

Assessing Person-Centered Health Outcomes in Patients with Juvenile Idiopathic Arthritis (JIA)

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 Juvenile Idiopathic Arthritis (JIA)

JIA and its treatments can significantly impact an individual's well-being. Common symptoms are waxing and waning levels of **pain intensity, pain interference, pain behavior, fatigue, sleep disturbance and depression, as well as decreased physical function and ability to participate in social roles and activities**. Patient-reported outcome (PRO) assessments of these domains in JIA have been used successfully in research settings and are beginning to move into quality improvement initiatives and healthcare delivery settings.

Suggested HealthMeasures for Primary Domains in JIA

Pain - Interference

Pain interference, or the extent to which pain hinders engagement with social, cognitive, emotional, physical, educational and recreational activities, is one of the primary areas of concern in JIA due to the chronicity of pain involved. The PROMIS® Pediatric Pain Interference measure is available as an 8-item short form or via computerized adaptive test (CAT).

Pain – Intensity

Joint pain is one of the primary symptoms in JIA and is often chronic and low grade. The PROMIS Pediatric Pain Intensity short form can quickly assess how much a child hurts or identify change in pain levels across treatment periods if repeated periodically. The PROMIS Pediatric Pain Intensity measure is available as a 3-item short form.

Physical Function – Mobility and Upper Extremity

JIA often impacts physical function due to joint pain, swelling, and stiffness. The PROMIS Pediatric Physical Function measures assess self-reported functioning of one's upper extremities (dexterity) and lower extremities (walking or mobility) such as getting dressed or walking up stairs. There are separate measures of Physical Functioning: PROMIS Pediatric – Physical Function Mobility and PROMIS Pediatric – Upper Extremity. Both are available as 8-item short forms or CAT assessment.

Fatigue

Persistent fatigue is a common symptom in JIA patients. The PROMIS Pediatric Fatigue (FACIT-Fatigue) measure assesses a child's experience of fatigue (frequency, duration, and intensity) and the impact of fatigue on physical, mental, and social activities including such areas as sports, attention, and school. It is available as a 10-item short form or via CAT assessment.

Summary

- Recommended primary domains for JIA include Pain (intensity and interference), Physical Function, and Fatigue.
- Recommended secondary domains for JIA include Pain Behavior, Depression, Anxiety 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.

Suggested HealthMeasures for Secondary Domains in Juvenile Idiopathic Arthritis

Arthritis may impact many aspects of a child's physical, emotional, social, and school functioning, which means that other health status and quality of life domains can also be significantly impacted and represent secondary domains worth assessment:

Secondary HealthMeasures	Description
PROMIS Pediatric Pain Behavior 8-item short form or CAT	Measures external manifestations of pain: behaviors that typically indicate to others that a child is experiencing pain (e.g. observable displays (sighing, crying), pain severity behaviors (resting, guarding, facial expressions, and asking for help), and verbal reports of pain).
PROMIS Pediatric Depressive Symptoms 8-item short form or CAT	Assesses negative mood (sadness, guilt), views of self (self-criticism, worthlessness), and social cognition (loneliness, interpersonal alienation), as well as decreased positive affect and engagement (loss of interest, meaning, and purpose).
PROMIS Pediatric Anxiety 8-item short form of CAT	Assesses self-reported fear, anxious misery, hyperarousal, and somatic symptoms related to arousal.
PROMIS Pediatric Peer Relationships 8-item short form or CAT	Assesses the perceived ability to perform one's usual social roles and activities.

Assessment Times

Ideally, a pre-intervention or pre-surgery (i.e., baseline) PRO 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. More frequent assessments (e.g., weekly) will occur around the period and less frequent assessments (e.g., monthly, 6-months) will occur post-treatment when the child's health is stable.

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 Arthritis Patients

- PROMIS Pediatric Pain Interference 8-item short form or CAT
- PROMIS Pediatric Pain Intensity 3-item short form
- PROMIS Pediatric Physical Function – Mobility and PROMIS Pediatric Physical Function – Upper Extremity; 8-item short forms or CAT
- PROMIS Pediatric Fatigue (FACIT-Fatigue) 10-item short form or CAT

Learn More!

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