Assessing Person-Centered Health Outcomes in Adults with Fibromyalgia

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 Fibromyalgia
Fibromyalgia and its treatments can have a significant impact on an individual’s symptoms of pain intensity, pain interference, physical function, fatigue, depression, anxiety, cognitive function, and sleep-related impairment. Patient-reported assessments can be used in both clinical care and clinical research for diagnosing, monitoring, and characterizing symptom burden and functional impact from fibromyalgia.

Suggested HealthMeasures for Primary Domains in Fibromyalgia

**Pain – Intensity and Interference**
Pain is the primary symptom in fibromyalgia and is often chronic. PROMIS* measures two areas of pain: Pain-Intensity (how much a person is hurting) and Pain-Interference (or the extent to which a person’s pain keeps them from participating in their normal daily activities). The PROMIS Pain – Intensity measure is available as a 3-item short form while the Pain – Interference measure is available as a 6-item short form or via computerized adaptive testing (CAT).

**Fatigue**
Persistent and chronic fatigue is also common in fibromyalgia patients. The PROMIS Fatigue (FACIT-Fatigue) measure assesses extent of fatigue experience and the effect of that fatigue on daily activities. It is available as a 13-item short form or via CAT.

**Physical Function**
Due to the pain and fatigue associated with fibromyalgia, physical function is often limited in persons with fibromyalgia. The PROMIS Physical Function measure assesses self-reported functioning of one’s upper extremities (dexterity), lower extremities (walking or mobility), and central regions (neck, back), as well as instrumental activities of daily living, such as running errands. It is available as a 10-item short form or CAT. PROMIS Upper Extremity Function is a useful addition for patients who have concerns specific to the upper body (e.g., hand, wrist, shoulder, and elbow). It is available as a 7-item short form or CAT.

**Cognitive Function**
Many patients with fibromyalgia experience cognitive symptoms (sometimes called “FibroFog”) that include impaired memory, concentration, focus, judgment and verbal fluency that can affect their daily life. The PROMIS Cognitive Function measure assesses 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. It is available as an 8-item short form or via CAT.

**Sleep-Related Impairment**
Many patients with fibromyalgia also have difficulty sleeping. The PROMIS Sleep-Related measure assesses perceptions of alertness, sleepiness, and tiredness during usual waking hours, and the perceived functional impairments during wakefulness associated with sleep problems or impaired alertness. It is available as an 8-item short form or via CAT.

**Suggested Health Measures for Secondary Domains in Fibromyalgia**
Fibromyalgia 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 assessing:

<table>
<thead>
<tr>
<th>Secondary HealthMeasures</th>
<th>Description</th>
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<tr>
<td>PROMIS Depression 8a short form or CAT</td>
<td>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).</td>
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<tr>
<td>PROMIS Anxiety 8a short form or CAT</td>
<td>Assesses fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms associated with arousal (racing heart, dizziness).</td>
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<tr>
<td>PROMIS Ability to Participate in Social Roles and Activities 8a short form or CAT</td>
<td>Assesses the perceived ability to perform one’s usual social roles and activities.</td>
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**Primary HealthMeasures for Fibromyalgia Patients**
- PROMIS Pain Intensity 3a short form
- PROMIS Pain Interference 6a short form or CAT
- PROMIS Fatigue (FACIT-Fatigue) 13a short form or CAT
- PROMIS Physical Function 10a short form or CAT
- PROMIS Physical Function Upper Extremity 7a short form or CAT
- PROMIS Cognitive Function 8a short form or CAT
- PROMIS Sleep-Related Impairment 8a short form or CAT

**Assessment Times**
Ideally, patient-report measures included in the set of primary domains (and secondary domains if patient burden is not too great) would be used at a variety of assessment time points including pre- and post-treatment / intervention both in clinical care and clinical trials.

**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 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.

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