PROMIS+HEART FAILURE PROFILES
SCORING MANUAL

A brief guide to scoring the PROMIS®+Heart Failure (PROMIS+HF) profiles:

ADULT
PROMIS+Heart Failure-27 Profile v1.0 PROMIS+Heart Failure-10 Profile v1.0

SCORES

Summary Scores

The PROMIS+Heart Failure-27 Profile v1.0 (PROMIS+HF-27) and PROMIS+Heart Failure-10 Profile v1.0 (PROMIS+HF-10) instruments produce four summary scores: physical health summary, mental health summary, social health summary, and overall health summary. These summary scores are on a scale of 0 to 100 with a high score representing better health. Scoring of the summary scores can be performed by using the scoring equations provided in this manual. Scoring for the summary scores is also available for REDCap and SAS.

Domain T-Scores

PROMIS T-Scores can be calculated for selected domains. For the PROMIS+HF-27, T-scores can be calculated for Dyspnea Severity, Fatigue, Physical Function, Sleep Disturbance, Pain Interference, Depression, Cognitive Function, and Ability to Participate in Social Roles and Activities. For the PROMIS+HF-10, T-scores can be calculated for Dyspnea Severity, Fatigue, Physical Function, Sleep Disturbance, Depression, and Ability to Participate in Social Roles and Activities. T-scores can be generated using the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoringservice) or using the instructions and tables in this Scoring Manual.

For PROMIS T-scores, 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. 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 positively-worded concepts like Physical Function, Cognitive Function, and Ability to Participate in Social Roles and Activities, a T-score of 60 is one SD better than average. By comparison, a Physical Function T-score of 40 is one SD worse than average. For negatively-worded concepts like Dyspnea Severity, Fatigue, Sleep Disturbance, and Depression, a T-score of 60 is one SD worse than average.

Standard Error (SE): PROMIS scores include a standard error (SE). The standard error is a measure of the variability for a given T-score across hypothetical repeated measurements. The standard error can be used to construct confidence intervals around a T-score. A 95% confidence interval is common. A 95% confidence interval means there is a 95% probability that the true T-score is within this range. The formula for a 95%

confidence interval is (T-score ± (1.96*SE). For example, if T=52 and SE=2, the lower boundary of the confidence interval is (52 – (1.96*2) = 48 and the upper boundary is (52 + (1.96*2) = 56.

SCORING INSTRUCTIONS

PROMIS+HF-27 Profile

The PROMIS+HF-27 produces 4 summary scores: physical health summary, mental health summary, social health summary, and overall health summary. It also produces PROMIS domain-level T-scores for Dyspnea Severity, Fatigue, Physical Function, Sleep Disturbance, Pain Interference, Depression, Cognitive Function, and Ability to Participate in Social Roles and Activities.

Summary Scores

Summary scores are calculated as follows:

1. **Physical Health Summary Score**
   For the physical health summary score, there are five related domains: Dyspnea Severity, Fatigue, Physical Function, Symptoms/Pain Interference (combined into a single domain for scoring), and Sleep Disturbance. All physical health items (except Dyspnea Severity) are scored on a scale of 1-5, and a higher response indicates a more of the domain (example: higher response on a sleep disturbance item indicates more problems with sleep). Dyspnea Severity items are scored on a scale of 0 to 3 plus X as "I did not do this in the past 7 days."

   To calculate the physical health summary score, you must first compute the raw average score (mean) of each individual domain as follows:

   Fatigue raw average score = (FATIMP19 + FATEXP18 + GFATIMP57) / 3
   Physical function raw average score = (PFA23 + PFC56) / 2
   Symptoms/pain interference raw average score = (GSYMP01 + GSYMP02 + GSYMP03 + PAININ5) / 4
   Sleep disturbance raw average score = (Sleep109 + Sleep44) / 2

   For dyspnea severity items, items scored as "X" should be treated as missing.

   Dyspnea severity raw average score = (DYSSV002 + DYSSV008 + DYSSV010) / 3

   The physical health summary score (mean) can then be calculated as follows. Note that the dyspnea severity raw average score is scaled to 1-5 to align with the other domains, and all domains are calculated to be in the same direction (that is, higher score = better health):

   Physical health summary score = ([([6 – fatigue raw average score] + physical function raw average score + [6 – symptom/pain interference raw average score] + [6 – sleep disturbance raw average score] + [5 – 4/3*dyspnea severity raw average score]) / 5] – 1) * 25

2. **Mental Health Summary Score**

For the mental health summary score, there are five related domains: Anxiety, Cognitive Function, Depression, Illness Burden, and Life Satisfaction. All mental health items are scored on a scale of 1-5, in which a higher response indicates a more of the domain (example: higher response on an anxiety item indicates a higher level of anxiety).

To calculate the mental health summary score, you must first compute the raw average score (mean) of each individual domain as follows:

Anxiety raw average score = (GANXW01 + GANXW04) / 2
Cognitive function raw average score = (PC25r + PC49r) / 2
Depression raw average score = (EDDEP19 + EDDEP29 + EDDEP41) / 3
Illness burden raw average score = GBURD02
Life satisfaction raw average score = GF3

The mental health summary score (mean) can then be calculated as follows. All raw average scores are calculated to be in the same direction (that is, higher score = better health):

Mental health summary score = ([([6 – anxiety raw average score] + cognitive function raw average score + [6 – depression raw average score] + [6 – illness burden raw average score] + life satisfaction raw average score) / 5] – 1) * 25

3. **Social Health Summary Score**

For the social health summary score, there are two related domains: Ability to Participate in Social Roles and Activities, and Independence). All social health items are scored on a scale of 1-5, in which a higher response indicates more of the domain (example: higher response on an independence item indicates higher level of independence).

To calculate the social health score, you must first compute the raw average score (mean) of each individual domain as follows:

Ability to participate in social roles raw average score = (SRPPER01r1 + SRPPER02r1) / 2
Independence raw average score= (GINDEP01 + GINDEP02) / 2

The social health summary score (mean) can then be calculated as follows:

Social health summary score = ([(social roles raw average score + independence raw average score) / 2] – 1) * 25

4. **Overall Health Summary Score**
   An overall health summary score can be computed using the calculated summary scores. This overall score is weighted such that the physical health summary score receives twice the weight of mental health and social health summary scores. The overall health summary score is calculated as follows:

   Overall health summary score = [(2 x physical health summary score) + mental health score + social health score] / 4

Missing Data: If data is missing for a particular item, remove that item and calculate raw average score (means) for that domain based on the items available. For example, for the dyspnea severity domain:

missing DYSSV002:
dyspnea severity score = (DYSSV008+DYSSV010) / 2

missing DYSSV002 and DYSSV008:
dyspnea severity score = DYSSV010

Summary scores can be computed regardless of the amount of missing data, however, we recommend that scores are only calculated when the following criteria are met:

1. To calculate a physical health summary score, at least half of items are non-missing within the domain
2. Summary scores for physical, mental, and social health must be present in order to calculate an overall health summary score

Also of note, we recommend physical, mental, and social health summary scores with missing raw average scores for domains are used with caution.

Domain T-Scores

PROMIS T-scores can be calculated for the following domains using the HealthMeasures Scoring Service or tables in this Scoring Manual: Dyspnea Severity, Fatigue, Pain Interference, Physical Function, Sleep Disturbance, Cognitive Function, Depression, and Ability to Participate in Social Roles and Activities. To use the scoring tables in this manual, calculate a summed score for each domain. Each question usually has five response options (with the exception of Dyspnea Severity) ranging in value from 1 to 5. To calculate the total raw summed score for a domain with all items answered, sum the values of the responses to each question. For example, for the Physical Function domain in the PROMIS+HF-27 Profile, the lowest possible total raw summed score is 2 ; the highest possible total raw summed score is 10. **All questions must be answered in order to produce a valid score using the scoring tables**. The table below indicates which items are summed together for each domain. With the total raw summed score for a domain, locate the applicable score conversion table in Appendix 1 and use this table to translate the total raw summed score into a T-score for each participant. The T-score rescales the total raw summed score into a standardized score (a T-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 example, for the adult PROMIS Physical Function domain from the PROMIS+HF-27, a raw score of 4 converts to a T-score of 30.1 with a standard error (SE) of 3.5 (see scoring table for Physical Function for the PROMIS+HF-27 in Appendix 1).

Domain	Items
Dyspnea Severity	DYSSV002, DYSSV008, DYSSV010
Fatigue	FATIMP19, FATEXP18
Physical Function	PFA23, PFC56
Sleep Disturbance	Sleep109, Sleep44
Pain Interference	PAININ5
Cognitive Function	PC25r, PC49r
Depression	EDDEP19, EDDEP29, EDDEP41
Ability to Participate in Social Roles and Activities	SRPPER01r1, SRPPER02r1

PROMIS+HF-10 Profile

The PROMIS+HF-10 produces 4 summary scores: physical health summary, mental health summary, social health summary, and overall health summary. It also produces PROMIS domain-level T-scores for Dyspnea Severity, Fatigue, Physical Function, Sleep Disturbance, Depression, and Ability to Participate in Social Roles and Activities.

Summary Scores

Summary scores are calculated as follows:

1. **Physical Health Summary Score**
   All physical health items (with the exception of dyspnea severity) are scored on a scale of 1-5, in which a higher response indicates a more of the construct being measured (example: higher response on a sleep disturbance item indicates more problems with sleep). The dyspnea severity item on a scale of 0 to 3 plus X as "I did not do this in the past 7 days."

   For the dyspnea severity item DYSSV002, if the score=X, then the item should be treated as missing.

   The physical health summary score (mean) is calculated and scaled on a scale of 0-100 as follows. Note that the dyspnea severity item is scaled to 1-5 to align with the other domain items, and all items are scaled to be in the same direction (that is, higher score = better health):

   Physical health summary score = ([([5 – 4/3*DYSSV002] + [6 – FATIMP19] + PFC56 + [6 – GSYMP01] + [6 – GSYMP03 + [6 –Sleep109])/ 6] – 1) * 25

2. **Mental Health Summary Score**
   All mental health items are scored on a scale of 1-5, in which a higher response indicates a more of the construct being measured (example: higher response on an anxiety item indicates higher level of anxiety).

   The mental health score (mean) is calculated and scaled on a scale of 0-100 as follows. Note that all items are called to be in the direction of higher score = better health:

   Mental health summary score = ([([6 – EDDEP19] + [6 – GANXW04]) / 2] – 1) * 25

3. **Social Health Summary Score**
   All social health items are scored on a scale of 1-5, in which a higher response indicates more of the construct being measured (example: higher response on an independence item indicates higher level of independence).

   The social health summary score (mean) is calculated and scaled on a scale of 0-100 as follows:

   Social health summary score = ([(SRPPER02r1 + GINDEP01) / 2] – 1) * 25

4. **Overall Health Summary Score**
   An overall health summary score can be computed using the calculated summary scores. This summary score is weighted such that physical health receives twice the weight of mental and social health. The overall score is calculated as follows:

   Overall health summary score = (2 x physical health summary score + mental health summary score + social health summary score) / 4

Missing Data: If data is missing for a particular item, remove that item and calculate summary scores (means) based on the items available. For example::

missing DYSSV002:
Physical health summary score = 100 – [([(FATIMP19 + PFC56 + GSYMP01 + GSYMP03 + Sleep109)/ 5] – 1) * 25]

missing EDDEP19:
Mental health summary score = 100 – [(GANXW04 – 1) * 25]

Summary scores can be computed regardless of the amount of missing data, however, we recommend that scores are only calculated when the following criteria are met:

1. To calculate a physical, mental, or social health summary score, at least half of items must be non-missing for each of these scores.
2. Summary scores for physical, mental, and social health summary must be present in order to calculate an overall health summary score

Domain T-Scores

PROMIS T-scores can be calculated for the following domains using the HealthMeasures Scoring Service or tables in this Scoring Manual: Dyspnea Severity, Fatigue, Physical Function, Sleep Disturbance, Depression, and Ability to Participate in Social Roles and Activities. Each domain score is produced by a single item (see table below). Note that T-scores calculated from single items like this are less precise than those calculated with multiple items.

To use the scoring tables in this manual, locate the applicable score conversion table in Appendix 2 and use this table to translate the raw score (0 to 3 for Dyspnea Severity, 1 to 5 for all other domains) into a T-score for each

participant. The T-score rescales the raw score into a standardized score (a T-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 example, for the PROMIS Physical Function domain from the PROMIS+HF-10, a raw score of 4 converts to a T-score of 38.2 with a standard error (SE) of 4.4 (see scoring table for Physical Function for the PROMIS+HF-10 in Appendix 2).

Domain	**Item**
Dyspnea Severity	DYSSV002r
Fatigue	FATIMP19
Physical Function	PFC56
Sleep Disturbance	Sleep109
Depression	EDDEP19
Ability to Participate in Social Roles and Activities	SRPPER02r1

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: 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—PROMIS DOMAIN T-SCORES FOR PROMIS+HF-27

PROMIS+HF-27 – Dyspnea Severity v1.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
0	32.7	5.3
1	39.1	4.3
2	43.4	3.9
3	47	3.8
4	50	3.7
5	52.9	3.6
6	55.8	3.7
7	59.1	4
8	62.9	4.3
9	68.5	5.5
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Fatigue v1.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
2	35.9	5.6
3	43.1	4.2
4	47.6	3.9
5	51.6	3.9
6	55.5	3.8
7	59.5	4
8	63.9	4
9	68.4	4.2
10	74.3	4.6
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Physical Function v2.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
2	22.6	4.6
3	26.6	3.7
4	30.1	3.5
5	33.3	3.4
6	35.8	3.8
7	37.8	3.7
8	40.3	3.8
9	43.5	4
10	54.4	7.6
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Sleep Disturbance v1.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
2	34.9	5.7
3	42.8	4.6
4	47.6	4.5
5	51.4	4.5
6	54.7	4.5
7	57.9	4.6
8	61.4	4.5
9	65.4	4.4
10	71.1	5.1
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Cognitive Function v2.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
2	28.7	5.1
3	33.6	4.2
4	36.7	4.1
5	39.3	4.1
6	41.8	4.1
7	44.4	4.1
8	47.3	4.2
9	50.9	4.4
10	58.9	6.5
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Depression v1.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
3	41.3	6.3
4	49.7	3.5
5	53	3.2
6	55.5	3
7	57.8	2.9
8	59.9	2.8
9	62	2.8
10	64.3	2.9
11	66.7	2.9
12	69	2.9
13	71.5	3
14	74.3	3.1
15	78.4	3.7
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Ability to Participate in Social Roles and Activities v2.0 *Short Form Conversion Table*		
Raw Summed Score	**T-score**	**SE***
2	28.9	4.9
3	33.8	3.8
4	37	3.9
5	40	3.7
6	43.4	3.6
7	47	3.6
8	50.5	3.7
9	54.4	3.9
10	61.7	5.8
*SE = Standard Error on T-score metric		

PROMIS+HF-27 - Pain Interference v1.1 *Short Form Conversion Table*		
Raw Score	**T-score**	**SE***
1	43.9	6.9
2	54.9	3.7
3	60.2	3.7
4	65.1	3.8
5	71.5	4.9
*SE = Standard Error on T-score metric		

APPENDIX 2—PROMIS DOMAIN T-SCORES FOR PROMIS+HF-10

PROMIS+HF-10 - Dyspnea Severity v1.0
Short Form Conversion Table

Raw Score	T-score	SE*
0	43.0	7.3
1	53.2	5.5
2	59.6	5.7
3	66.4	6.7

*SE = Standard Error on T-score metric

PROMIS+HF-10 - Fatigue v1.0
Short Form Conversion Table

Raw Score	T-score	SE*
1	40.2	6.6
2	49.2	4.9
3	55.5	5.0
4	62.3	5.3
5	70.1	6.2

*SE = Standard Error on T-score metric

PROMIS+HF-10 - Physical Function v2.0
Short Form Conversion Table

Raw Score	T-score	SE*
1	24.0	5.7
2	28.5	4.9
3	33.5	4.7
4	38.2	4.4
5	52.4	8.4

*SE = Standard Error on T-score metric

PROMIS+HF-10 - Sleep Disturbance v1.0 *Short Form Conversion Table*		
Raw Score	**T-score**	**SE***
1	36.0	6.2
2	45.6	5.3
3	53.9	5.2
4	61.2	5.1
5	68.2	6.1
*SE = Standard Error on T-score metric		

PROMIS+HF-10 - Depression v1.0 *Short Form Conversion Table*		
Raw Score	**T-score**	**SE***
1	45.1	7.6
2	55.7	4.9
3	60.6	5.2
4	66.0	5.5
5	71.5	6.5
*SE = Standard Error on T-score metric		

PROMIS+HF-10 - Ability to Participate in Social Roles and Activities v2.0 *Short Form Conversion Table*		
Raw Score	**T-score**	**SE***
1	33.3	5.7
2	39.8	4.4
3	45.2	4.5
4	51.2	4.4
5	60.1	6.3
*SE = Standard Error on T-score metric		