Assessing Person-Centered Health Outcomes in Anemia

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 in Anemia

Anemia and its treatments can have significant impacts on an individual's global health, particularly fatigue and physical function. Related issues include depression, cognitive function, ability to participate in social roles and activities, physical function, anxiety, and sleep disturbance. Patient-reported outcome (PRO) assessments of these domains in anemia have been used successfully in research settings. More recently, there has been a move to use PRO assessments in quality improvement initiatives and healthcare delivery settings. This guidance includes relevant PROMIS® measures but does not include anemia-specific PRO measures.

Suggested HealthMeasures for Primary Domains in Anemia

Fatigue
Persistent and chronic fatigue is the most prevalent symptom among individuals with anemia. The PROMIS Fatigue measure assesses the extent of fatigue experienced and the effect of that fatigue on daily activities including physical function. Optimal management of anemia can improve an individual’s fatigue and fatigability. The PROMIS Fatigue Measure is available as an 8-item short form or via CAT. In clinical research, one might also consider the PROMIS Fatigue-13a short form (aka FACIT Fatigue Scale), because it has been used in several dozen clinical trials and has been published extensively.

Physical Function
The interplay of an individual’s physical function and fatigue suggests that the use of the two measures together may facilitate a more complete characterization of the patient’s experience of anemia. The PROMIS Physical Function Measure is available as a 10-item short form or via CAT. The PROMIS Physical Function Upper Extremity CAT or 7-item short form is a useful addition for patients with concerns specific to the upper body.

Global Health
Global health refers to the general domains of health and functioning including overall physical health, mental health, social health, pain, fatigue, and overall perceived quality of life. The PROMIS Global Health 10-item scale assesses each of these facets for individuals with anemia and provides overall physical and mental health scores.

Summary

- Recommended primary domains for Anemia include fatigue, physical function, and global health
- Recommended secondary domains for Anemia include Ability to Participate in Social Roles and Activities, Depression, Anxiety, Cognitive Function Abilities, Sleep Disturbance, and Dyspnea – Functional Limitations
- HealthMeasures offers brief, psychometrically sound measures for these domains.
- Recommended assessment times include those scheduled to capture the effects of treatment and disease course.
Suggested HealthMeasures for Secondary Domains in Anemia

Anemia impacts many other aspects of a person’s physical, emotional and social functioning. While many of these domains are covered briefly in the Global Health instrument, the measures listed below will give you a more detailed look into each of these areas of symptoms and function relevant to patients with anemia:

<table>
<thead>
<tr>
<th>Secondary HealthMeasures</th>
<th>Description</th>
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<tr>
<td>PROMIS Cognitive Function 8-item short form or PROMIS CAT</td>
<td>Patient-perceived functional abilities with regard to cognitive tasks, including the perception that one’s cognitive ability with regard to the domain of inquiry (e.g., concentration, memory) has not changed</td>
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<tr>
<td>PROMIS Ability to Participate in Social Roles and Activities 8-item short form or CAT</td>
<td>Perceived ability to perform one’s usual social roles and activities (e.g., “I have to limit my regular family activities”)</td>
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<tr>
<td>PROMIS Depression 8-item short form or PROMIS CAT</td>
<td>Self-reported negative mood, views of self and social cognition, as well as decreased positive affect and engagement.</td>
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<td>PROMIS Anxiety 8-item short form or PROMIS CAT</td>
<td>Self-reported fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms related to arousal (racing heart, dizziness)</td>
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<tr>
<td>PROMIS Dyspnea - Functional Limitations 10a short form or CAT</td>
<td>Self-reported 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).</td>
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<tr>
<td>PROMIS Sleep Disturbance 8-item short form or PROMIS CAT</td>
<td>Perceptions of sleep quality, sleep depth, and restoration associated with sleep.</td>
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Assessment Times

Ideally, a pre-intervention assessment should be captured to serve as a reference point (i.e., baseline) for monitoring response to treatment, with periodic assessments after initiation of and during therapy. Assessment can also be used to measure stability and improvement in people with stable Anemia.

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 and View Measures](http://www.HealthMeasures.net) 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).