



## DYSPNEA

A brief guide to the PROMIS<sup>®</sup> Dyspnea instruments:

ADULT
PROMIS Item Bank v1.0 – Dyspnea Functional Limitations
PROMIS Item Bank v1.0 – Dyspnea Severity
PROMIS Pool v1.0 – Dyspnea Activity Motivation
PROMIS Pool v1.0 – Dyspnea Activity Requirements
PROMIS Pool v1.0 – Dyspnea Airborne Exposure
PROMIS Pool v1.0 – Dyspnea Assistant Devices Resources
PROMIS Pool v1.0 – Dyspnea Characteristics
PROMIS Pool v1.0 – Dyspnea Emotional Response
PROMIS Pool v1.0 – Dyspnea Task Avoidance
PROMIS Pool v1.0 – Dyspnea Time Extension
PROMIS Short Form v1.0 – Dyspnea Functional Limitations 10a
PROMIS Short Form v1.0 – Dyspnea Severity 10a

### ABOUT DYSPNEA

The PROMIS Dyspnea (shortness of breath) item banks and pools assess self-reported Functional Limitations, Severity, Activity Motivation, Activity Requirements, Airborne Exposure, Assistant Devices Resources, Characteristics, Emotional Response, Task Avoidance and Time Extension as they related to dyspnea. These instruments are generic rather than disease-specific, but they were developed for and validated in people with chronic obstructive pulmonary disease (COPD). These instruments may also be relevant to other conditions where dyspnea is a prominent symptom.

### SUBDOMAIN DEFINITIONS – Item Banks

- (1) The PROMIS Dyspnea Functional Limitations item bank assesses the impact of dyspnea (i.e. shortness of breath or difficulty breathing) on an adult’s ability to function while performing specific daily activities (e.g., dressing oneself without help, preparing meals, walking up 20 stairs). Each activity is rated in terms of degree of difficulty while engaging in the activity over the past 7 days (no difficulty, a little difficulty, some difficulty, much difficulty), with higher scores reflecting greater functional limitations. Respondents who indicate that they did not perform an activity in the past 7 days will not produce a score for that item. The PROMIS Dyspnea Functional Limitation item bank includes 33 items.
- (2) The PROMIS Dyspnea Severity item bank assesses the severity of shortness of breath or difficulty breathing an adult experiences in response to various specific activities (the same activities assessed in Dyspnea Functional Limitations). Each activity is rated in terms of degree of dyspnea (no shortness of breath, mildly short of breath, moderately short of breath, severely short of breath) while engaging in the activity over the past 7 days, with higher scores reflecting greater levels of dyspnea. Respondents who indicate that they did not perform an activity in the past 7 days will not produce a score for that item. The bank includes 33 items.

### SUBDOMAIN DEFINITIONS – Pools

- 1) The PROMIS Dyspnea Activity Motivation item pool is a collection of items that assess an adult’s relative dispositional tendency or preference toward being active or sedentary. Dyspnea Activity Motivation is a facet that falls within the “Characteristics of the Individual<sup>1</sup>” concept (which includes

Emotional Response to Dyspnea). The items do not reference a specific time frame. There are seven items in the item pool.

- 2) The PROMIS Dyspnea Activity Requirements item pool are items that assess the impact of an adult's environment on their physical activity levels, such as work outside the home and aspects of the home environment (e.g., stairs). Dyspnea Activity Requirements is a facet that falls within the "Characteristics of the Environment<sup>2</sup>" concept (which includes Airborne Exposures and Assistive Devices and Resources). Most of the items assess Dyspnea Activity Requirements over the past month. There are four items in this item pool.
- 3) The PROMIS Dyspnea Airborne Exposure item pool is a collection of items that assess environmental factors related to dyspnea, including exposure to airborne allergens, pollutants and smoke. Dyspnea Airborne Exposure is a facet that falls within the "Characteristics of the Environment<sup>2</sup>" concept (which includes Activity Requirements and Assistive Devices and Resources). Dyspnea Airborne Exposure items assess whether or not an adult is exposed to airborne factors in their environment that could impact their shortness of breath. Most items do not reference a specific time frame with the exception of one item that assess airborne exposure over the past 7 days. There are six items in the item pool.
- 4) The PROMIS Dyspnea Assistive Devices and Resources items assess the availability and use of assistive devices (e.g., oxygen, walking aids). Dyspnea Assistive Devices and Resources is a facet that falls within the "Characteristics of the Environment<sup>2</sup>" concept (which includes Activity Requirements and Airborne Exposures). Dyspnea Assistive Devices and Resources are items that assess whether or not an individual uses devices such as a cane, grab bar or oxygen. The items do not reference a specific time frame. There are seven items in the item pool.
- 5) The PROMIS Dyspnea Characteristics item pool is a collection of items that assess various descriptive aspects of a person's experience of dyspnea. This includes both quantitative and qualitative descriptions of the severity and intensity of shortness of breath as well as its frequency and duration. Items use either a 0-10 numeric rating scale or 0-4 rating scale and assess dyspnea characteristics over the past 7 days. There are five items in the item pool.
- 6) The PROMIS Dyspnea Emotional Response item pool is a collection of items that assess emotions experienced related to dyspnea, including embarrassment, fear and worry. Dyspnea Emotional Response is a facet that falls within the "Characteristics of the Individual<sup>1</sup>" concept (which also includes Activity Motivation). The items do not reference a specific time frame. There are seven items in the item pool.
- 7) The PROMIS Dyspnea Task Avoidance item pool is a collection of items that assess an adult's decision to stop engaging in certain activities when the breathing discomfort associated with continuing the activity can no longer be tolerated. Dyspnea Task Avoidance is a facet that falls within the "Task Avoidance and Time Extension" concept (which also includes Time Extension). There are three items in the item pool and items do not reference a specific time frame.
- 8) The PROMIS Dyspnea Time Extension item pool is a collection of items that assess whether there has been a meaningful increase or decrease in the duration of time needed by an adult to perform a given task in the past 7 days (compared to 3 months ago) due to shortness of breath. Dyspnea Task



Avoidance is a facet that falls within the "Task Avoidance and Time Extension" concept (which includes Time Extension). There are seven items in the item pool.

Dyspnea instruments are available for adults (ages 18+).

<sup>1</sup>Characteristics of the Individual: items assess individual differences in motivational and psychological factors that influence dyspnea and functional limitations.

<sup>2</sup>Characteristics of the Environment: items assess the environment of the individual, which can have a direct effect upon the experience and reporting of dyspnea and functional limitations.

## INTRODUCTION TO ASSESSMENT OPTIONS

Two dyspnea domains, Functional Limitations and Severity, are item banks that can be administered as computer adaptive tests (CATs) or short forms. The remaining eight domains (Airborne Exposure, Activity Motivation, Activity Requirements, Assistant Devices Resources, Characteristics, Emotional Response, Task Avoidance and Time Extension) are not scored. Instead, these domains provide information that may aid in having a more complete understanding of an individual respondent. In PROMIS, this type of instrument is known as an item pool. Use the raw response scores for these domains.

When administering a Severity or Functional Limitations 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. Although items differ across respondents taking a 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 a CAT.

Whether one uses a short form or CAT for Severity or Functional Limitations, 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 dyspnea represented by all items in the item bank. When choosing between a CAT and 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.

## SHORT FORMS

There is one dyspnea Functional Limitation and one dyspnea Severity adult short form. Items were selected based on content and psychometric characteristics.

## SCORING THE INSTRUMENT

Short Forms: PROMIS Dyspnea Functional Limitations and Severity are scored using item-level calibrations. This means that the most accurate way to score the Dyspnea Functional Limitations and Severity short forms is to use the [HealthMeasures Scoring Service](https://www.assessmentcenter.net/ac_scoring-service) ([https://www.assessmentcenter.net/ac\\_scoring-service](https://www.assessmentcenter.net/ac_scoring-service)) or a data collection tool that automatically calculates scores (e.g., Assessment Center, REDCap auto-score). This method of scoring uses responses to each item for each participant. We refer to this as "response pattern scoring." Because response pattern scoring is more accurate than the use of raw score/scale score look up tables included in this manual, it is preferred. Response pattern scoring is especially useful when there is missing data (i.e., a

respondent skipped an item), different groups of participants responded to different items, or you have created a new questionnaire using a subset of questions from a PROMIS item bank.

For the two short forms, response options range from 0 to 3. Respondents who indicate that they did not perform an activity in the past 7 days will not produce a score for that item, which is equivalent to missing data for purposes of scoring the dyspnea short forms. **To use the scoring tables, respondents must indicate that they have done (answered) all 10 items. If a respondent indicates that they did not do one or more activities (either they responded with “I did not do this in the past 7 days or they did not answer an item), you must use the HealthMeasures Scoring Service ([https://www.assessmentcenter.net/ac\\_scoring-service](https://www.assessmentcenter.net/ac_scoring-service)) or other data collection tool that automatically calculates scores in order to obtain a valid score.** If the respondent has answered all items, the total raw score for a short form can be obtained by summing the values of the response to each question. For example, for the adult 10-item short form, the lowest possible raw score is 0; the highest possible raw score is 30 (see both short form scoring tables in Appendix 1).

Locate the applicable score conversion table in Appendix 1 and use this table to translate the total raw 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.

For the adult PROMIS Dyspnea Severity 10a short form, a raw score of 10 converts to a T-score of 48.8 with a standard error (SE) of 2.0 (see scoring table for the 10a short form in Appendix 1). Thus, the 95% confidence interval around the observed score ranges from 44.88 to 52.72 (T-score  $\pm$  (1.96\*SE) or  $48.8 \pm (1.96*2.0)$ ).

CAT: A minimum number of items (4 for adults) must be answered in order to receive a score for the Dyspnea Function Limitations and Severity CATs. 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 (3.0 on the T-score metric CATs), or the participant has answered the maximum number of questions (12), whichever occurs first.

Pools: For all Dyspnea item pools, sum the raw response scores for all items.

Meaning of 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, the dyspnea instruments were calibrated on a sample of adults with COPD, so a score of 50 is the average of this group of people with COPD. You can read more about the calibration and centering samples at HealthMeasures.net in the [Interpret PROMIS](#) section. 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 Severity and Functional Limitations, a T-score of 60 is one SD worse than average. By comparison, a Severity and Functional Limitations T-score of 40 is one SD better than average.

## **STATISTICAL CHARACTERISTICS**

There are four key features of the score for Dyspnea:



- **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).

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

### PREVIEW OF SAMPLE ITEM

Figure 1 is an excerpt from the paper version of the adult Functional Limitations 10-item short form. This is the paper version format used for all dyspnea instruments. It is important to note that the CAT is not available for paper administration.

Considering your shortness of breath over the past 7 days, rate the amount of difficulty you had when doing the following activities...		No difficulty	A little difficulty	Some difficulty	Much difficulty	I did not do this in the past 7 days
		0	1	2	3	X
DYSFL001	Dressing yourself without help .....	<input type="checkbox"/>				
DYSFL002	Walking 50 steps/paces on flat ground at a normal speed without stopping .....	<input type="checkbox"/>				

Figure 1



## FREQUENTLY ASKED QUESTIONS (FAQs)

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

Review the HealthMeasures website at [www.healthmeasures.net](http://www.healthmeasures.net).

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

No.

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 an item bank. This can be scored using the Scoring Service ([https://www.assessmentcenter.net/ac\\_scoring-service](https://www.assessmentcenter.net/ac_scoring-service)). You can also create a custom short form using selected items from an item pool. Use the raw response scores.

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?

To learn more about research on the meaning of a change in scores, we suggest conducting a literature review to identify the most current information. The HealthMeasures website (<http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis>) has additional information on interpreting scores.



## APPENDIX 1 - SCORING TABLES

<b>Dyspnea Functional Limitations 10a - Adult v1.0</b>		
<i>Short Form Conversion Table</i>		
<b>Raw Score</b>	<b>T-score</b>	<b>SE*</b>
0	29.7	4.7
1	34.9	3.4
2	38.0	3.0
3	40.3	2.7
4	42.1	2.5
5	43.8	2.4
6	45.2	2.3
7	46.5	2.2
8	47.8	2.2
9	49.0	2.2
10	50.1	2.1
11	51.2	2.1
12	52.3	2.1
13	53.4	2.1
14	54.4	2.0
15	55.4	2.0
16	56.4	2.0
17	57.4	2.0
18	58.4	2.0
19	59.4	2.0
20	60.4	2.1
21	61.4	2.1
22	62.4	2.1
23	63.5	2.2
24	64.7	2.2
25	66.0	2.3
26	67.3	2.4
27	68.9	2.6
28	70.7	2.8
29	73.0	3.2
30	76.7	4.1

SE\* = Standard Error on T-Score metric



<b>Dyspnea Severity 10a - Adult v1.0</b>		
<i>Short Form Conversion Table</i>		
<b>Raw Score</b>	<b>T-Score</b>	<b>SE*</b>
0	27.7	4.7
1	32.8	3.7
2	36.1	3.2
3	38.6	2.8
4	40.6	2.6
5	42.3	2.4
6	43.8	2.2
7	45.2	2.2
8	46.4	2.1
9	47.6	2.1
10	48.8	2.0
11	50.0	2.0
12	51.1	2.0
13	52.1	1.9
14	53.2	1.9
15	54.2	1.9
16	55.2	1.9
17	56.2	1.9
18	57.2	1.9
19	58.1	1.9
20	59.2	1.9
21	60.2	2.0
22	61.2	2.0
23	62.3	2.0
24	63.5	2.1
25	64.8	2.1
26	66.1	2.3
27	67.7	2.4
28	69.5	2.6
29	71.9	3.0
30	75.9	4.0

SE\* = Standard Error on T-Score metric