibration. When possible, to ease responder burden, initial short forms developed from Neuro-QOL item banks comprise items with a common set of response options.

3.3- Notes on Administration

Neuro-QOL instruments were developed based on data collected on a computer platform. As such, it can safely be considered valid for internet or personal computer-based applications with screen presentations of individual items. Comparability of results obtained using paper or telephone administration should be tested in the future. On average, respondents answer 5 questions per minute, suggesting, for example, that a CAT administration of 10 banks with an average of 5 items per bank will take about 10 minutes to complete.

4.0- Selecting the Right Instrument for your Study

4.1- Domain Selection

Neuro-QOL instruments were developed to be appropriate for a range of neurological conditions. They are not disease-specific measures. Consequently, researchers will need to consider what domains of self-reported health are worth assessing within a given disease and within a given study methodology. For example, a researcher in a given condition may prioritize assessment of cognitive function when that condition is known to cause significant changes in cognitive abilities.

4.2- Instrument Type

There are two instrument types to consider when selecting a Neuro-QOL measure for your study: CAT or static short forms. CATs are administered adaptively with participants receiving a variable number of items and item content. A short form is of fixed length with all participants responding to the same items. Within these two general options are several specific considerations to guide your optimal selection. In all cases, when you create an assessment from a Neuro-QOL item bank, a score will be produced on the same common (Theta) metric which has been converted to a T-distribution based on the United States general population. The choice you make for assessment in your study should be driven by your relative interests in precision, brevity, item content, and flexibility/portability.

4.3- Precision

Precision, the conceptual inverse of error, is typically increased by adding questions from the same item bank. The amount of increase in precision gained by adding a question decreases as the number of questions increases. Therefore, a 6-item scale is much more precise than a 1-item scale, but the increase in precision gained by adding yet another 5 questions to create an 11-item scale is considerably less. Also, not all questions in a bank are equally informative, so it *matters* which question you add. This is the reason that CAT assessment will virtually always be more precise than a fixed short form of the same length. Neuro-QOL banks using CAT can achieve precision that meets standards for individual level assessment, usually with fewer than 5 questions. If precision is your main goal (such as might be the case in tracking an individual person over time to detect reliable change), then CAT (or a static short form of 8-10 items) would be an excellent choice.

4.4- Brevity

Both CAT and static short forms can be brief. CAT typically out-performs a static short form of the same length due to its iterative item selection nature, so if brevity *and* precision are desired, CAT would be the better choice. However, often brevity is desired in settings where CAT is not possible or even desired. Some applications (e.g., large sample studies seeking population estimates; large sample clinical trials that plan group comparisons) do not require the precision offered by CAT or lengthy short forms. In that case, careful selection of a small number of questions per bank (even one question per bank) will produce T-scores that can

still be referenced to the general population or a defined clinical population. Although confidence in the individual score estimates derived from very short forms is low, large group averages are reliable. Using item statistics in Assessment Center, customized short forms of any length can be created from the Neuro-QOL item banks. We have created sample short forms for each bank, generally ranging in length from 8-10 items per form. Items selected for these short forms cover the measurement range with some of the more informative questions. Each of them is suited for individual assessment in the middle range of the trait being measured. Extremes on the measurement continuum (e.g., very little fatigue or extreme fatigue) are less reliably estimated. Briefer short forms can be custom made.

4.5- Item Content

Sometimes a researcher will prefer to determine which questions in a bank are administered. Reasons for this preference can be the clinical relevance of a desired subset of items, or the lack of relevance of a subset of questions in a given target research population. Similarly, some researchers may wish to ensure that the same questions get administered at every time point in a longitudinal design. In these cases, CAT would not be desirable. The strength of CAT is in its flexibility with regard to selection and sequence of specific questions asked in any given assessment. Generally, then, only one question in the bank (the first one) administered by the CAT engine would be guaranteed to be repeated at each assessment. In these cases (desire to determine which questions get asked or desire to ask the same questions at each administration), static short forms would be the preferred option.

4.6- Flexibility/Portability

For all practical purposes, CAT administration depends upon access to computer administration (either web-based or standalone computer). Although options exist for branched assessment that approximates CAT on paper, these are not currently available for Neuro-QOL banks. Thus, any research project that does not have the capability to electronically enter participant responses in real time should select paper (or telephone) administration of static short forms.

5.0- Scoring

When data is collected through Assessment Center, Neuro-QOL CATs are automatically scored as they are being administered. Short forms administered through Assessment Center or on paper require manual scoring.

5.1- Instructions

For a given short form, each response option is assigned a value (e.g., 1=Not at all). To find the total raw score, sum the values of the response to each question. For example, for an 8-item form that includes items with 5 response options, the lowest possible raw score is 8; the highest possible raw score is 40.

You can use the conversion tables below to translate the total raw score into an IRT-based T-score for each participant. These conversions are accurate ONLY when all questions on the short form have been answered. Using Anxiety short-form as an example, which contains 8 items for both adult and pediatric versions, for adults, a raw score of 8 converts to a T-score of 36.4 with a standard error of 5.2. Thus, we can say with 95% confidence that the actual score is within twice the standard error of the T-score: $36.4 \pm 8 = 28.4$ to 44.4 . For pediatric, a raw score of 8 converts to a T-score of 37.5 with a standard error of 5.8. Thus, we can say with 95% confidence that the actual score is within twice the standard error of the T-score: $37.5 \pm 8 = 29.5$ to 45.5 .

T-score distributions rescale raw scores into standardized scores with a mean of 50 and a standard deviation (SD) of 10. Thus, a person who has a T-score of 60 is one SD above the average of the referenced populations, either the US general population or clinical populations.

Important: A higher Neuro-QOL T-score represents more of the concept being measured. For positively-worded concepts like Ability to Participate in Social Roles and Activities, a T-score of 60 is one SD better than average. By comparison, for symptoms and other negatively-worded concepts like Fatigue and Depression, a T-score of 60 is one SD worse than the averaged reference population.

Table 6: Direction of Neuro-QOL Scores

	Domains
High scores indicate <u>worse</u> (undesirable) self-reported health	Anxiety, Depression, Anger, Fatigue, Emotional and Behavioral Dyscontrol, Sleep Disturbance, Stigma, Pain
High scores indicate <u>better</u> (desirable) self-reported health	Upper Extremity Function – Fine Motor, ADL, Lower Extremity Function - Mobility, Applied Cognition – General Concerns, Applied Cognition – Executive Function, Positive Affect and Well-Being, Ability to Participate in Social Roles and Activities, Satisfaction with Social Roles and Activities, Social Relations – Interaction with Peers, Social Relations – Interaction with Adults, Communication

5.2- Scoring Tables

Use the following look-up tables to transform a raw score to a T-score. Note that they are only accurate when all questions on the short form have been answered.

Table 7a: Adult Anxiety

Anxiety 8-item Short Form (Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	36.4	5.2	25	59.3	1.8
9	42.1	2.9	26	60.1	1.8
10	44.3	2.4	27	60.9	1.8
11	45.9	2.1	28	61.8	1.8
12	47.3	2.0	29	62.6	1.7
13	48.4	1.9	30	63.4	1.7
14	49.5	1.9	31	64.2	1.7
15	50.5	1.8	32	65.1	1.8
16	51.4	1.8	33	65.9	1.8
17	52.3	1.8	34	66.8	1.8
18	53.3	1.8	35	67.8	1.9
19	54.2	1.8	36	68.9	2.0
20	55.0	1.8	37	70.0	2.1
21	55.9	1.8	38	71.5	2.3
22	56.8	1.8	39	73.3	2.7
23	57.6	1.8	40	76.8	3.8
24	58.4	1.8			

Table 7b: Adult Depression

Depression 8-item Short Form (Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	36.9	5.2	25	58.2	1.5
9	43.1	2.6	26	59.0	1.5
10	45.3	2.1	27	59.8	1.5
11	46.8	1.8	28	60.6	1.5
12	47.9	1.7	29	61.4	1.5
13	48.9	1.6	30	62.2	1.5
14	49.8	1.5	31	63.0	1.5
15	50.6	1.5	32	63.8	1.5
16	51.3	1.5	33	64.6	1.5
17	52.1	1.5	34	65.4	1.5
18	52.8	1.5	35	66.3	1.5
19	53.6	1.5	36	67.3	1.6
20	54.3	1.5	37	68.3	1.7
21	55.1	1.5	38	69.6	1.9
22	55.9	1.5	39	71.3	2.3
23	56.7	1.5	40	75.0	3.7
24	57.4	1.5			

Table 7c: Adult Fatigue

Fatigue 8-item Short Form (Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	29.5	4.4	25	52.3	1.7
9	34.1	2.7	26	53.3	1.7
10	36.5	2.2	27	54.4	1.7
11	38.2	2.0	28	55.4	1.7
12	39.5	1.9	29	56.5	1.8
13	40.7	1.8	30	57.6	1.8
14	41.8	1.7	31	58.8	1.8
15	42.8	1.7	32	59.9	1.8
16	43.8	1.7	33	61.1	1.8
17	44.7	1.7	34	62.3	1.8
18	45.6	1.7	35	63.5	1.8
19	46.5	1.7	36	64.8	1.9
20	47.4	1.7	37	66.2	2.0
21	48.4	1.7	38	67.9	2.2
22	49.3	1.7	39	70.1	2.7
23	50.3	1.7	40	74.1	4.0
24	51.3	1.8			

Table 7d: Adult Upper Extremity Function – Fine Motor, ADL

Upper Extremity Function – Fine Motor, ADL 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	12.8	2.0	25	27.3	2.0
9	13.7	2.3	26	28.0	2.0
10	14.7	2.4	27	28.7	2.0
11	15.8	2.5	28	29.5	2.0
12	16.9	2.4	29	30.2	2.1
13	18.0	2.4	30	30.9	2.1
14	19.0	2.3	31	31.7	2.1
15	19.9	2.2	32	32.6	2.2
16	20.8	2.1	33	33.5	2.3
17	21.6	2.1	34	34.5	2.4
18	22.4	2.1	35	35.6	2.7
19	23.1	2.0	36	37.1	3.2
20	23.9	2.0	37	39.3	4.2
21	24.6	2.0	38	41.2	4.5
22	25.3	2.0	39	43.7	4.7
23	26.0	2.0	40	53.8	7.8
24	26.7	2.0			

Table 7e: Adult Lower Extremity Function - Mobility

Lower Extremity Function - Mobility 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	16.5	3.0	25	35.2	2.1
9	19.2	2.8	26	36.0	2.1
10	21.1	2.6	27	36.7	2.1
11	22.6	2.4	28	37.5	2.1
12	23.9	2.3	29	38.3	2.1
13	25.1	2.3	30	39.1	2.2
14	26.2	2.2	31	39.9	2.2
15	27.2	2.2	32	40.8	2.3
16	28.1	2.1	33	41.7	2.4
17	29.0	2.1	34	42.8	2.5
18	29.9	2.1	35	43.9	2.6
19	30.7	2.1	36	45.2	2.9
20	31.5	2.1	37	46.7	3.1
21	32.2	2.1	38	48.6	3.3
22	33.0	2.1	39	51.2	3.8
23	33.7	2.0	40	58.6	6.4
24	34.5	2.1			

Table 7f: Adult Applied Cognition – Executive Function

Applied Cognition-Executive Function 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	13.1	2.2	25	31.7	2.2
9	14.4	2.5	26	32.5	2.2
10	16.1	2.7	27	33.3	2.2
11	17.9	2.7	28	34.2	2.3
12	19.5	2.6	29	35.0	2.3
13	20.8	2.6	30	35.9	2.3
14	22.0	2.5	31	36.9	2.3
15	23.1	2.4	32	37.9	2.4
16	24.1	2.4	33	38.9	2.4
17	25.1	2.3	34	40.1	2.5
18	26.0	2.3	35	41.3	2.7
19	26.8	2.2	36	42.8	2.9
20	27.7	2.2	37	44.6	3.2
21	28.5	2.2	38	46.8	3.6
22	29.3	2.2	39	50.0	4.3
23	30.1	2.2	40	57.6	6.7
24	30.9	2.2			

Table 7g: Adult Applied Cognition – General Concerns

Applied Cognition-General Concerns 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	20.0	3.4	25	37.1	1.9
9	23.0	2.6	26	37.9	1.9
10	24.5	2.4	27	38.7	1.9
11	25.8	2.2	28	39.5	1.9
12	26.9	2.0	29	40.3	1.9
13	27.8	1.9	30	41.1	1.9
14	28.7	1.9	31	41.9	1.9
15	29.5	1.8	32	42.8	1.9
16	30.3	1.8	33	43.6	1.9
17	31.1	1.8	34	44.6	2.0
18	31.8	1.8	35	45.6	2.1
19	32.6	1.8	36	46.8	2.2
20	33.3	1.8	37	48.1	2.5
21	34.1	1.9	38	49.9	2.9
22	34.8	1.9	39	52.3	3.4
23	35.6	1.9	40	59.3	6.2
24	36.3	1.9			

Table 7h: Adult Emotional and Behavioral Dyscontrol

Emotional and Behavioral Dyscontrol 8-item Short Form (Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	32.2	4.9	25	60.8	2.4
9	37.2	3.5	26	62.1	2.4
10	39.9	3.0	27	63.3	2.4
11	42.0	2.7	28	64.5	2.4
12	43.7	2.6	29	65.8	2.4
13	45.3	2.5	30	66.9	2.3
14	46.7	2.4	31	68.1	2.3
15	48.1	2.4	32	69.3	2.3
16	49.4	2.4	33	70.6	2.4
17	50.7	2.4	34	71.8	2.4
18	52.0	2.4	35	73.1	2.4
19	53.2	2.4	36	74.5	2.5
20	54.5	2.4	37	76.0	2.7
21	55.8	2.4	38	77.7	2.8
22	57.0	2.4	39	79.8	3.1
23	58.3	2.4	40	82.6	3.3
24	59.6	2.4			

Table 7i: Adult Positive Affect and Well-Being

Positive Affect and Well-Being 9-item Short Form (Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
9	26.3	3.9	27	46.3	1.5
10	30.2	2.3	28	47.2	1.5
11	32.0	1.8	29	48.1	1.5
12	33.3	1.6	30	49.0	1.4
13	34.3	1.5	31	49.9	1.4
14	35.3	1.4	32	50.7	1.4
15	36.1	1.4	33	51.5	1.4
16	37.0	1.4	34	52.3	1.4
17	37.8	1.4	35	53.2	1.4
18	38.6	1.4	36	54.0	1.4
19	39.4	1.4	37	54.9	1.4
20	40.2	1.4	38	55.8	1.5
21	41.0	1.4	39	56.8	1.5
22	41.8	1.4	40	57.8	1.5
23	42.7	1.4	41	58.8	1.5
24	43.5	1.4	42	59.9	1.6
25	44.4	1.5	43	61.3	1.9
26	45.3	1.5	44	63.3	2.4
			45	68.0	4.5

Table 7j: Adult Sleep Disturbance

Sleep Disturbance 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	32.0	5.9	25	61.6	3.4
9	36.3	5.0	26	62.8	3.4
10	39.1	4.7	27	63.9	3.4
11	41.7	4.4	28	65.1	3.4
12	43.8	4.2	29	66.4	3.4
13	45.6	4.0	30	67.6	3.5
14	47.3	3.9	31	68.9	3.5
15	48.9	3.8	32	70.3	3.5
16	50.4	3.7	33	71.7	3.6
17	51.8	3.6	34	73.2	3.6
18	53.1	3.6	35	74.7	3.7
19	54.4	3.5	36	76.4	3.8
20	55.6	3.5	37	78.2	3.9
21	56.8	3.5	38	80.2	3.9
22	58.0	3.4	39	82.2	3.8
23	59.2	3.4	40	84.2	3.5
24	60.4	3.4			

Table 7k: Adult Ability to Participate in Social Roles

Ability to Participate in Social Roles 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	24.1	3.8	25	41.3	1.4
9	27.7	2.5	26	42.0	1.4
10	29.5	2.1	27	42.7	1.4
11	30.8	1.8	28	43.4	1.4
12	31.8	1.6	29	44.0	1.4
13	32.7	1.5	30	44.7	1.4
14	33.5	1.5	31	45.4	1.4
15	34.3	1.4	32	46.1	1.4
16	35.0	1.4	33	46.8	1.4
17	35.7	1.4	34	47.5	1.5
18	36.4	1.4	35	48.3	1.5
19	37.1	1.4	36	49.2	1.6
20	37.8	1.4	37	50.2	1.8
21	38.5	1.4	38	51.6	2.2
22	39.2	1.4	39	53.4	2.6
23	39.9	1.4	40	60.2	5.8
24	40.6	1.4			

Table 7l: Adult Satisfaction w/Social Roles and Activities

Satisfaction w/Social Roles and Activities 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	28.4	4.1	25	43.2	1.3
9	32.6	2.3	26	43.7	1.3
10	34.0	2.0	27	44.2	1.3
11	35.1	1.8	28	44.7	1.3
12	35.9	1.7	29	45.2	1.3
13	36.7	1.5	30	45.8	1.4
14	37.4	1.5	31	46.3	1.4
15	38.0	1.4	32	46.9	1.4
16	38.6	1.4	33	47.5	1.4
17	39.1	1.4	34	48.2	1.5
18	39.7	1.3	35	48.9	1.5
19	40.2	1.3	36	49.8	1.6
20	40.7	1.3	37	50.7	1.8
21	41.2	1.3	38	52.0	2.1
22	41.7	1.3	39	53.7	2.5
23	42.2	1.3	40	60.5	5.7
24	42.7	1.3			

Table 7m: Adult Stigma

Stigma 8-item Short Form					
(Adult)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	39.2	5.8	25	61.6	1.9
9	45.7	3.3	26	62.4	1.9
10	47.6	3.0	27	63.2	1.9
11	49.3	2.6	28	64.0	1.9
12	50.6	2.4	29	64.8	1.9
13	51.7	2.2	30	65.7	2.0
14	52.8	2.1	31	66.6	2.0
15	53.7	2.0	32	67.5	2.0
16	54.6	2.0	33	68.5	2.1
17	55.4	2.0	34	69.6	2.1
18	56.2	1.9	35	70.8	2.2
19	57.0	1.9	36	72.2	2.3
20	57.8	1.9	37	73.7	2.4
21	58.5	1.9	38	75.6	2.6
22	59.3	1.9	39	78.1	3.0
23	60.1	1.9	40	81.5	3.5
24	60.8	1.9			

Table 7n: Pediatric Stigma

Stigma 8-item Short Form (Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	37.1	5.6	25	58.4	2.1
9	42.8	3.5	26	59.1	2.1
10	44.6	3.4	27	59.8	2.1
11	46.3	2.9	28	60.6	2.1
12	47.7	2.7	29	61.3	2.2
13	48.9	2.5	30	62.1	2.2
14	49.9	2.4	31	62.9	2.2
15	50.8	2.3	32	63.8	2.2
16	51.7	2.3	33	64.7	2.2
17	52.5	2.2	34	65.6	2.3
18	53.3	2.2	35	66.6	2.3
19	54.0	2.2	36	67.7	2.4
20	54.8	2.1	37	68.9	2.5
21	55.5	2.1	38	70.4	2.7
22	56.2	2.1	39	72.2	3.0
23	56.9	2.1	40	75.8	4.0
24	57.7	2.1			

Table 7o: Pediatric Depression

Depression 8-item Short Form (Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	36.4	5.4	25	60.7	1.9
9	42.0	3.3	26	61.8	1.9
10	44.3	2.9	27	62.8	1.9
11	46.1	2.4	28	63.8	1.9
12	47.6	2.2	29	64.7	1.8
13	48.8	2.0	30	65.7	1.8
14	49.9	1.9	31	66.6	1.8
15	50.9	1.9	32	67.5	1.8
16	51.8	1.8	33	68.5	1.8
17	52.8	1.8	34	69.4	1.9
18	53.7	1.8	35	70.5	1.9
19	54.6	1.8	36	71.6	2.1
20	55.6	1.9	37	72.9	2.2
21	56.6	1.9	38	74.5	2.5
22	57.6	1.9	39	76.3	2.8
23	58.7	1.9	40	79.4	3.6
24	59.7	1.9			

Table 7p: Pediatric Anxiety

Anxiety 8-item Short Form (Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	37.5	5.8	25	62.3	2.0
9	42.8	4.1	26	63.3	2.0
10	45.7	3.4	27	64.3	2.0
11	47.7	2.9	28	65.3	2.0
12	49.3	2.5	29	66.2	1.9
13	50.7	2.2	30	67.1	1.9
14	51.8	2.0	31	68.0	1.9
15	52.8	2.0	32	68.9	1.9
16	53.8	1.9	33	69.7	1.8
17	54.7	1.9	34	70.6	1.9
18	55.6	1.9	35	71.6	1.9
19	56.6	1.9	36	72.6	2.0
20	57.5	1.9	37	73.7	2.1
21	58.5	2.0	38	75.1	2.3
22	59.4	2.0	39	76.7	2.6
23	60.4	2.0	40	79.7	3.4
24	61.4	2.0			

Table 7q: Pediatric Social Relations-Interaction with Peers

Social Relations- Interaction with Peers 8-item Short Form (Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	18.5	3.5	25	39.8	2.2
9	21.5	3.0	26	41.0	2.1
10	23.5	2.6	27	42.2	2.1
11	25.0	2.4	28	43.4	2.1
12	26.3	2.2	29	44.6	2.0
13	27.4	2.1	30	45.7	2.0
14	28.5	2.0	31	46.8	2.0
15	29.4	2.0	32	47.9	2.0
16	30.4	2.0	33	49.0	2.1
17	31.3	2.0	34	50.2	2.1
18	32.2	2.0	35	51.4	2.2
19	33.2	2.0	36	52.8	2.3
20	34.2	2.1	37	54.4	2.5
21	35.2	2.1	38	56.4	2.9
22	36.3	2.2	39	59.1	3.5
23	37.5	2.2	40	64.5	5.3
24	38.6	2.2			

Table 7r: Pediatric Applied Cognition-General Concerns

Applied Cognition-General Concerns 8-item Short Form					
(Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	24.4	4.3	25	45.3	2.7
9	27.9	3.5	26	46.2	2.7
10	29.9	3.3	27	47.1	2.7
11	31.5	3.1	28	48.0	2.7
12	32.9	3.0	29	48.9	2.8
13	34.1	2.9	30	49.9	2.8
14	35.3	2.8	31	50.9	2.8
15	36.3	2.8	32	52.0	2.9
16	37.3	2.7	33	53.1	2.9
17	38.3	2.7	34	54.3	3.0
18	39.2	2.7	35	55.6	3.0
19	40.1	2.7	36	57.0	3.2
20	41.0	2.7	37	58.7	3.3
21	41.9	2.7	38	60.6	3.5
22	42.7	2.7	39	63.3	3.9
23	43.6	2.7	40	67.9	5.2
24	44.5	2.7			

Table 7s: Pediatric Fatigue

Fatigue 8-item Short Form					
(Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	33.3	5.7	24	61.1	3.0
9	38.4	4.6	25	62.1	3.0
10	41.7	4.2	26	63.1	3.0
11	44.2	3.9	27	64.2	3.0
12	46.2	3.7	28	65.2	3.0
13	48.0	3.6	29	66.3	3.0
14	49.5	3.5	30	67.3	3.0
15	51.0	3.4	31	68.4	3.0
16	52.3	3.3	32	69.6	3.1
17	53.5	3.2	33	70.8	3.1
18	54.7	3.2	34	72.1	3.1
19	55.8	3.1	35	73.5	3.2
20	56.9	3.1	36	75.0	3.3
21	58.0	3.1	37	76.7	3.4
22	59.0	3.1	38	78.8	3.6
23	60.1	3.0	39	81.6	3.8

Table 7t: Pediatric Pain

Pain 8-item Short Form (Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
10	38.5	5.6	31	60.7	1.5
11	45.0	3.0	32	61.2	1.5
12	47.2	2.5	33	61.8	1.5
13	48.7	2.2	34	62.3	1.5
14	49.9	2.0	35	62.8	1.5
15	51.0	1.9	36	63.3	1.5
16	51.8	1.8	37	63.9	1.5
17	52.6	1.7	38	64.4	1.5
18	53.4	1.7	39	65.0	1.5
19	54.0	1.6	40	65.6	1.6
20	54.7	1.6	41	66.2	1.6
21	55.3	1.6	42	66.8	1.6
22	55.9	1.6	43	67.5	1.6
23	56.4	1.5	44	68.2	1.7
24	57.0	1.5	45	69.0	1.7
25	57.6	1.5	46	69.9	1.8
26	58.1	1.5	47	70.9	2.0
27	58.6	1.5	48	72.2	2.2
28	59.2	1.5	49	73.9	2.5
29	59.7	1.5	50	77.4	3.6
30	60.2	1.5			

Table 7u: Pediatric Anger

Anger Short Form					
(Pediatric)					
Raw Score	T-Score	SE	Raw Score	T-Score	SE
8	35.6	5.2	25	60.1	1.8
9	41.2	3.1	26	61.2	1.8
10	43.5	2.6	27	62.2	1.8
11	45.3	2.2	28	63.3	1.7
12	46.7	2.0	29	64.3	1.7
13	47.9	1.8	30	65.2	1.6
14	49.0	1.7	31	66.1	1.6
15	50.0	1.7	32	67.0	1.6
16	51.0	1.7	33	67.9	1.6
17	51.9	1.7	34	68.9	1.6
18	52.8	1.7	35	69.9	1.7
19	53.7	1.7	36	70.9	1.7
20	54.7	1.7	37	72.1	1.9
21	55.7	1.8	38	73.5	2.1
22	56.7	1.8	39	75.3	2.5
23	57.8	1.8	40	78.5	3.5
24	59.0	1.8			

6.0- Instrument Statistics

Descriptive statistics were calculated for the Neuro-QOL measures. The following section provides summary information for each instrument including the overall calibration sample size, alpha reliability, error and reliability at various scale (T) scores, and raw and scale (T) scores for different percentiles. All item banks were calibrated using the Graded Response Model. For Neuro-QOL scales (e.g., pediatric Upper Extremity Function - Fine Motor, ADL and Lower Extremity Function - Mobility, summation of total raw scores is recommended.

6.1- Neuro-QOL Item Bank Statistics

Table 8: Adult Neuro-QOL Item Bank Standard Error and Reliability by T-scores

Item Bank	N		T-Scores								
			10	20	30	40	50	60	70	80	90
Anxiety	513	SE	9.7	8.8	5.9	2.4	1.4	1.3	1.5	3.4	6.9
		Reliability	0.06	0.23	0.65	0.94	0.98	0.98	0.98	0.88	0.53
Depression	513	SE	10.0	9.70	7.1	2.2	1.0	1.0	1.3	5.3	9.4
		Reliability	0.00	0.05	0.49	0.95	0.99	0.99	0.98	0.72	0.12
Fatigue	511	SE	9.9	8.90	3.6	1.4	1.3	1.3	1.6	4.2	8.5
		Reliability	0.02	0.22	0.87	0.98	0.98	0.98	0.98	0.83	0.28
Upper Extremity - Fine motor, ADL	1095	SE	2.8	1.4	1.2	1.7	4.7	8.9	9.9	10.0	10.0
		Reliability	0.92	0.98	0.99	0.97	0.78	0.21	0.02	0.00	0.00
Lower Extremity - Mobility	1046	SE	4.8	1.8	1.4	1.3	1.9	5.1	9.2	10.0	10.0
		Reliability	0.77	0.97	0.98	0.98	0.96	0.74	0.15	0.01	0.00
Applied Cognition - Executive Function	1109	SE	3.2	2.00	1.7	1.9	3.3	6.6	9.3	9.9	10.0
		Reliability	0.90	0.96	0.97	0.96	0.89	0.56	0.13	0.02	0.00
Applied Cognition - General Concerns	1109	SE	6.4	2.30	1.3	1.3	1.9	5.3	9.0	9.9	10.0
		Reliability	0.59	0.95	0.98	0.98	0.96	0.72	0.20	0.02	0.00
Emotional and Behavioral Dyscontrol	511	SE	9.8	8.5	4.7	2.2	1.8	1.8	1.8	2.2	4.0
		Reliability	0.05	0.28	0.78	0.95	0.97	0.97	0.97	0.95	0.84
Positive Affect and Well-being	513	SE	9.5	5.60	1.6	1.0	1.0	1.1	3.4	8.7	9.9
		Reliability	0.10	0.69	0.98	0.99	0.99	0.99	0.88	0.24	0.01
Sleep Disturbance	1087	SE	9.5	8.4	6.4	4.3	3.5	3.2	3.3	3.9	5.3
		Reliability	0.09	0.30	0.60	0.81	0.88	0.90	0.89	0.85	0.72
Ability to Participate in Social Roles and Activities	549	SE	9.2	4.5	1.0	0.6	0.6	3.0	8.7	9.9	10.0
		Reliability	0.15	0.80	0.99	0.99	0.99	0.91	0.24	0.02	0.00
Satisfaction with Social Roles and Activities	549	SE	9.7	6.4	1.5	0.6	0.7	3.4	9.4	10.0	10.0
		Reliability	0.06	0.59	0.98	0.99	0.99	0.88	0.12	0.00	0.00
Stigma	511	SE	9.9	9.7	8.3	4.1	1.5	1.2	1.3	2.3	5.6
		Reliability	0.01	0.06	0.31	0.84	0.98	0.99	0.98	0.95	0.69

- Higher scores indicate more of that domain. A T-Score distribution has a mean of 50 and standard deviation of 10. SE is on the T-score metric and computed based on the Fisher information conditional on T-score. Reliability is approximated based on the conditional SE.

Table 9: Adult Neuro-QOL Item Bank Calibration Sample T-Score Means and Standard Deviations, and Distributions by Percentile

Item Bank	# Items	N	Mean	SD	P5	P10	P25	P50	P75	P90	P95
Anxiety	21	513	48.93	9.48	30.98	36.01	42.22	48.93	56.11	60.94	63.16
Depression	24	513	47.68	9.09	32.88	32.88	41.58	47.47	54.66	60.00	62.06
Fatigue	19	511	49.76	9.93	32.88	36.45	42.82	50.01	56.95	61.55	65.64
Upper Extremity - Fine motor, ADL	20	1095	45.12	10.85	27.28	31.05	37.42	45.10	57.00	57.00	57.00
Lower Extremity – Mobility	19	1046	47.03	9.91	30.54	33.96	39.77	46.83	54.30	62.39	62.39
Applied Cognition - Executive Function	13	1109	47.76	9.75	31.06	35.01	41.21	47.76	54.59	60.46	60.46
Applied Cognition - General Concerns	18	1109	46.85	9.45	31.44	34.91	40.36	46.62	53.02	62.49	62.49
Emotional and Behavioral Dyscontrol	18	511	49.88	9.67	34.09	38.17	43.49	49.57	56.23	62.28	64.81
Positive Affect and Well-being	23	513	51.28	9.82	36.03	38.78	45.69	51.80	57.67	63.17	68.32
Sleep Disturbance	8	1087	49.98	9.21	35.71	38.04	43.61	49.81	56.27	61.69	65.18
Ability to Participate in Social Roles and Activities	45	549	50.43	9.56	36.10	38.62	42.79	49.04	58.58	64.91	64.91
Satisfaction with Social Roles and Activities	45	549	50.42	9.52	36.06	38.31	42.81	49.23	58.74	63.94	63.94
Stigma	24	511	49.70	9.47	35.62	35.62	41.68	50.49	56.48	61.37	64.39

- T-score means, standard deviations and T-scores by percentile are computed for the calibration sample to describe this sample.

Table 10: Pediatrics Neuro-QOL Item Bank Standard Error and Reliability by T-scores

Item Bank	N		T-Scores								
			10	20	30	40	50	60	70	80	90
Applied Cognition – General Concerns	171	SE	8.9	5.4	2.5	2.0	2.1	2.5	5.2	8.9	9.9
		Reliability	0.20	0.71	0.94	0.96	0.96	0.94	0.73	0.22	0.03
Anxiety	513	SE	10.0	9.7	8.1	3.8	1.4	1.3	1.3	2.6	7.1
		Reliability	0.01	0.06	0.35	0.86	0.98	0.98	0.98	0.93	0.50
Depression	513	SE	9.8	8.9	6.3	3.0	1.3	1.4	1.3	3.0	7.9
		Reliability	0.04	0.21	0.61	0.91	0.98	0.98	0.98	0.91	0.38
Fatigue	171	SE	9.8	8.5	5.5	3.4	2.5	2.3	2.4	3.1	6.0
		Reliability	0.05	0.28	0.70	0.88	0.94	0.95	0.94	0.90	0.64
Pain	171	SE	10.0	10.0	9.8	5.7	1.8	1.5	1.7	5.5	9.8
		Reliability	0.00	0.00	0.04	0.67	0.97	0.98	0.97	0.70	0.05
Stigma	168	SE	10.0	9.9	8.4	3.4	1.5	1.4	1.7	4.2	8.9
		Reliability	0.00	0.02	0.30	0.89	0.98	0.98	0.97	0.83	0.20
Social relations – Interaction with Peers	513	SE	5.4	2.4	1.5	1.7	1.6	2.8	6.8	9.5	9.9
		Reliability	0.71	0.94	0.98	0.97	0.97	0.92	0.54	0.11	0.01
Anger	513	SE	10.0	10.0	8.9	3.4	1.5	1.8	1.5	4.7	9.4
		Reliability	0.00	0.01	0.22	0.88	0.98	0.97	0.98	0.78	0.11

- Higher scores indicate more of that domain. A T-Score distribution has a mean of 50 and standard deviation of 10. SE is on the T-score metric and computed based on the Fisher information conditional on T-score. Reliability is approximated based on the conditional SE.

Table 11: Neuro-QOL Pediatric Item Bank Calibration Sample T-Score Means and Standard Deviations, and Distributions by Percentile

Item Bank	# Items	N	Mean	SD	P5	P10	P25	P50	P75	P90	P95
Applied Cognition – General Concerns	14	171	50.03	9.70	30.02	37.28	44.92	51.51	56.13	60.17	62.99
Anxiety	19	513	49.89	9.61	35.15	35.15	42.25	49.62	55.72	63.56	66.15
Depression	17	513	49.88	9.68	32.01	36.77	43.31	49.63	56.98	62.40	65.85
Fatigue	13	171	49.98	9.55	35.17	38.59	43.96	49.15	56.00	61.58	64.27
Pain	10	171	49.68	9.21	38.53	38.53	39.25	49.46	56.23	61.56	64.17
Stigma	18	168	49.55	9.51	35.11	35.11	42.71	49.26	54.84	59.77	68.11
Social relations – Interaction with Peers	16	513	50.09	9.68	35.50	38.04	43.38	49.28	56.52	63.54	67.12
Anger	8	513	49.91	9.59	35.61	35.61	43.33	49.91	57.31	61.55	66.17

- T-score means, standard deviations and T-scores by percentile are computed for the calibration sample to describe this sample.

6.2- Item Statistics

Item-level statistics were calculated for all Neuro-QOL items, including the frequency of endorsement for each response category is reported as well as the mean score and standard deviation, alpha reliability, adjusted alpha reliability, item total correlation, and adjusted item total correlations.

Using MULTILOG and other software as needed, the following information was calculated within an Item Response Theory framework when sample size was greater than 500: 1) item fit indices, $S-X^2$ and $S-G^2$ statistics developed by Orlando & Thissen; 2) exhibition of differential item function on conditions of gender, age, education and diagnosis; 3) item information function curves to demonstrate measurement precision across the continuum of interest; 4) response category characteristic curves of each item; and 5) parameter estimations including slope and threshold values. For domains with a sample size less than 500, Rasch analysis was used.

There are several hundred calibrated and uncalibrated items in the Neuro-QOL system. Detailed item statistics can be found in the Appendix (Technical Report).