Patient-Reported Outcomes Measurement Information System

Dynamic Tools to Measure Health Outcomes From the Patient Perspective

PSYCHOSOCIAL ILLNESS IMPACT-POSITIVE

A brief guide to the PROMIS Psychosocial Illness Impact-Positive instruments:

ADULT
PROMIS Bank v1.0 – Psychosocial Illness Impact-Pos PROMIS Short Form v1.0 – Psychosoc Illness Impact-Pos 4a PROMIS Short Form v1.0 – Psychosoc Illness Impact-Pos 8a

ABOUT PSYCHOSOCIAL ILLNESS IMPACT-POSITIVE

The PROMIS Psychosocial Illness Impact-Positive, also known as “Positive Illness Impact”, instruments assess positive psychosocial (emotional and social) outcomes of illness, previously conceptualized in various ways including post-traumatic growth, benefit-finding, and meaning making. Positive Illness Impact refers to positive psychosocial outcomes of illness that can occur as a result of confrontation with one’s mortality, such as greater life appreciation, interpersonal relationships and personal resources. Positive Illness-Impact items do NOT seek to capture the positive impact of illness on physical or functional/role domains of functioning. The Psychosocial Illness Impact-Positive CAT is universal rather than disease-specific.

The item bank instructs participants to think about how their illness has affected them. Two items are presented on each screen. Participants are asked to respond to each item. The item bank uses the time frames “before your illness” and “since your illness” when assessing “positive illness impact”.

Psychosocial Illness Impact-Positive instruments are available for adults (ages 18+).

(*For complete definition see* http://nihpromis.org/measures/domainframework2)

INTRODUCTION TO ASSESSMENT OPTIONS

There are two administration options for assessing Psychosocial Illness Impact-Positive: short forms and computerized adaptive test (CAT). When administering a short form, instruct participants to answer all of the items (i.e., questions or statements) presented. With CAT, participant responses guide the system’s choice of subsequent items from the full item bank (39 items in total). Although items differ across respondents taking CAT, scores are comparable across participants. Some administrators may prefer to ask the same question of all respondents or of the same respondent over time, to enable a more direct comparability across people or time. In these cases, or when paper administration is preferred, a short form would be more desirable than CAT. This guide provides information on all Psychosocial Illness Impact-Positive short form and CAT instruments.

Whether one uses a short form or CAT, the score metric is Item Response Theory (IRT), a family of statistical models that link individual questions to a presumed underlying trait or concept of psychosocial illness impact-positive represented by all items in the item bank. When choosing between CAT and a short form, it is useful to consider the demands of computer-based assessment, and the psychological, physical, and cognitive burden placed on respondents as a result of the number of questions asked.

Figure 1 illustrates the correlations (strength of relationship) of the full bank with CAT and with short forms of varying length. The correlation of CAT scores with the full bank score is greater than a short form of any length. A longer CAT or longer short form offers greater correlation, as well as greater precision. When evaluating precision, not all questions are equally informative. The flexibility of CAT to choose more informative questions offers more precision.

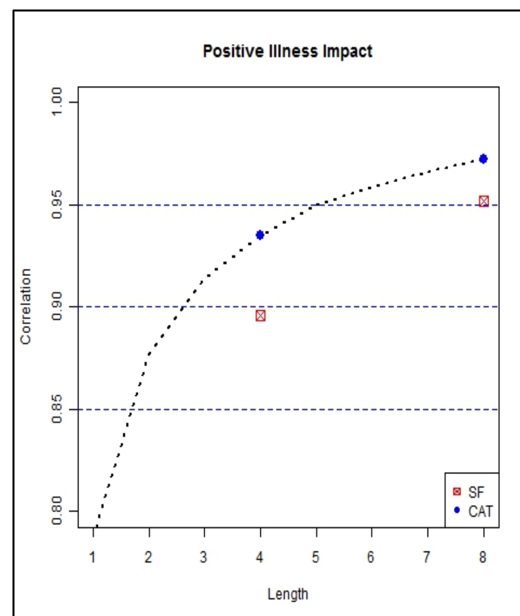


Figure 1

SHORT FORM DIFFERENCES

The short forms (4a and 8a) were constructed by the domain team with a focus on representing the range of the trait and also representing the content of the item bank. Domain experts reviewed short forms to give input on the relevance of each item. Psychometric properties and clinical input were both used.

Similar selection criteria guided the choice of items to include for each short form version. The longer version of the short form will provide a more precise score with less error than the shorter short form. However, this does increase the respondent burden.

In selecting between short forms, the difference is instrument length. The reliability and precision of the short forms within a domain is highly similar. If you are working with an adult sample in which you wanted the most precise measure, select the 8a short form. If you are working in an adult sample in which you expected huge variability in a domain area and wanted different subdomains covered, you should select the 8a short form. If you had little room for additional measures but really wanted to capture something as a secondary outcome, you should use the shorter instrument (4a).

SCORING THE INSTRUMENT

Short Forms: PROMIS instruments are scored using item-level calibrations. This means that the most accurate way to score a PROMIS instrument is to utilize scoring tools within Assessment Center or API that look at responses to each item for each participant. Data collected in either of these platforms will automatically score in this way. We refer to this as "response pattern scoring." Response pattern scoring can be used when data was collected on paper or in another software package through the Assessment Center Scoring Service. Because response pattern scoring is more accurate than the use of raw score/scale score look up tables, it is preferred. However, if you aren't able to use response pattern scoring, you can use the instructions below which rely on raw score/scale score look-up tables.

For adults, each question has five response options ranging in value from two to five. The first two response categories are collapsed which results in the response score being the same (2) for response options "Not at all" and "A little bit". To find the total raw score for a short form with all questions answered, sum the values of the response to each question. For example, for the 8-item form, the lowest possible raw score is 16; the highest possible raw score is 40 (see all short form scoring tables in Appendix).

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, were answered. For example, a 4-item short form can only be scored with complete data. A 5-item short form

can be scored as long as 4 items were answered. A 10-item short form can be scored as long as the participant answered at least 5 items. For branched instruments (e.g., Alcohol Use), the screening question is not used in calculating the score and therefore shouldn't be counted when assessing if the minimum number of items were answered. After confirming that enough responses were provided, sum the response scores from the items that were answered (not including any screening question). 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 answered (5). Here (10x8)/5=16. If the result is a fraction, round up to the nearest whole number. This is a pro-rated raw score.

Again, the formula is:

$$\frac{\text{(Raw sum x number of items on the short form)}}{\text{Number of items that were actually answered}}$$

Locate the applicable score conversion table in the Appendix and use this table to translate the total raw score or pro-rated score into a T-score for each participant. The T-score rescales the raw score into a standardized score with a mean of 50 and a standard deviation (SD) of 10. Therefore a person with a T-score of 40 is one SD below the mean. It is important to note that Assessment Center will convert a participant's pattern of responses to a standardized T-score after they have finished a CAT. The standardized T-score is reported as the final score for each participant.

The Psychosocial Illness Impact items are paired. One item asks about the respondent's experience before his or her illness and the second item asks about his or her experience since the illness. Only the "since your illness" item is used in calculating a score. When creating a summed score, only sum the "since" items. These have an "A" for "after" in the item ID.

For the PROMIS Psychosocial Illness Impact-Positive 8a short form, a raw score of 10 converts to a T-score of 25.6 with a standard error (SE) of 3.5 (see scoring table for the 8a short form in appendix). Thus, the 95% confidence interval around the observed score ranges from 18.74 to 32.46 (T-score $\pm$ (1.96*SE) or 25.6 $\pm$ (1.96*3.5).

For pro-rated scores, this calculation assumes that responses are missing at random. This isn't always true. Therefore, use caution when interpreting the final pro-rated T-score.

CAT: A minimum number of items (4) must be answered in order to receive a score for Psychosocial Illness Impact-Positive CAT. The first item is selected because it provides the most information about the U.S. general population. The response to this item will guide the system's choice of the next item for the participant. The participant's response to this item will dictate the selection of the following question, and so on. As additional items are administered, the potential for error is reduced and confidence in the respondent's score increases. CAT will continue until either the standard error drops below a specified level, or the participant has answered the maximum number of questions (12), whichever occurs first.

For most PROMIS instruments, a score of 50 is the average for the United States general population with a standard deviation of 10 because calibration testing was performed on a large sample of the general population. However, Psychosocial Illness Impact-Positive instruments were not calibrated on a national sample and so a score of 50 represents the average of the calibration sample which was generally more enriched for chronic

illness. As these instruments, a score of 50 likely represents somewhat sicker people than the general population. The T-score is provided with an error term (Standard Error or SE). The Standard Error is a statistical measure of variance and represents the "margin of error" for the T-score.

Important: *A higher PROMIS T-score represents more of the concept being measured.* For positively-worded concepts like Psychosocial Illness Impact-Positive, a T-score of 60 is one SD better than average. By comparison, a Psychosocial Illness Impact-Positive T-score of 40 is one SD worse than average.

STATISTICAL CHARACTERISTICS

There are four key features of the score for Psychosocial Illness Impact-Positive:

- **Reliability**: The degree to which a measure is free of error. It can be estimated by the internal consistency of the responses to the measure, or by correlating total scores on the measure from two time points when there has been no true change in what is being measured (for z-scores, reliability = 1 – SE^2).
- **Precision**: The consistency of the estimated score (reciprocal of error variance).
- **Information:** The precision of an item or multiple items at different levels of the underlying continuum (for z-scores, information = $1/SE^2$).
- **Standard Error (SE):** The possible range of the actual final score based upon the scaled T-score. For example, with a T-score of 52 and a SE of 2, the 95% confidence interval around the actual final score ranges from 48.1 to 55.9 (T-score $\pm$ (1.96*SE) = 52 $\pm$ 3.9 = 48.1 to 55.9).

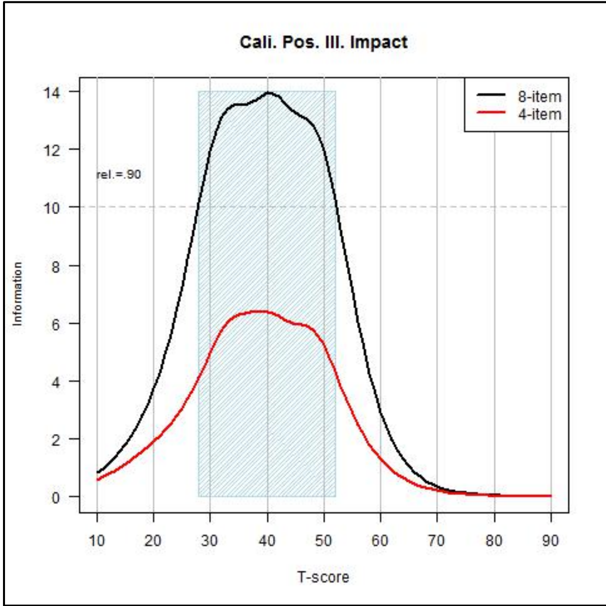


Figure 2

The final score is represented by the T-score, a standardized score with a mean of 50 and a standard deviation (SD) of 10.

In Figure 2 (4a and 8a short forms), the two dotted horizontal lines each represent a degree of internal consistency reliability (i.e., .90 or .95) typically regarded as sufficient for an accurate individual score. The shaded blue region marks the range of the scale where measurement precision is comparable to the reliability of .90. Figure 2 tells us where on the scale the form is most informative based upon the T-score. The 8-item form is more informative than the 4-item form.

Scaling Model Used For Calibration	Graded Response Model

Sample	N	Alpha Reliability
Illness Impact Pos. Full Bank	509	0.96

Score Distributions									
	Mean	SD	P5	P10	P25	P50	P75	P90	P95
Raw	126.24	20.69	87.00	97.00	114.00	129.00	142.00	150.00	154.00
Scale	49.83	9.23	35.01	38.80	44.02	49.20	55.75	62.71	66.39

										Min	Max
Scale Score	10.0	20.0	30.0	40.0	50.0	60.0	70.0	80.0	90.0	13.8	68.7
SE	3.70	2.30	1.60	1.50	1.60	2.50	4.60	7.10	8.80		
Reliability	.87	.95	.98	.98	.97	.94	.78	.49	.23		

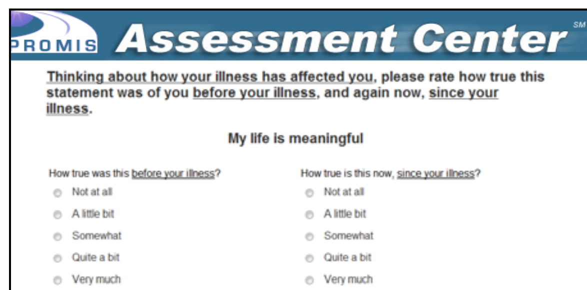
Figure 3

Figure 3 is a sample of the statistical information available in Assessment Center for the Psychosocial Illness Impact-Positive CAT.

More information is available online via Assessment Center (assessmentcenter.net).

PREVIEW OF SAMPLE ITEM

Figure 4 shows a Psychosocial Illness Impact-Positive item from the full item bank as it would appear to a study participant during data collection in Assessment Center. Several formats for presenting the items are available for computer-based administration through Assessment Center (see FAQ section).


PROMIS Assessment Center

Thinking about how your illness has affected you, please rate how true this statement was of you before your illness, and again now, since your illness.

My life is meaningful

How true was this before your illness?	How true is this now, since your illness?
Not at all	Not at all
A little bit	A little bit
Somewhat	Somewhat
Quite a bit	Quite a bit
Very much	Very much

Figure 4

Figure 5 is an excerpt from the paper version of the adult eight-item short form. This is the paper version format used for all Psychosocial Illness Impact-Positive instruments. It is important to note, CAT is not available for paper administration.

Thinking about how your illness has affected you, please rate how true these statements were of you before your illness, and again now, since your illness.

		Not at all	A little bit	Somewhat	Quite a bit	Very much
II2	I am comfortable with who I am					
II2-B	How true was this before your illness?	☐ 2	☐ 2	☐ 3	☐ 4	☐ 5
II2-A	How true is this now, since your illness?	☐ 2	☐ 2	☐ 3	☐ 4	☐ 5
II17	I realize who my real friends are					
II17-B	How true was this before your illness?	☐ 2	☐ 2	☐ 3	☐ 4	☐ 5
II17-A	How true is this now, since your illness?	☐ 2	☐ 2	☐ 3	☐ 4	☐ 5

Figure 5

FREQUENTLY ASKED QUESTIONS (FAQ)

Q: *I am interested in learning more. Where can I do that?*

All instruments are available on the PROMIS website through Assessment Center, which houses all PROMIS instruments for each domain.

Assessment Center is a free online research management tool. It enables researchers to create study-specific websites for capturing participant data securely. Studies can include measures within the Assessment Center library, as well as custom instruments created or entered by the researcher. PROMIS instruments (short forms, CATs, profiles) are a central feature of the instrument library within Assessment Center. Any PROMIS measure can be included in an online study or downloaded for administration on paper.

Detailed statistical information and development history about PROMIS items and instruments are available for review at nihpromis.org or assessmentcenter.net. To learn more, contact help@assessmentcenter.net.

Q: *Do I need to register with PROMIS to use these instruments?*

Yes, to get a copy of these instruments, we ask that you register with Assessment Center and endorse the PROMIS Terms and Conditions of Use, so that we are better able to track who has accessed instruments for research. Assessment Center is available at assessmentcenter.net.

Q: *Are these instruments available in other languages?*

These instruments are not currently available in multiple languages in Assessment Center. The PROMIS group is also working to translate this form into other languages. Information on available translations is updated periodically at http://nihpromis.org/measures/translations.

Q: Can I make my own short form?

Yes, custom Psychosocial Illness Impact-Positive short forms can be made by selecting any items from the item bank. Instructions for creating a custom short form in Assessment Center can be found in the Assessment Center User Manual https://www.assessmentcenter.net/UserManuals.aspx.

Q: How do I handle multiple responses when administering a short form on paper?

Guidelines on how to deal with multiple responses have been established. Resolution depends on the responses noted by the research participant.

- If two or more responses are marked by the respondent, and they are next to one another, then a data entry specialist will be responsible for randomly selecting one of them to be entered and will write down on the form which answer was selected. *Note: To randomly select one of two responses, the data entry specialist will flip a coin (heads - higher number will be entered; tails – lower number will be entered).To randomly select one of three (or more) responses, a table of random numbers should be used with a statistician's assistance.*
- If two or more responses are marked, and they are NOT all next to one another, the response will be considered missing.

Q: *What is the minimum change on a PROMIS instrument that represents a clinically meaningful difference?*

This question is related to an area of active research in the PROMIS network, namely the determination of the "minimally important difference" or "MID" for a PROMIS instrument. A manuscript in the *Journal of Clinical Epidemiology* outlines the process for MIDs for adult PROMIS measures and estimates the MIDs for six PROMIS-Cancer scales: Yost, K. J., Eton, D. T., Garcia, S. F., & Cella, D. (2011). Minimally important differences were estimated for six PROMIS-Cancer scales in advanced-stage cancer patients. *Journal of Clinical Epidemiology, 64(5)*, 507-16.

As described in that manuscript, the MID is a tool to enhance the interpretability of patient-reported outcomes and is often defined as the "the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management" (Jaeschke R, Singer J, Guyatt GH. Measurement of health status. Ascertaining the minimal clinically important difference. *Controlled Clinical Trials* 1989; 10(4):407-415).

APPENDIX - SCORING TABLES

Illness Impact Pos 4a Short Form Conversion Table		
Raw Score	T Score	SE*
8	23.9	5.3
9	27.5	4.7
10	30.4	4.4
11	33	4.2
12	35.5	4.1
13	37.8	4
14	40.1	4
15	42.3	4
16	44.7	4.2
17	47.3	4.4
18	50.3	4.6
19	54.1	5
20	60.6	6.5

SE= Standard Error on Tscore Metric

Illness Impact Pos 8a Short Form Conversion Table		
Raw Score	T Score	SE*
16	20.3	4.5
17	23.4	3.9
18	25.6	3.5
19	27.5	3.3
20	29.2	3.1
21	30.8	3
22	32.2	2.9
23	33.5	2.8
24	34.8	2.8
25	36.1	2.8
26	37.3	2.8
27	38.5	2.8
28	39.7	2.8
29	40.9	2.8
30	42.1	2.8
31	43.4	2.8
32	44.6	2.8
33	45.9	2.8
34	47.3	2.9
35	48.8	3
36	50.5	3.2
37	52.4	3.4
38	54.6	3.8
39	57.6	4.3
40	63.1	5.9

SE=Standard Error on Tscore Metric

Adult version