Guidelines for the Appearance of HealthMeasures
Approved October 12, 2021

PROMIS®, Neuro-QoL™, ASCQ-Me®, and select NIH Toolbox® measures can be integrated into data collection systems. The appearance of self- and proxy-report items must be consistent with how the measures were developed, tested, and validated, and should follow best practices in data collection.

Requirements

- The item syntax must be identical to that used in the PDF version of the measure. No alterations including but not limited to verb tense, responses, person perspective (i.e., "your" versus "my"), time frame, or item text may be made without permission from HealthMeasures (help@healthmeasures.net). To learn more about our position on modifying items, please read this thread on the HealthMeasures.net User Forum: http://www.healthmeasures.net/resource-center/user-community/forum/promis/87-modifying-promis-items.

- If an item has a context (i.e., the time frame displayed at the top of the PDF version of the measure like "In the past 7 days…" or "In general…"), it must be on the first row of the template used by a computer-based data collection system. The item stem (i.e., the portion of the item shown in the grid portion of the PDF version of the measure like "I have a lack of energy") must be on a new row. Examples:

Figure 1: PROMIS item with a context and stem

Figure 2: Item with only a stem

- PROMIS includes some items (e.g., pain intensity) that use a 0-10 numeric rating scale. These items must have responses presented horizontally with labels under the anchor points. See Figure 3 for illustration.

Figure 3: Layout for the adult PROMIS Pain Intensity item

- If you need to utilize a table or grid-like format for short forms, all items listed in a given table must share the same response options and the context must be at the top (if part of the item). An illustration for how we have done this for paper-based forms is shown in Figure 4.

Figure 4: Table Layout for Multiple Items per Page

Please respond to each question or statement by marking one box per row.

	During the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
HI7	I feel fatigued	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
AN3	I have trouble <u>starting</u> things because I am tired..............................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
FATEXP41	How run-down did you feel on average? ...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
FATEXP40	How fatigued were you on average?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
FATEXP35	How much were you bothered by your fatigue on average?.................................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
FATIMP49	To what degree did your fatigue interfere with your physical functioning?................	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	In the past 7 days...	Never	Rarely	Sometimes	Often	Always
FATIMP3	How often did you have to push yourself to get things done because of your fatigue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
FATIMP16	How often did you have trouble finishing things because of your fatigue?..............	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

- Measures with branching or skip logic (e.g., PROMIS gastro-intestinal symptoms) must adhere to the skip logic described in the PDF version of the measure.

Recommendations
- Response options (e.g., Never, Rarely, Sometimes, Often, Always) should be in the same order as in the PDF version of the measure.
  - o Note, however, that there are some short forms with both positively and negatively phrased items. For example, PROMIS Fatigue 7a includes six items like "How often did you feel tired" where "Always" indicates more fatigue and one item ("How often did you have enough energy to exercise strenuously?") where "Always" indicates less fatigue. In these cases, it may be helpful to reverse the order of the response options for the single non-matching item so that the response at the bottom of a vertical list of choices or furthest right always means more of the domain.
- Do not display the instrument name.
- Do not display the response scores.
- Do not display the Item IDs.

- If a digital interface (e.g., web-based, tablet, smartphone) is used, response options should be in a vertical list except for with 0-10 numeric rating scale items.
- Minimize additional text, logos, or branding on the data collection interface.
- Do not display the copyright statement.
- Avoid requiring a respondent scroll down to see all response options.
- The PDF version of a measure may include an instruction at the top (e.g., "Please respond to each question or statement by marking one box per row."). This is not considered part of an item. This instruction should be used on paper forms or when items are presented in a grid (see Figure 4 for example).
- If an instruction is needed in an electronic data collection system, we recommend using "**Please select [mark] one response for each question or statement.**"
- Provide screen shots of your data collection interface to help@healthmeasures.net for review and approval.

FAQs
- There is no requirement to adhere to the item order used in a fixed length short form or profile.