STIGMA
MEASURE DIFFERENCES

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

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

*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.

PROMIS Stigma – Skin instruments also 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 do not specify a condition. The Stigma – Skin item bank includes all of the items from PROMIS Stigma plus additional items that tailored to skin-related concerns (e.g., "Because of my condition, others avoided touching me (ex: holding my hand)"). The measures assess stigma "lately (in the last 1-2 months)." Each measure produces a single Stigma – Skin score.

Stigma and Stigma – Skin 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 forms and CATs.

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. The 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

Pediatric **Stigma** versus **Stigma – Skin**

- The PROMIS Pediatric Stigma v1.0 item bank included 18 items.
- The PROMIS Pediatric Stigma – Skin v1.0 item bank included all 18 of those items and added 6 new items tailored specifically to skin-related concerns. The 18 shared items retained their item-level calibrations. This means that scores from Pediatric Stigma v1.0 and Pediatric Stigma – Skin v1.0 can be compared. They are on the same metric.

Pediatric Stigma and Stigma – Skin **v1.0** versus **v1.1**

- One item in the Pediatric Stigma 1.0 item bank was updated. This item is part of three measures (Pediatric Stigma bank v1.0, Pediatric Stigma short form v1.0 8a, and Pediatric Stigma – Skin bank v1.0). Consequently, these measures were revised to become v1.1 measures. The Pediatric Stigma – Skin short form v1.0 8a did not include the updated item, but the version number of the measure was updated to v1.1 to harmonize with the other Pediatric measures. The content of the v1.0 and v1.1 Pediatric Stigma – Skin short forms 8a are identical.
- Scores from the Stigma v1.0, Stigma v1.1, Stigma – Skin v1.0, and Stigma – Skin v1.1 measures can be compared to each other. They are on the same metric.
- The PROMIS Pediatric Short Form – Stigma – Skin 8b was created after the v1.1 measures were constructed. There is no v1.0 for the 8b short form.

Parent Proxy **Stigma** versus **Stigma – Skin**

- The PROMIS Parent Proxy Stigma v1.0 item bank includes 16 items.

- The PROMIS Parent Proxy Stigma – Skin v1.0 item bank includes all 16 of those items and added 6 new items tailored specifically to skin-related concerns. The 16 shared items retained their item-level calibrations. This means that scores from Parent Proxy Stigma v1.0 and Parent Proxy Stigma – Skin v1.0 can be compared. They are on the same metric.
- There is only one version (v1.0) of the Parent Proxy Stigma and Stigma—Skin instruments.

The measures within the PROMIS Stigma domain were initially released as "Pediatric Stigma" measures (e.g., PROMIS Pediatric bank v1.0 – Pediatric Stigma). The second "Pediatric" was removed to avoid confusion between the domain and respondent.

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)

SHORT FORM DIFFERENCES

Pediatric

- There is one Pediatric Stigma short form: **PROMIS Pediatric SF v1.1 – Stigma 8a**. Items were chosen based on considerations of psychometric properties, including the most frequently selected items in CAT simulation, item information function, and content coverage. It is appropriate for evaluating stigma and in any population with a chronic condition.
- There are two Pediatric Stigma – Skin short forms: **PROMIS Pediatric SF v1.1 – Stigma – Skin 8a** and **8b.**
    - The **Pediatric SF v1.1 – Stigma – Skin 8a** was created to capture the appropriate precision across the measurement continuum. It includes some items that are tailored to skin (i.e., perceived as unclean, avoiding touch).
    - The **Pediatric SF v1.1 – Stigma – Skin 8b** shares 4 items with Stigma 8a and 4 items with Stigma – Skin 8a. One of those items is specific to the Stigma – Skin item bank, but its content is not unique to individuals with a skin condition (others don't see good things about me). Item selection was based on both qualitative and quantitative data, ensuring a balanced representation of external and internal stigma items. Additionally, items were selected based on their distribution across emotional, physical, and mental domains, as well as their ability to discriminate effectively according to findings from the stigma study. **This 8b short form is preferred over the Pediatric Stigma – Skin 8a short form.**
    - Use a Stigma – Skin measure (not a Stigma measure) when working with a population managing a skin-related condition.
- Scores from the PROMIS Pediatric SF v1.1 – Stigma 8a, Pediatric SF v1.1 – Stigma – Skin 8a, and Pediatric SF v1.1 – Stigma – Skin 8b are comparable.

Parent Proxy

- There is one Parent Proxy Stigma short form: **PROMIS Parent Proxy SF v1.0 – Stigma 8a**. Eight items were chosen based on considerations of psychometric properties, including the most frequently selected items in CAT simulation, item information function, and content coverage. It is appropriate for evaluating stigma and in any population with a chronic condition. Note that the item content for this Parent Proxy short form is NOT fully aligned with the Pediatric SF v1.1 – Stigma 8a.
- There are two Parent Proxy Stigma – Skin short forms: **PROMIS Parent Proxy SF v1.0 – Stigma – Skin 8a** and **8b.**
    - The **Parent Proxy SF v1.0 – Stigma – Skin 8a** was created to capture the appropriate precision across the measurement continuum. It shares 5 items with the Stigma – 8a short form (which are also part of the Stigma – Skin item bank) and 3 items that are tailored to skin (i.e., perceived as unclean, avoiding touch). The item content of this Parent Proxy short form is aligned with the Pediatric SF v1.1 – Stigma – Skin 8a.
    - The **Parent Proxy SF v1.0 – Stigma – Skin 8b** includes 8 items. Of these, 5 items overlap with the Stigma 8a short form and 4 items are also part of the Stigma – Skin 8a short form. One item is specific to the Stigma – Skin item bank, but its content is not unique to individuals with a skin condition (others don't see good things about my child). Item selection was based on both qualitative and quantitative data, ensuring a balanced representation of external and internal stigma items. Additionally, items were selected based on their distribution across emotional, physical, and mental domains, as well as their ability to discriminate effectively according to findings from the stigma study. This 8b short form is preferred over the Parent Proxy Stigma – Skin 8a short form. The item content of this Parent Proxy short form is aligned with the Pediatric SF v1.1 – Stigma – Skin 8b.
    - Use a Stigma – Skin measure (not a Stigma measure) when working with a population managing a skin-related condition.
- Scores from the PROMIS Parent Proxy SF v1.0 – Stigma 8a, PROMIS Parent Proxy SF v1.0 – Stigma – Skin 8a, and PROMIS Parent Proxy SF v1.0 – Stigma – Skin 8b are comparable.

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 $\pm$ (1.96*SE) = 52 $\pm$ 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.

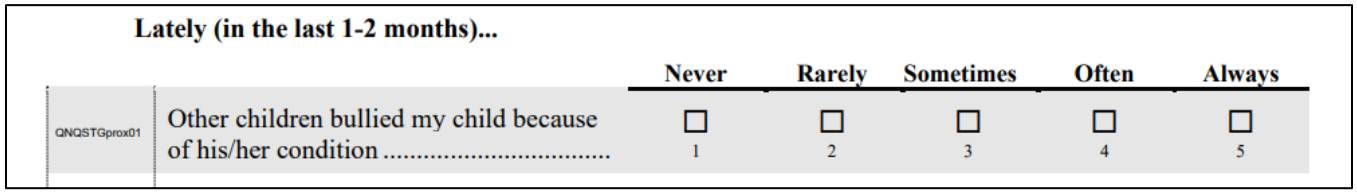

Figure 1

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).