Quality of Life in Neurological Disorders

Scoring Manual

Version 6.1

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Scoring Options

When data are collected through the Assessment Center API (including users of the API like REDCap), Neuro-QoL computer adaptive tests (CATs) and short forms are automatically scored. When data are collected on paper or in other data collection systems, you can either utilize the Scoring Service or calculate scores by hand.

Scoring Service

The Scoring Service is a free, web-based application that calculates scores using item response theory. Each response to each item is utilized. It is the most accurate scoring method. The output of the Scoring Service includes Theta, T-score, and standard error for each respondent at each time point.

How to use the HealthMeasures Scoring Service

1. Download the Input Template from the top right corner of the website.
2. Add your data (all respondents' individual answers to questions) for one Neuro-QoL measure to the template (multiple timepoints are okay).
3. Determine how much data is missing. In order to produce a precise score, a respondent must answer at least 4 items in measures that include 4 or more items. If a precise score is required, remove respondents who answered less than 4 items from the input template and do not calculate a T-score.
4. Upload your spreadsheet to the HealthMeasures Scoring Service (if this is your first time, register as a new user).
5. Access your email to receive a spreadsheet with calculated scores.

The HealthMeasures Scoring Service is especially useful when:

- You administered a short form, but not all participants answered every question
- Different groups of participants responded to different items
- You have created a new custom short form using a subset of items from one Neuro-QoL item bank

Manual Scoring

If you are not able to use the Scoring Service, you can calculate scores by hand. This is only available for existing short forms. CATs and custom short forms you constructed by selecting items from an item bank cannot use manual scoring.

Instructions for Manual Scoring

For a given short form, each response option is assigned a value (e.g., 1=Not at all). The PDF version of that measure has the correct values for each response option. Calculate a total summed raw score for each respondent. 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 ranging from 1 to 5, the lowest possible raw score is 8 (8 x 1); the highest possible raw score is 40 (8 x 5).

Use the conversion tables below to translate the total raw score into an IRT-based T-score for each participant. These conversions are accurate when all questions on the short form have been answered. Using the 8-item Anxiety short-form for adults as an example, a raw score of 8 converts to a T-score of 36.4 with a standard error of 5.2. In order to calculate the 95% confidence interval for a score, you should use the following formula: T-Score +/- (1.96 x SE). Thus, for this example, we can say with 95% confidence that the actual score is within 1.96 x 5.2 or T- Score= 36.4 +/- 10.2 = 26.2 to 46.6. All English and Spanish versions of Neuro-QoL can be manually scored using the same conversion tables, except for Adult Ability to Participate in Social Roles and Activities. This measure has separate tables for English and Spanish.

Managing Missing Data

A score can be approximated if a participant skips a question. If items are missing, first check how many items

were answered. For short forms with at least 5 items, confirm that 4 or 50% of items, whichever is greater, have been answered. A 10-item short form can be scored as long as the participant answered at least 5 items. After confirming that enough responses were provided, sum the response scores from the items that were answered. Multiply this sum by the total number of items in the short form. Finally, divide by the number of items that were answered. For example, if a respondent answered 5 of 8 questions and answered all items with the second lowest response option (2), you would sum all responses (10), multiply by the number of items in the short form (8) and divide by the number of items that were actually answered (5). Here (10x8)/5=16. If the result is a fraction, round to the nearest whole number. This is a prorated raw score. However, this prorated score should be used with caution as the advantages of IRT calibrations and their contribution to precision is lost in the process.

Scoring Scales (Uncalibrated Sets of Items)

Scales (i.e., uncalibrated sets of items) can be scored by summing the values of the response to each item (i.e., finding the total raw score). For the 20-item pediatric Lower Extremity Function - Mobility, and Upper Extremity Function scales, the range of responses is 0 to 4, with 0 being the worst possible total score and 80 being the best. A score is obtained by adding up the values of the response to each question, then multiplying the total sum by 100 and dividing by 80, or (summed score x 100)/80.

If there are missing responses, multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered, to obtain a prorated score. However, as explained above, this should be done only if at least half of the items were completed (e.g., at least 10 of the 20 items were answered). In the case of the adult 5-item Communication scale, when all five items are answered, the score is obtained by adding up the values of the response to each question, then subtracting 5 from the total sum, multiplying by 100 and dividing by 20, or (Summed score - 5) X100/20. In the case of 4 out of 5 questions being answered, a score can still be derived by prorating the sum score first, and then converting to the 0-100 scale. The prorated sum is obtained by multiplying the sum of the item scores by 5, then dividing by 4. Then, subtract 5 from the total prorated sum, multiply by 100 and divide by 20. Thus, when 4 of 5 items were answered, the 0-100 score is computed algebraically as:

[(Raw sum score X 5 / 4) – 5] X 100/20

We do not recommend prorating 5- or 6-item scales when fewer than 4 questions have been answered. For scales longer than 6 items, we do not recommend prorating when fewer than 50% of the total number of questions have been answered.

Meaning of T-Scores

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 reference population, 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.

Reference Populations

- For adults, a clinical reference population was used for Stigma, Fatigue, Emotional and Behavioral Dyscontrol, and Sleep Disturbance measures.
- For the HDQLIFE™ measures, a large sample of individuals with Huntington Disease was used as a

reference population.

- For the TBI-CareQOL measures, caregivers of people with traumatic brain injury were used as a reference population.
- For the Medication Adherence measures, a large sample of individuals with type 2 diabetes mellitus was used as a reference population.
- All other adult Neuro-QoL measures used a general population reference sample.
- For children, a clinical reference population was used for stigma and pain measures.
- All other pediatric measures used a general reference population.

Table 1: Direction of Neuro-QoL Scores

	Domains		
	Neuro-QoL	**HDQLIFE**	**TBI-CareQOL**
High scores indicate worse (undesirable) self-reported health	• Anger • Anxiety • Depression • Emotional and Behavioral Dyscontrol • Fatigue • Low Blood Pressure Impact on Health-Related Quality of Life • Pain • Sleep Disturbance • Stigma	• Chorea • Concern with Death and Dying • Speech Difficulties • Swallowing Difficulties	• Caregiver-Specific Anxiety • Caregiver Strain • Caregiver Vigilance • Emotional Suppression • Feelings of Loss • Feelings of Loss – Self • Feeling Trapped • Military Health Care Frustration
High scores indicate better (desirable) self-reported health	• Upper Extremity Function – Fine Motor, ADL • Lower Extremity Function – Mobility • Cognitive 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 • Medication Adherence	• End of Life Planning	

Low Blood Pressure Impact on Health-Related Quality of Life (LBP-HRQOL)

The Low Blood Pressure Impact on Health-Related Quality of Life (LBP-HRQOL) measures evaluate how symptoms experienced by individuals with spinal cord injury, under conditions of low blood pressure, affect their health-related quality of life (HRQOL). It is intended to be used with individuals with spinal cord injury, not the general population. The LBP-HRQOL measures were developed through a separate NIH sponsored research project. The measures were later adopted into Neuro-QoL. The item bank was developed with a small exploratory sample. Consequently, the CAT administration algorithm is a little different from other Neuro-QoL measures. This means that the Neuro-QoL LBP-HRQOL CAT tends to be a little longer than other Neuro-QoL CATs.

Medication Adherence

The Medication Adherence measures within the Neuro-QoL measurement system assess the knowledge and ability of participants to take medications as prescribed, including getting prescriptions filled on time and taking medications at the correct time. The Medication Adherence measure was developed through a separate NIH sponsored research project. The measures were later adopted into Neuro-QoL. The item bank was developed with a small exploratory sample. Consequently, the CAT administration algorithm is a little different from other Neuro-QoL measures. This means that the Neuro-QoL Medication Adherence CAT tends to be a little longer than other Neuro-QoL CATs.

HDQLIFE

HDQLIFE is a set of self-report measures within the Neuro-QoL measurement system that assesses the health-related quality of life (HRQOL) of adults with Huntington disease (HD). The HDQLIFE measures were developed through a collaborative, multi-site NIH-sponsored research project to construct a psychometrically-sound and clinically-relevant health-related quality of life measurement tool for individuals with HD. HDQLIFE is comprised of item banks and scales that evaluate symptoms and concerns important to those with HD. The HDQLIFE measures are intended for use in both clinical trials and clinical practice.

TBI-CareQOL

TBI-CareQOL is a set of self-report measures within the Neuro-QoL measurement system that assesses the health-related quality of life (HRQOL) of caregivers of adults with traumatic brain injury (TBI). The TBI-CareQOL measures were developed through a collaborative, multi-site NIH-sponsored research project to construct a psychometrically-sound and clinically-relevant health-related quality of life measurement tool for caregivers of individuals with TBI. TBI-CareQOL is comprised of item banks and scales that evaluate symptoms and concerns important to caregivers. The TBI-CareQOL measures are intended for use in both clinical trials and clinical practice.

Version Differences

Some Neuro-QoL measures have multiple versions (e.g., version 1.0, version 2.0). Differences between versions are described below.

- Cognitive Function: Instead of two item banks (version 1) to assess adult cognitive function (Applied Cognition – Executive Function and Applied Cognition – General Concerns), version 2 has a single Cognitive Function item bank comprised of items measuring both executive function and general concerns. Additionally, Cognitive Function v2.0 items were recalibrated using data obtained from a general population sample. Consequently, scores from different versions of these domains cannot be compared. Cognitive Function v2.0 is recommended over v1.0. Adult Applied Cognition-Executive Function. Adult and Pediatric Applied Cognition-General Concerns instruments are available upon request.

- Pediatric Fatigue: Version 2.1 pediatric Fatigue was recalibrated using data obtained from a general population sample. Consequently, scores from different versions of pediatric fatigue cannot be compared. Pediatric Fatigue v2.1 is recommended. Pediatric Fatigue v2.0 is available upon request.

Scoring Tables

Use the following look-up tables to transform a raw total summed score to a T-score. Note that they are only accurate when all questions on the short form have been answered or you have prorated the score to account for missing responses (see instructions above). Approximations can be estimated by prorating the raw sum score based upon those questions that are answered; however this diminishes the advantages of IRT scoring.

Neuro-QoL

Table 1: Adult Ability to Participate in Social Roles and Activities (English)

Ability to Participate in Social Roles and Activities 8-item Short Form (Adult-English)					
Raw Summed Score	T-Score	SE	Raw Summed 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 2: Adult Ability to Participate in Social Roles and Activities (Spanish)

Ability to Participate in Social Roles and Activities 7-item Short Form (Adult-Spanish)					
Raw Summed Score	T-Score	SE	Raw Summed Score	T-Score	SE
7	24.5	3.9	22	41.6	1.5
8	28.2	2.5	23	42.4	1.5
9	30.0	2.1	24	43.2	1.5
10	31.4	1.8	25	43.9	1.5
11	32.6	1.7	26	44.7	1.5
12	33.5	1.6	27	45.5	1.5
13	34.4	1.5	28	46.2	1.5
14	35.2	1.5	29	47.0	1.5
15	36.0	1.5	30	47.9	1.6
16	36.8	1.5	31	48.8	1.7
17	37.6	1.5	32	49.9	1.9
18	38.4	1.5	33	51.3	2.3
19	39.2	1.5	34	53.2	2.6
20	40.0	1.5	35	60.1	5.8
21	40.8	1.5			

Note: Items NQPRF03 (I am able to do all of my regular family activities.) and NQPRF30 (I have to limit the things I do for fun outside my home.) were removed from the Spanish version due to dimensionality issues. NQPRF03 was in the SF, so the Spanish SF has one less item than the English SF.

Table 3: Adult Anxiety

Anxiety 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 4: Adult Applied Cognition – Executive Function v1.0

Applied Cognition-Executive Function v1.0 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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			

For version 1.0 instrument only. Version 2.0 instrument users should refer to the v2.0 scoring tables.

Table 5: Adult Applied Cognition – General Concerns v1.0

Applied Cognition-General Concerns v1.0 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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			

For version 1.0 instruments only. Version 2.0 instrument users should refer to the v2.0 scoring tables.

Table 6: Adult Cognitive Function v2.0

Cognitive Function v2.0 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed Score	T-Score	SE
8	17.3	4.3	25	39.9	2.6
9	20.4	3.8	26	40.9	2.6
10	22.6	3.5	27	41.9	2.6
11	24.4	3.3	28	42.9	2.6
12	25.9	3.1	29	43.9	2.7
13	27.3	3	30	44.9	2.7
14	28.6	2.9	31	46	2.7
15	29.8	2.8	32	47.1	2.7
16	30.9	2.7	33	48.3	2.8
17	32	2.7	34	49.6	2.8
18	33	2.6	35	50.9	2.9
19	34	2.6	36	52.4	3.1
20	35	2.6	37	54.2	3.3
21	36	2.6	38	56.3	3.7
22	37	2.6	39	59	4.2
23	37.9	2.6	40	64.2	5.7
24	38.9	2.6			

Table 7: Adult Depression

Depression 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 8: Adult Emotional and Behavioral Dyscontrol

Emotional and Behavioral Dyscontrol 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 9: Adult Fatigue

Fatigue 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 10: Adult Low Blood Pressure Impact on Health-Related Quality of Life

Low Blood Pressure Impact on Health-Related Quality of Life 10-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed Score	T-Score	SE
10	35.7	5.9	27	61.9	2.9
11	40.8	4.6	28	62.9	2.9
12	43.1	4.3	29	63.8	2.9
13	45.3	3.9	30	64.8	2.9
14	47.1	3.7	31	65.8	2.9
15	48.7	3.5	32	66.8	2.9
16	50.1	3.3	33	67.8	2.9
17	51.4	3.2	34	68.9	3.0
18	52.6	3.2	35	70.0	3.0
19	53.7	3.1	36	71.1	3.0
20	54.8	3.0	37	72.3	3.0
21	55.9	3.0	38	73.5	3.1
22	57.0	3.0	39	74.8	3.2
23	58.0	3.0	40	76.3	3.3
24	59.0	3.0	41	78.0	3.4
25	60.0	2.9	42	79.9	3.6
26	60.9	2.9	43	82.4	3.7

Table 11: Adult Lower Extremity Function – Mobility

Lower Extremity Function - Mobility 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 12: Adult Medication Adherence

Medication Adherence		
Raw Summed Score	T-score	SE
6	14.7	3.5
7	16.2	3.8
8	17.8	4.1
9	19.6	4.3
10	21.2	4.4
11	22.9	4.4
12	24.6	4.4
13	26.2	4.4
14	27.9	4.5
15	29.5	4.5
16	31.1	4.5
17	32.8	4.4
18	34.5	4.4
19	36.1	4.4
20	37.9	4.4
21	39.6	4.4
22	41.4	4.4
23	43.2	4.4
24	45.1	4.5
25	47.1	4.6
26	49.3	4.7
27	51.6	4.9
28	54.4	5.2
29	57.2	5.4
30	62.6	6.5

Table 13: Adult Positive Affect and Well-Being

Positive Affect and Well-Being 9-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 14: Adult Satisfaction with Social Roles and Activities

Satisfaction w/Social Roles and Activities 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 15: Adult Sleep Disturbance

Sleep Disturbance 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 16: Adult Stigma

Stigma 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 17: Adult Upper Extremity Function – Fine Motor, Activities of Daily Living

Upper Extremity Function – Fine Motor, ADL 8-item Short Form (Adult)					
Raw Summed Score	T-Score	SE	Raw Summed 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 18: Pediatric Anger

Anger Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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			

Table 19: Pediatric Anxiety

Anxiety 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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 20: Pediatric Cognitive Function

Cognitive Function 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed Score	T-Score	SE
8	21.4	4.1	25	41.3	2.2
9	24.6	3.2	26	42.2	2.2
10	26.5	2.9	27	43.1	2.2
11	28.1	2.6	28	44.0	2.2
12	29.4	2.5	29	45.0	2.3
13	30.5	2.4	30	46.0	2.3
14	31.6	2.3	31	47.0	2.3
15	32.6	2.2	32	48.1	2.3
16	33.5	2.2	33	49.2	2.3
17	34.4	2.2	34	50.4	2.4
18	35.3	2.2	35	51.7	2.4
19	36.2	2.2	36	53.1	2.5
20	37.0	2.2	37	54.7	2.6
21	37.9	2.2	38	56.6	3.0
22	38.7	2.2	39	59.2	3.5
23	39.6	2.2	40	64.5	5.3
24	40.4	2.2			

Table 21: Pediatric Depression

Depression 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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 22: Pediatric Fatigue v1.0

Fatigue v1.0 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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

For version 1.0 instruments only. Version 2.0 instrument users should refer to the v2.0 scoring tables.

Table 23: Pediatric Fatigue v2.1 (8-item version)

Fatigue v2.1 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed Score	T-Score	SE
8	33.9	5.7	25	61.6	2.2
9	39.1	4.5	26	62.5	2.2
10	42.8	3.7	27	63.4	2.2
11	45.4	3.3	28	64.3	2.2
12	47.4	3.0	29	65.2	2.2
13	49.1	2.8	30	66.1	2.2
14	50.5	2.6	31	67.0	2.2
15	51.8	2.5	32	68.0	2.2
16	53.0	2.4	33	68.9	2.2
17	54.1	2.3	34	70.0	2.3
18	55.1	2.3	35	71.1	2.3
19	56.1	2.2	36	72.3	2.4
20	57.0	2.2	37	73.6	2.5
21	58.0	2.2	38	75.2	2.7
22	58.9	2.2	39	77.1	3.0
23	59.8	2.2	40	80.3	3.9
24	60.7	2.2			

Table 24: Pediatric Pain

Pain 10-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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 25: Pediatric Social Relations-Interaction with Peers

Social Relations- Interaction with Peers 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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 26: Pediatric Stigma

Stigma 8-item Short Form (Pediatric)					
Raw Summed Score	T-Score	SE	Raw Summed 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			

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Table 27: HDQLIFE Chorea

Chorea		
Raw Summed Score	T- Score	SE
6	42	6.37
7	50	3.03
8	52	2.67
9	54	2.34
10	55	2.20
11	56	2.02
12	57	1.94
13	57	1.90
14	58	1.87
15	59	1.84
16	60	1.83
17	60	1.83
18	61	1.82
19	61	1.81
20	62	1.82
21	63	1.83
22	63	1.84
23	64	1.86
24	65	1.90
25	65	1.96
26	66	2.07
27	67	2.20
28	68	2.38
29	70	2.56
30	74	3.95

Table 28: HDQLIFE Concern with Death and Dying

Concern with Death and Dying		
Raw Summed Score	T- Score	SE
6	36	6.27
7	41	5.03
8	44	4.76
9	46	4.46
10	48	4.38
11	51	4.01
12	52	3.69
13	54	3.5
14	56	3.48
15	57	3.48
16	59	3.44
17	60	3.38
18	61	3.35
19	63	3.35
20	64	3.38
21	65	3.38
22	67	3.37
23	68	3.36
24	70	3.41
25	71	3.48
26	73	3.66
27	74	3.71
28	76	3.86
29	77	4.03
30	80	4.64

Table 29: HDQLIFE End of Planning – Scoring for Full Scale

End of Life Planning					
Raw Summed Score	T-Score	SE*	Raw Summed Score	T-Score	SE*
16	24	5.6	38	52	3.1
17	27	5.2	39	53	3.2
18	29	4.8	40	54	3.3
19	31	4.7	41	55	3.4
20	32	4.5	42	56	3.6
21	34	4.3	43	57	3.7
22	35	4.1	44	58	3.9
23	37	3.9	45	59	4.1
24	38	3.8	46	60	4.3
25	39	3.7	47	61	4.5
26	40	3.6	48	63	4.7
27	42	3.5	49	64	4.9
28	43	3.4	50	65	5.0
29	44	3.3	51	67	5.2
30	45	3.2	52	68	5.4
31	46	3.1	53	70	5.6
32	46	3.1	54	72	5.8
33	47	3.0	55	74	5.9
34	48	3.0	56	75	6.1
35	49	3.0	57	78	6.2
36	50	3.0	58	80	6.5
37	51	3.1	59	82	6.7
*SE = Standard Error on T-score metric					

Note: All items must be answered in order to produce a valid score using the scoring table; this includes answering something other than "Not Applicable" for the Child care planning item.

Table 30: HDQLIFE End of Life Planning – Scoring for Subscales

End of Life Planning							
Legal Planning Items		**Preferences for Care**		**Death and Dying Preferences**		**Financial Planning**	
Raw Summed Score	T-Score	Raw Summed Score	T-Score	Raw Summed Score	T-Score	Raw Summed Score	T-Score
3	33	3	41	5	34	4	31
4	39	4	48	6	39	5	35
5	43	5	53	7	42	6	39
6	45	6	56	8	45	7	41
7	48	7	59	9	47	8	44
8	49	8	62	10	49	9	46
9	51	9	66	11	52	10	49
10	54	10	69	12	54	11	52
11	55	11	74	13	56	12	55
12	61	12	78	14	59	13	58
				15	61	14	63
				16	64		
				17	68		

Legal Planning Items: Advanced directive, Health care power of attorney, Living will

Preferences for Care Items: Nursing home care, Palliative care, Hospice care

Death and Dying Preferences Items: Location of death preferences, Conversations about death and dying, Resuscitation preference, Funeral arrangements, Preference about death

Financial Planning Items: Life insurance, Finances, Estate planning, Support to make decisions

Note: The Child care planning item is not included in any of the subscales.

Table 31: HDQLIFE Speech Difficulties

Speech Difficulties		
Raw Summed Score	T- Score	SE
6	38	5.61
7	44	3.19
8	47	2.50
9	49	2.18
10	50	1.97
11	51	1.89
12	52	1.85
13	54	1.83
14	55	1.81
15	55	1.80
16	56	1.78
17	57	1.75
18	58	1.75
19	59	1.74
20	60	1.72
21	61	1.72
22	61	1.74
23	62	1.75
24	63	1.80
25	64	1.91
26	65	2.02
27	66	2.20
28	68	2.43
29	70	3.06
30	74	4.37

Table 32: HDQLIFE Swallowing Difficulties

Swallowing Difficulties		
Raw Summed Score	T- Score	SE
6	41	6.24
7	49	3.30
8	51	2.83
9	53	2.55
10	54	2.39
11	55	2.19
12	56	2.09
13	57	2.04
14	58	2.01
15	59	1.99
16	60	1.98
17	61	1.97
18	62	1.95
19	63	1.93
20	63	1.93
21	64	1.93
22	65	1.93
23	66	1.95
24	67	1.99
25	68	2.05
26	69	2.17
27	71	2.33
28	73	2.80
29	77	4.08

Note: One item collapses responses categories, thus 29 is the maximum raw score.

Table 33: TBI-CareQOL Caregiver – Specific Anxiety

Caregiver-Specific Anxiety		
Raw Summed Score	T- Score	SE
6	33.92	5.26
7	39.00	3.71
8	41.28	3.43
9	43.35	3.07
10	45.05	2.91
11	46.62	2.78
12	48.07	2.72
13	49.45	2.69
14	50.81	2.68
15	52.14	2.70
16	53.46	2.70
17	54.74	2.71
18	56.00	2.71
19	57.24	2.71
20	58.49	2.70
21	59.75	2.70
22	61.02	2.69
23	62.32	2.70
24	63.66	2.75
25	65.06	2.82
26	66.57	2.97
27	68.16	3.13
28	70.10	3.45
29	72.02	3.68
30	75.57	4.50

Table 34: TBI-CareQOL Caregiver Strain

Caregiver Strain		
Raw Summed Score	T- Score	SE
6	32.13	5.08
7	36.93	3.71
8	39.21	3.46
9	41.34	3.11
10	43.14	2.94
11	44.78	2.83
12	46.31	2.78
13	47.78	2.78
14	49.23	2.80
15	50.67	2.82
16	52.09	2.84
17	53.48	2.85
18	54.85	2.85
19	56.22	2.84
20	57.61	2.83
21	59.01	2.80
22	60.40	2.78
23	61.81	2.78
24	63.25	2.81
25	64.76	2.90
26	66.40	3.04
27	68.22	3.24
28	70.26	3.53
29	72.57	3.87
30	76.12	4.62

Table 35: TBI-CareQOL Caregiver Vigilance

Caregiver Vigilance		
Raw Summed Score	T- Score	SE
6	30.81	5.01
7	35.23	3.73
8	37.44	3.41
9	39.32	3.11
10	40.97	2.88
11	42.47	2.72
12	43.84	2.60
13	45.12	2.53
14	46.34	2.50
15	47.55	2.49
16	48.76	2.50
17	49.97	2.50
18	51.18	2.51
19	52.40	2.52
20	53.64	2.53
21	54.91	2.53
22	56.19	2.52
23	57.48	2.53
24	58.82	2.55
25	60.23	2.61
26	61.75	2.72
27	63.44	2.89
28	65.38	3.17
29	67.71	3.54
30	71.78	4.70

Table 36: TBI-CareQOL Emotional Suppression

Emotional Suppression		
Raw Summed Score	T- Score	SE
6	25.51	4.44
7	29.50	3.56
8	32.05	3.26
9	34.13	3.09
10	35.98	2.99
11	37.67	2.92
12	39.27	2.89
13	40.80	2.87
14	42.29	2.86
15	43.77	2.86
16	45.24	2.86
17	46.72	2.86
18	48.20	2.86
19	49.70	2.86
20	51.25	2.87
21	52.87	2.90
22	54.55	2.92
23	56.29	2.94
24	58.07	2.96
25	59.91	2.97
26	61.86	2.99
27	63.94	3.02
28	66.24	3.14
29	68.96	3.47
30	73.08	4.48

Table 37: TBI-CareQOL Feelings of Loss – Person with TBI

Feelings of Loss - Person with TBI		
Raw Summed Score	T- Score	SE
6	31.14	4.96
7	35.87	3.56
8	38.08	3.38
9	40.12	3.06
10	41.71	2.95
11	43.20	2.82
12	44.54	2.77
13	45.82	2.74
14	47.05	2.73
15	48.26	2.73
16	49.44	2.74
17	50.61	2.74
18	51.75	2.74
19	52.90	2.73
20	54.03	2.73
21	55.17	2.72
22	56.32	2.72
23	57.48	2.73
24	58.69	2.78
25	59.93	2.84
26	61.31	3.02
27	62.70	3.13
28	64.59	3.52
29	66.19	3.63
30	70.31	4.82

Table 38: TBI-CareQOL Feelings of Loss – Self

Feelings of Loss - Self		
Raw Summed Score	T- Score	SE
6	35.24	5.38
7	40.62	3.64
8	42.79	3.39
9	44.87	2.96
10	46.47	2.79
11	47.93	2.63
12	49.27	2.54
13	50.55	2.48
14	51.78	2.44
15	52.97	2.41
16	54.13	2.39
17	55.27	2.38
18	56.38	2.37
19	57.48	2.36
20	58.57	2.34
21	59.65	2.33
22	60.72	2.32
23	61.81	2.32
24	62.92	2.34
25	64.07	2.37
26	65.31	2.43
27	66.66	2.54
28	68.25	2.76
29	70.12	2.96
30	74.11	4.16

Table 39: TBI-CareQOL Feeling Trapped

Feeling Trapped		
Raw Summed Score	T- Score	SE
6	37.00	5.39
7	42.90	3.07
8	44.97	2.73
9	46.70	2.38
10	48.06	2.22
11	49.29	2.11
12	50.41	2.06
13	51.49	2.04
14	52.55	2.04
15	53.60	2.06
16	54.65	2.07
17	55.69	2.08
18	56.72	2.08
19	57.74	2.08
20	58.75	2.07
21	59.76	2.06
22	60.76	2.04
23	61.76	2.02
24	62.76	2.02
25	63.80	2.05
26	64.89	2.12
27	66.09	2.22
28	67.55	2.48
29	69.16	2.68
30	73.16	4.10

Table 40: TBI-CareQOL Military Health Care Frustration – Person with TBI

Military Health Care Frustration – Person with TBI		
Raw Summed Score	T- Score	SE
6	33.55	4.98
7	38.58	3.18
8	40.64	2.87
9	42.16	2.69
10	43.43	2.55
11	44.57	2.42
12	45.59	2.34
13	46.54	2.29
14	47.43	2.26
15	48.28	2.24
16	49.12	2.22
17	49.93	2.22
18	50.74	2.21
19	51.55	2.22
20	52.36	2.22
21	53.19	2.24
22	54.03	2.26
23	54.91	2.29
24	55.84	2.34
25	56.84	2.41
26	57.95	2.54
27	59.20	2.69
28	60.66	2.88
29	62.56	3.14
30	67.38	4.85

Table 41: TBI-CareQOL Military Health Care Frustration – Self

Military Health Care Frustration - Self		
Raw Summed Score	T-score	SE
6	33.0	4.9
7	37.9	3.2
8	39.9	2.9
9	41.4	2.7
10	42.6	2.6
11	43.8	2.4
12	44.8	2.3
13	45.7	2.3
14	46.6	2.3
15	47.4	2.2
16	48.2	2.2
17	49.0	2.2
18	49.8	2.2
19	50.5	2.2
20	51.3	2.2
21	52.1	2.2
22	52.9	2.2
23	53.7	2.3
24	54.6	2.3
25	55.6	2.4
26	56.6	2.6
27	57.8	2.8
28	59.2	3.0
29	60.9	3.2
30	66.0	5.0

Scoring Manual Modifications

The Scoring Manual was updated to version 6.1 on July 13, 2026. The statement on page 5 "If the result is a fraction, round up to the nearest whole number," was changed to "If the result is a fraction, round to the nearest whole number".