

Assessing Person-Centered Health Outcomes in Adults with Inflammatory Bowel Disease (IBD)

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 IBD

IBD and its management can have a significant impact on an individual's symptoms of **belly pain, diarrhea, constipation, fatigue, pain interference, anxiety** and **depression, sleep disturbance, and ability to participate in social roles and activities**. Patient-reported outcome (PRO) assessments of these domains in IBD have been used successfully in research settings. More recently, there has been a move to use PRO assessments in clinical trials, quality improvement initiatives, and healthcare delivery settings. This guidance includes relevant PROMIS® measures but does not include IBD-specific PRO measures.

Suggested HealthMeasures for Primary Domains in IBD

Gastrointestinal – Belly Pain

The Patient-Reported Outcomes Measurement Information System (PROMIS) Gastrointestinal – Belly Pain 5-item scale assesses the severity of belly pain in adult populations. It evaluates intensity, nature (sharp vs. dull), frequency, bothersomeness, and predictability (e.g. ability to tell in advance when a pain episode would occur) when measuring belly pain severity.

Gastrointestinal – Diarrhea

The PROMIS Gastrointestinal – Diarrhea 6-item scale assesses the frequency, form, bothersomeness, impact, controllability, and predictability of bowel urgency.

Gastrointestinal – Constipation

The PROMIS Gastrointestinal – Constipation 9-item scale assesses the frequency, intensity, bothersomeness, and/or impact the many facets of constipation, including incomplete evacuation, straining, infrequent stools, hard stools, associated symptoms of rectal pain, and need for manual maneuvers to facilitate stool evacuation.

Summary

- Recommended primary domains for IBD research or care include belly-pain, diarrhea, and constipation.
- Recommended secondary domains for IBD research or care include Fatigue, Pain Interference, Anxiety, Depression, Sleep Disturbance, Ability to Participate in Social Roles and Activities. (PROMIS-57 Profile may be used in lieu of individual instruments.)
- 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 IBD

IBD may impact many aspects of a person's physical, emotional and social 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 Fatigue (FACIT-Fatigue) 13a short form or CAT	Assesses experience of fatigue (frequency, duration, and intensity) and the impact of fatigue on physical, mental, and social activities.
PROMIS Pain Interference 6a short form or CAT	Assesses the extent to which pain hinders engagement with social, cognitive, emotional, physical, and recreational activities.
PROMIS Anxiety 8a short form or CAT	Self-reported fear, anxious misery, hyperarousal, and somatic symptoms related to arousal.
PROMIS Depression 8a short form or CAT	Negative mood, negative views of self, negative social cognition, decreased positive affect and engagement.
PROMIS Sleep Disturbance 8a short form or CAT	Perceptions of sleep quality, sleep depth, and restoration associated with sleep.
PROMIS Ability to Participate in Social Roles and Activities 8a short form or CAT	Perceived ability to perform one's usual social roles and activities (e.g., "I have to limit my regular family activities")
PROMIS-57 Profile (8 items per domain)	In place of the individual measures above, the PROMIS-57 measures Physical Function, Fatigue, Pain Interference, Pain Intensity, Sleep Disturbance, Depression, Anxiety, Ability to Participate in Social Roles and Activities.

Primary HealthMeasures for IBD Patients

- PROMIS Gastrointestinal – Belly Pain 5a scale
- PROMIS Gastrointestinal – Diarrhea 6a scale
- PROMIS Gastrointestinal – Constipation 9a scale

Learn More!

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

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 a follow-up assessment post intervention. Assessment can also be used to measure stability and improvement in people with stable IBD.

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.