

Assessing Person-Centered Health Outcomes in Pediatric Cancer Patients

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 Pediatric Cancer

Pediatric cancer and its treatments have a significant impact on a child's **physical functioning** and symptoms of **fatigue, pain, anxiety** and **depression**. In addition, **family relationships** are critically important for the child's care. Patient-reported assessments have long been used successfully in oncology clinical trials, observational studies, population surveillance studies, and, more recently, quality improvement initiatives and healthcare delivery settings to capture these effects.

Suggested HealthMeasures for Primary Domains in Pediatric Cancer

Physical Function-Mobility

The PROMIS® Pediatric Physical Function Mobility measure assesses self-reported functioning over the past 7 days in regard to walking and lower body mobility. The PROMIS – Physical Function Mobility is available as an 8-item short form or Computerized Adaptive Testing (CAT) based assessment.

Fatigue

Fatigue is a common symptom resulting from both illness and therapy. The PROMIS Pediatric Fatigue measure assesses a person's experience of fatigue (frequency, duration, and intensity) and the impact of fatigue on physical, mental, and social activities. It is available as a 10-item short form or via CAT.

Pain Interference

The PROMIS Pediatric Pain Interference assesses pain experiences of anger, difficulty sleeping, paying attention, performing physical activities and participating in daily activities. It is available as an 8-item short form or CAT assessment.

Anxiety

The PROMIS Pediatric Anxiety measure assesses emotions of nervousness, worried, scared and dread. It is available as an 8-item short form or CAT assessment.

Depressive Symptoms

The PROMIS Pediatric Depressive Symptoms measure assesses affective symptoms of sadness, loneliness, unhappiness and inability to enjoy usual activities. It is available as an 8-item short form or CAT assessment.

Family Relationships

The PROMIS Pediatric Family Relationships scale assesses elements of a child's social-emotional support, security, connection, and acceptance in the family. The measure is available as an 8-item short form or CAT assessment.

Summary

- Recommended primary domains for pediatric cancer research or care include mobility, fatigue, pain interference, anxiety, depression, and family relationships.
- Recommended Secondary Measures include cognitive functioning and peer relationships.
- HealthMeasures offers brief, psychometrically sound measures for these domains.
- Recommended assessment times include those scheduled to capture the effects of treatment as well as longer-term outcomes, such as survivorship.

Suggested HealthMeasures for Secondary Domains in Pediatric Cancer

Because pediatric cancer impacts many aspects of a person's physical, emotional and social functioning, other health status and quality of life domains can also be significantly impacted and represent secondary domains worth assessment:

Secondary HealthMeasures	Description
PROMIS Pediatric Cognitive Function 7-item short form (or CAT) or NIH Toolbox® Cognition Battery (approx. 30 min.)	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
PROMIS Pediatric Peer Relationships 8-item short form (or CAT)	Assesses acceptance among friends/peers and strength of friendships.
PROMIS Pediatric Sleep Disturbance 8-item short form (or CAT)	Assesses reported thoughts of one's sleep quality, and perceived difficulties with falling or staying asleep. Conceptual facets include sleep quality, sleep onset, and sleep continuity.
PROMIS Pediatric-49 Profile (In place of primary and secondary measures)	Used in place of the individual primary and secondary domains, the PROMIS Pediatric-37 Profile Measures Physical Function-Mobility, Fatigue, Pain Interference, Pain Intensity, Sleep Disturbance, Depressive Symptoms, Anxiety, and Peer Relationships
PROMIS Pediatric Scale – Global Health 7 +2	Assesses global health and quality of life, depressive mood, peer relationships, family relationships, tiredness and difficulty sleeping.

Note: There are a number of treatment adverse events that are relevant but not currently included in PROMIS for pediatric patients; including neuropathy, nausea, vomiting, hair loss, diarrhea, and constipation.

Assessment Times

Ideally, a pre-treatment assessment should be captured to serve as a baseline point for monitoring response to treatment, with follow-up assessments more frequently during treatment (eg. weekly or bi-weekly during chemotherapy) and monthly to every 6-months after treatment ends.

Additional Information

The www.HealthMeasures.net website includes more information about measurement selection, data collection tools, scoring, and interpretation. Its [Search and View 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.

Primary HealthMeasures for Pediatric Cancer Patients

- PROMIS Physical Function – Mobility 8-item short form or CAT
- PROMIS Pediatric Fatigue 10-item short form or CAT.
- PROMIS Pediatric Pain Interference 8-item short form or CAT.
- PROMIS Pediatric Anxiety 8-item short form or CAT.
- PROMIS Pediatric Depressive Symptoms 8-item short form or CAT.
- PROMIS Pediatric Family Relationships 8-item short form or CAT.

Learn More!

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