STIGMA
MEASURE DIFFERENCES

A brief guide to differences between the PROMIS® Stigma instruments:

PEDIATRIC	PARENT PROXY
PROMIS Pediatric Bank v1.1 – Stigma PROMIS Pediatric Short Form v1.1 – Stigma 8a PROMIS Pediatric Bank v1.1 – Stigma – Skin PROMIS Pediatric Short Form v1.1 – Stigma – Skin 8a PROMIS Pediatric Bank v1.0 – Stigma* PROMIS Pediatric Short Form v1.0 – Stigma 8a* PROMIS Pediatric Bank v1.0 – Stigma – Skin* PROMIS Pediatric Short Form v1.0 – Stigma – Skin 8a*	PROMIS Parent Proxy Bank v1.0 – Stigma PROMIS Parent Proxy Short Form v1.0 – Stigma 8a PROMIS Parent Proxy Bank v1.0 – Stigma – Skin PROMIS Parent Proxy Short Form v1.0 – Stigma – Skin 8a

*Retired measure

ABOUT STIGMA

PROMIS Stigma instruments measure perceptions of self and publicly enacted negativity, prejudice, and discrimination as a result of disease-related manifestations. The items reference a person's health condition (e.g., "Because of my condition…") but are not targeted to any specific condition. In this way, the Stigma instruments are appropriate for children with any chronic health condition. The measures assess stigma "lately (in the last 1-2 months). Each measure produces a single Stigma score.

Stigma instruments are available for pediatric self-report (ages 8-17) and for parents serving as proxy reporters for their child (youth ages 5-17).

For complete list of all PROMIS definitions, go to: http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures

INTRODUCTION TO ASSESSMENT OPTIONS

There are two administration options for assessing Stigma: short forms and computer adaptive tests (CATs). When administering a short form, instruct participants to answer all of the items (i.e., questions or statements) presented. With a CAT, participant responses guide the system's choice of subsequent items from the full item bank (18 and 24 items in total in the Pediatric v1.1 Stigma and the Pediatric v1.1 Stigma—Skin banks, respectively). 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 Stigma short form and CAT instruments.

CAT: A minimum number of items (e.g., 4) must be answered in order to receive a score for Stigma CAT. The response to the first item will guide the system's choice of the next item for the participant. The participant's response to the second 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 (e.g., on the T-score metric 3.0), or the participant has answered the maximum number of questions (e.g., 8), whichever occurs first. For some CATs,

specifically “recommended” and “screen-to-CAT” there are additional stopping rules. These include stopping when the standard error isn’t improving much or if a respondent is asymptomatic. For details on the exact stopping rules for Stigma CATs, see below.

CAT versus Short Form: Whether one uses a short form or CAT, the measure’s score is produced by using Item Response Theory (IRT). IRT is a family of statistical models that link individual questions to a presumed underlying trait or concept of Stigma 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.

VERSION DIFFERENCES

Some PROMIS domains have multiple versions of instruments (i.e., v1.0, v1.1, v2.0). Generally, **it is recommended that you use the most recent version available which can be identified as the instrument with the highest version number.** In most cases, an instrument that has a decimal increase (v1.0 to v1.1) retains the same item-level parameters as well as instrument reliability and validity. In cases where a version number increases by a whole number (e.g., v1.0 to v2.0), the changes to the instrument are more substantial.

Pediatric and Parent Proxy

The measures within the PROMIS Stigma domain were formerly released as “Pediatric Stigma” measures. The “Pediatric” portion of this phrase has since been removed to avoid confusion between Domain and Response Type.

There are two versions (v1.0 and v1.1) of the PROMIS Pediatric Stigma and Stigma – Skin instruments. The first version (v1.0) of the Stigma Bank included 18 items. The Stigma—Skin (v1.0) Bank is an extension of the Stigma, which encompasses all of the PROMIS Pediatric Stigma items along with 6 additional items tailored specifically to skin-related concerns, resulting in a total of 24 items. One item included in the PROMIS Pediatric Bank v1.0 – Stigma, PROMIS Pediatric Short Form v1.0 – Stigma 8a, and PROMIS Pediatric Bank v1.0 – Stigma – Skin instruments was updated, resulting in the v1.1 measures. The affected item was not included in the PROMIS Pediatric Short Form v1.0 – Stigma – Skin 8a, so its content remained unchanged; however, the version number of this measure was updated from v1.0 to v1.1 to harmonize with the other Pediatric Stigma set. Scores obtained from v1.0 and v1.1 Pediatric Stigma instruments are comparable.

There is only one version (v1.0) of the Parent Proxy Stigma and Stigma—Skin instruments.

Stopping Rules: The PROMIS Pediatric Bank v1.1 – Stigma, PROMIS Pediatric Bank v1.1 – Stigma – Skin, PROMIS Parent Proxy Bank v1.0 – Stigma, and PROMIS Parent Proxy Bank v1.0 – Stigma – Skin measures are administered by default as computer adaptive tests using the following stopping rules:

- Minimum number of items administered = 4
- Stop when one of these occurs:
    - 8 items are administered, OR
    - Standard error is below 0.3 on the theta metric (3.0 on the T-score metric)
    - Standard error changes by less than 0.01 on the theta metric (0.1 on the T-score metric)

PROMIS

SHORT FORM DIFFERENCES

There are two Stigma short forms for pediatric self-report (ages 8-17): **PROMIS Pediatric SF v1.1 – Stigma 8a** and **PROMIS Pediatric SF v1.1 – Stigma – Skin 8a**. Short-form items were chosen based on considerations of psychometric properties, including the most frequently selected items in CAT simulation, item information function, and content coverage. PROMIS Pediatric SF v1.1 – Stigma – Skin 8a comprises four items that overlap with PROMIS Pediatric SF v1.1 – Stigma 8a and three items from PROMIS Pediatric Stigma – Skin. Scores between PROMIS Pediatric SF v1.1 – Stigma 8a and PROMIS Pediatric SF v1.1 – Stigma – Skin 8a are comparable.

There are also two Stigma short forms for parents serving as proxy reporters for their child (youth ages 5-17): **PROMIS Parent Proxy SF v1.0 – Stigma 8a** and **PROMIS Parent Proxy SF v1.0 – Stigma – Skin 8a**. PROMIS Parent Proxy SF v1.1 – Stigma – Skin 8a comprises five items that overlap with PROMIS Parent Proxy SF v1.1 – Stigma 8a. Scores between PROMIS Parent Proxy SF v1.1 – Stigma 8a and PROMIS Parent Proxy SF v1.1 – Stigma – Skin 8a are comparable.

The item content included in the PROMIS Parent Proxy SF v1.0 – Stigma 8a is not fully aligned with the Pediatric SFv1.1 – Stigma 8a. However, the item content included in the PROMIS Parent Proxy SF v1.0 – Stigma - Skin 8a is aligned with the Pediatric SF v1.1 – Stigma – Skin 8a.

SELECTING A PEDIATRIC OR PARENT PROXY INSTRUMENT

In selecting whether to use the pediatric versus parent proxy instrument for this domain, it is important to consider both the population and the domain which you are studying. Pediatric self-report should be considered the standard for measuring patient-reported outcomes among children. However, circumstances exist when the child is too young, cognitively impaired, or too ill to complete a patient-reported outcome instrument. While information derived from self-report and proxy-report is not equivalent, it is optimal to assess both the child and the parent since their perspectives may be independently related to healthcare utilization, risk factors, and quality of care.

SCORES

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, for Stigma and Stigma – Skin, a score of 50 is the average for a sample of individuals with a chronic condition. You can read more about the calibration and centering samples on HealthMeasures.net (http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis). 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 negatively-worded concepts like Stigma and Stigma - Skin, a T-score of 60 is one SD worse than average. By comparison, a T-score of 40 is one SD better than average.

STATISTICAL CHARACTERISTICS

There are four key features of the score for Stigma and Stigma - Skin:

- **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 ± (1.96*SE) = 52 ± 3.9 = 48.1 to 55.9).

PREVIEW OF SAMPLE ITEM

Figure 1 is an excerpt from the paper version of the v1.0 Parent Proxy Stigma Bank. This is the paper version format used for all Stigma instruments. It is important to note, CAT is not available for paper administration.

Lately (in the last 1-2 months)...

		Never	Rarely	Sometimes	Often	Always
QNQSTGprox01	Other children bullied my child because of his/her condition	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Figure 1

FREQUENTLY ASKED QUESTIONS (FAQ)

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

Review the HealthMeasures website at www.healthmeasures.net.

Q: Are PROMIS instruments available in other languages?

Yes! Look at the HealthMeasures website (http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/available-translations) for current information on PROMIS translations.

Q: Can I make my own short form?

Yes, custom short forms can be made by selecting any items from the item bank. This can be scored using the Scoring Service (https://www.assessmentcenter.net/ac_scoringservice).