
APPENDICES

Appendix A. Survey Instrument for People With Heart Failure

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Survey instrument overview

Instruments administered in field-testing with the cross-sectional and longitudinal samples included the following components:

1. Demographics
2. PROMIS Global Health Measure (10-item short form)
3. New and existing PROMIS items: Items were grouped and block-randomized by domain type (mental, physical, and social)
4. Global Rating of Change Scale (GRCS)
5. Condition-specific legacy instrument: Kansas City Cardiomyopathy Questionnaire (KCCQ)

Only participants in the longitudinal study were asked to complete the GRCS. This scale was used to obtain patient's perceptions of the extent to which their health had changed since baseline in each of the domains being measured. The assessment ranged from very much worse (-4) to very much better (+4). Patients in the longitudinal sample were also asked to set a goal at baseline and then rate their achievement of that goal at 3-month follow-up.

Domain definitions for the existing PROMIS domains can be found on the HealthMeasures website: <http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures>. Definitions for the newly created PROMIS domains are:

- *Life satisfaction*: Appreciation for and enjoyment of life, including impact of illness on life satisfaction.
- *Symptoms*: Physical changes or sensations specific to the illness or condition.
- *Health behavior outcomes*: Behaviors associated with health improvement or health maintenance, such as dietary intake, exercise, etc.
- *Illness burden*: Behavioral, psychological or emotional burden of managing illness and/or living with illness.
- *Independence*: Loss of independence due to illness or condition. Includes reliance on others for assistance, fears of losing independence, and desire to regain independence.

The following tables contain the new and existing PROMIS items administered in field-testing, organized by the category (Mental, Physical, Social) and domain.

Appendix A, Table 1: New and Existing PROMIS items for Heart Failure, Mental category

Instrument	Item	Responses and Scores
Anger		
New PROMIS	In the past 7 days... I felt frustrated by my health.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Anxiety		
New PROMIS	In the past 7 days... I worried about losing my independence.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried about fainting.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried that I would get swelling in my feet or legs.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried that my health would get worse	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried about dying.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Cognitive Abilities		
Existing PROMIS	In the past 7 days... I have been able to bring to mind words that I wanted to use while talking to someone	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... I have been able to concentrate	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... My ability to concentrate has been good	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Cognitive Function		
Existing PROMIS	In the past 7 days... My thinking has been slow	5=Never, 4=Rarely (Once), 3=Sometimes (Two or three times), 2=Often (About once a day), 1=Very often (Several times a day)
Existing PROMIS	In the past 7 days... I have had to work really hard to pay attention or I would make a mistake	5=Never, 4=Rarely (Once), 3=Sometimes (Two or three times), 2=Often (About once a day), 1=Very often (Several times a day)
Existing PROMIS	In the past 7 days... I have been upset about my problems with memory, concentration, or making mental mistakes	5=Never, 4=Rarely (Once), 3=Sometimes (Two or three times), 2=Often (About once a day), 1=Very often (Several times a day)

Instrument	Item	Responses and Scores
Depression		
Existing PROMIS	In the past 7 days... I felt helpless	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... I felt sad	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... I felt that I wanted to give up on everything	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... I felt depressed	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... I felt unhappy	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... I felt hopeless	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Illness Burden		
New PROMIS	In the past 7 days... Did you feel pressure to lose weight?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... Did you feel burdened by having to monitor your health?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... Did you feel burdened by having to monitor your weight?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... Did you feel burdened by restrictions on what you could eat or drink?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Life Satisfaction		
New PROMIS	Does your health now limit you in achieving your goals?	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
New PROMIS	In the past 7 days... I am able to enjoy life.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much

Appendix A, Table 2: New and Existing PROMIS items for Heart Failure, Physical category

Instrument	Item	Responses and Scores
Dyspnea		
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Walking 50 steps/paces on flat ground at a normal speed without stopping	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Lifting something weighing 10-20 lbs. (about 4.5-9 kg, like a large bag of groceries)	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Walking (faster than your usual speed) for ½ mile (almost 1 km) without stopping	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Walking 10 steps/paces on flat ground at a normal speed without stopping	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Walking up 5 stairs without stopping	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Walking up 10 stairs (1 flight) without stopping	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Lifting something weighing less than 5 lbs. (about 2 kg, like a houseplant)	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Lifting something weighing 5-10 lbs. (about 2-4.5 kg, like a basket of clothes)	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days

Instrument	Item	Responses and Scores
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Lifting something weighing more than 20 lbs. (about 9 kg, like a medium-sized suitcase)	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Existing PROMIS	Over the past 7 days, how short of breath did you get with each of these activities?: Carrying something weighing less than 5 lbs. (about 2 kg, like a houseplant) from one room to another	1=No shortness of breath, 2=Mildly short of breath, 3=Moderately short of breath, 4=Severely short of breath, 5=I did not do this in the past 7 days
Fatigue		
Existing PROMIS	In the past 7 days... To what degree did you have to push yourself to get things done because of your fatigue?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... How often did your fatigue make you feel slowed down in your thinking?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... How often did you have to limit your social activities because of your fatigue?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... How often were you too tired to do your household chores?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... How often did you run out of energy?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days... How often did you feel tired?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	During the past 7 days... I feel weak all over	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	During the past 7 days... I feel tired	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	During the past 7 days... I have energy	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
Existing PROMIS	During the past 7 days... I am able to do my usual activities	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
New PROMIS	In the past 7 days... How often did you need to take breaks to finish daily tasks?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always

Instrument	Item	Responses and Scores
Health Behavior Outcomes		
New PROMIS	In the past 7 days... Were you able to control your salt intake?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... Were you able to keep a healthy diet?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... Were you able to control your weight?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Pain Interference		
Existing PROMIS	In the past 7 days... How much did pain interfere with your ability to participate in leisure activities?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... How much did pain interfere with your ability to concentrate?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Physical Function		
Existing PROMIS	Does your health now limit you in bending, kneeling, or stooping?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Existing PROMIS	Does your health now limit you in doing heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Existing PROMIS	Are you able to push open a heavy door?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to go for a walk of at least 15 minutes?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Does your health now limit you in going OUTSIDE the home, for example to shop or visit a doctor's office?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Existing PROMIS	Are you able to walk a block (about 100 m) on flat ground?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to run 100 yards (100 m)?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do

Instrument	Item	Responses and Scores
Existing PROMIS	Are you able to walk up and down two steps?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Does your health now limit you in climbing one flight of stairs?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Existing PROMIS	Does your health now limit you in walking about the house?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Sleep Disturbance		
Existing PROMIS	In the past 7 days... My sleep quality was...	5=Very poor, 4=Poor, 3=Fair, 2=Good, 1=Very good
Existing PROMIS	In the past 7 days... I got enough sleep.	5=Never, 4=Rarely, 3=Sometimes, 2=Often, 1=Always
Existing PROMIS	In the past 7 days... I had a problem with my sleep.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... I had difficulty falling asleep.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... I tried hard to get to sleep.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days... I had trouble sleeping.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Symptoms		
New PROMIS	In the past 7 days... Did you feel dizzy or lightheaded?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... Did you have chest pain?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... Did you have swelling in your feet or legs?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always

Appendix A, Table 3: New and Existing PROMIS items for Heart Failure, Social category

Instrument	Item	Responses and Scores
Ability to Participate in Social Roles and Activities		
Existing PROMIS	I have trouble doing my regular daily work around the house	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble meeting the needs of my family	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I am limited in doing my work (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing everything for my family that I feel I should do	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble accomplishing my usual work (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing everything for work that I want to do (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Independence		
New PROMIS	In the past 7 days... Were you dependent on others to get things done?	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
New PROMIS	Does your health now limit you in doing things that make you feel independent?	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
New PROMIS	In the past 7 days... I was satisfied with my ability to be independent.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Satisfaction with Social Roles and Activities		
Existing PROMIS	I am satisfied with my ability to maintain friendships	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with how much work I can do (include work at home)	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to work (include work at home)	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do household chores/tasks	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do things for fun at home (like reading, listening to music, etc.)	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much

Instrument	Item	Responses and Scores
Existing PROMIS	I am satisfied with the amount of time I spend performing my daily routines	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Social Isolation		
Existing PROMIS	People get the wrong idea about my situation	1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always
Existing PROMIS	I feel left out	1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always