

# Assessing Person-Centered Health Outcomes in Heart Failure

*These recommendations are offered as a starting point for consideration. They are not necessarily the best choices for every application and do not substitute for a comprehensive literature review.*

## Key Domains to Consider for Heart Failure

Heart failure is a common, chronic, and life-threatening condition that is most typically associated with reduced **physical functioning** and increased **fatigue** and **dyspnea** (shortness of breath). Patient-centered health outcomes measures have been used successfully in observational studies and clinical trials to inform clinical decision making, target healthcare resources, enable accurate surveillance of and quantify disease burden in cardiology, and in quality improvement initiatives. In 2013, the American Heart Association issued a statement advocating for broader inclusion of patient-reported health status as a key measure of cardiovascular health in clinical research, clinical practice, and disease surveillance.

## Suggested HealthMeasures for Primary Domains in Heart Failure

### Physical Function

Because heart failure results in a significant compromise to the patient's overall ability to function physically, this domain is of primary importance to assess. Thus, we recommend the Patient-Reported Outcomes Measurement Information System® (PROMIS®) Physical Function Computer Adaptive Test (CAT ; V1.0 bank; 4-12 questions), which measures mobility and upper extremity function. A CAT maximizes score precision for the most possible patients and minimizes how many questions a patient has to answer, but must be computer-administered. If CAT is not possible, the Physical Function V1.0 10a (10 questions) short form is available. Additionally, the NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox®) also offers measures administered by a trained proctor to evaluate motor function. The full battery takes about 30 minutes.

### Fatigue

The PROMIS Fatigue CAT (V1.0 bank; 4-12 questions) is appropriate for patients with heart failure, and the PROMIS Fatigue V1.0 7a (7 questions) short form is available if a CAT is not feasible. PROMIS Fatigue measures assess experience of fatigue (frequency, duration, and intensity) and the impact of fatigue on physical, mental, and social activities.

### Dyspnea

Dyspnea is one of the more prominent symptoms of heart failure. PROMIS offers two CATs (V1.0 banks; 4-12 questions each) and two V1.0 10-item short forms that measure severity of dyspnea (Severity) and functional limitations resulting from dyspnea (Functional Limitations), both in the context of activities. Because the two domains are highly correlated, we recommend administering only one. The measures have been validated in chronic obstructive pulmonary disease but are not disease-specific.

## Summary

- Recommended primary domains include physical function, fatigue and dyspnea. On average, this would involve administration of about 15 questions, requiring 3-4 minutes to complete.
- HealthMeasures offers brief, psychometrically sound measures for these domains.
- Evaluating patients both pre- and post-intervention is most useful.

## Suggested HealthMeasures for Secondary Domains in Heart Failure

Because of the impact of heart failure on a patient's physical functioning, other health status domains can also be compromised. Thus, we recommend secondary domains that may be important to include in a comprehensive assessment of health outcomes.

Secondary HealthMeasures	Description
PROMIS Depression CAT <u>or</u> Depression 4a (4 questions) short form	Negative mood, negative views of self, negative social cognition, decreased positive affect and engagement
PROMIS Anxiety CAT <u>or</u> Anxiety 4a (4 questions) short form	Self-reported fear, anxious misery, hyperarousal, and somatic symptoms related to arousal
PROMIS Cognitive Function 8a (8 questions) short form <u>or</u> NIH Toolbox Cognition Battery (30 minutes)	PROMIS: Concerns and perceived decline in mental acuity, concentration, verbal and nonverbal memory, verbal fluency; NIH Toolbox: <b>Executive Function, Attention, Episodic Memory, Language, Processing Speed and Working Memory</b>
PROMIS Satisfaction with Social Roles and Activities 4a (4 questions) short form; Ability to Participate in Social Roles and Activities 4a (4 questions) short form; Social Isolation 4a (4 questions) short form	Satisfaction: Satisfaction with performing one's usual social roles and activities; Ability: Perceived ability to perform one's usual social roles and activities; Isolation: Perceptions of being avoided, excluded, detached, disconnected from, or unknown by others
PROMIS-29 Profile (29 questions)	Physical Function, Fatigue, Pain Interference, Pain Intensity, Sleep Disturbance, Depression, Anxiety, Ability to Participate in Social Roles and Activities, with scores produced for each domain and one pain intensity item
PROMIS Global Health Scale (10 questions)	Global ratings of general health. Scores are produced for physical health and mental health.

### Primary HealthMeasures for Heart Failure Patients

- PROMIS Physical Function Computer Adaptive Test (CAT) or PROMIS Physical Function Short form 10a.
- NIH Toolbox Motor Battery (ages 7+)
- PROMIS Fatigue CAT or PROMIS Fatigue 7a short form.
- PROMIS Dyspnea V1.0 CAT or PROMIS Dyspnea 10-item short forms.

### Learn More!

You can read about CATs and watch a video tutorial at the HealthMeasures.net website [here!](#)

## Assessment Times

Ideally, a pre-intervention or pre-surgery assessment should be captured to serve as a reference point for monitoring response to treatment, with a follow-up assessment outside of the post-operative recovery period or post intervention. Assessment can also be used to measure decompensation, stability and improvement in people with stable heart failure.

## Additional Information

The [www.HealthMeasures.net](http://www.HealthMeasures.net) website includes more information about measurement selection, data collection tools, scoring, and interpretation. Its *Search for Measures* tool includes access to all HealthMeasures described here. A Forum allows for questions and responses from the HealthMeasures community. The HealthMeasures team is also available for collaboration or consultation via [help@healthmeasures.net](mailto:help@healthmeasures.net).