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.

Summary of Recommended Domains and HealthMeasures
- 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.

Key Domains to Consider in 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 clinical trials, observational studies, to inform clinical decision making, to target healthcare resources, to 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

Primary Domains to Consider in Heart Failure

Physical Function
Because heart failure results in a significant comprise to the patient’s overall ability to function physically, this domain is of primary importance. A computer adaptive test (CAT) maximizes the precision of the score for the most possible patients and minimizes how many questions a patient has to answer (but requires a computer for administration). Thus, we recommend the Physical Function CAT (V1.0 bank; 4-12 questions), which measures mobility and upper extremity physical function and handles patients ranging from high to low in their physical function. If CAT is not possible, the Physical Function V1.0 10a (10 questions) short form is available.

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.

Learn More! You can read about CATs and watch a video tutorial at the HealthMeasures.net website here!
Dyspnea

Dyspnea is one of the prominent symptoms of heart failure. PROMIS includes two CATs (V1.0 banks; 4-12 questions each) and two V1.0 10-item short forms that measure the Severity of dyspnea and dyspnea-related Functional Limitations, both in the context of a set specified activities. The two domains are highly correlated, so we recommend administering only one of them.

Secondary Domains to Consider in Heart Failure

Because of the impact of heart failure on a patient’s physical functioning, other health status domains can also be impacted and represent secondary domains worth assessment.

<table>
<thead>
<tr>
<th>Secondary HealthMeasures</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROMIS Depression CAT or Depression 4a (4 questions) short form</td>
<td>Negative mood, negative views of self, negative social cognition, decreased positive affect and engagement</td>
</tr>
<tr>
<td>PROMIS Cognitive Function 8a (8 questions) short form or NIH Toolbox Cognition Battery (30 minutes)</td>
<td>PROMIS: Concerns and perceived decline in mental acuity, concentration, verbal and nonverbal memory, and verbal fluency; NIH Toolbox: Assessment of Executive Function, Attention, Episodic Memory, Language, Processing Speed and Working Memory</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td>PROMIS-29 Profile (29 questions)</td>
<td>Measures Physical Function, Fatigue, Pain Interference, Pain Intensity, Sleep Disturbance, Depression, Anxiety, Ability to Participate in Social Roles and Activities</td>
</tr>
<tr>
<td>PROMIS Global Health Scale (10 questions)</td>
<td>Global ratings of general health. Scores are produced for physical health and mental health.</td>
</tr>
</tbody>
</table>

Depending on the clinical and/or research focus, additional HealthMeasures instruments that may be relevant for heart failure include anger, anxiety, sleep disturbance, sexual function and self-efficacy. Heart failure-relevant areas that HealthMeasures does not address include additional symptoms (peripheral edema, dizziness, weakness, and chest pain), caregiver burden and loss of independence.

Assessment Times

Ideally, a pre-surgery or pre-intervention assessment would 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.

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 for clinical research, clinical practice, and information technology via [healthmeasures@northwestern.edu](mailto:healthmeasures@northwestern.edu).