

Assessing Person-Centered Health Outcomes in Adults with HIV

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 HIV

Human immunodeficiency virus (HIV) attacks the immune system and leaves an individual open to illnesses that a person with a healthy immune system may more easily fight off. Treatments aimed at reducing HIV and improving immune function can be hard on the body. HIV and its treatments can significantly impact an individual's **global health, including: fatigue, cognitive function, depression, anxiety, pain, social satisfaction, and experiences with stigma**. Patient-reported assessments can be used in clinical care and research to monitor and characterize symptom burden and functional impacts of HIV and its treatments.

Suggested HealthMeasures for Primary Domains in HIV

Fatigue

Persistent and chronic fatigue is common in HIV patients both as a symptom of high viral loads and as a side effect of some treatments or related insomnia. The PROMIS® 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 computer adaptive testing (CAT) assessment.

Cognitive Function

People living with HIV may experience cognitive impairment. Such impairment is usually mild to moderate in severity, and may involve a combination of problems with attention, learning and memory, executive functions, speed of processing new information, verbal fluency and complex motor skills. These HIV-associated neurocognitive disorders can have measureable impacts on everyday functioning and quality of life. The PROMIS Cognitive Function measure assesses mental acuity, concentration, verbal and nonverbal memory, verbal fluency, and perceived changes in these cognitive functions. The measure is available as an 8-item short form or via CAT.

Depressive Symptoms

Quality of life for people living with HIV may also be affected by depression, as many may experience depressed mood. A lifetime history of major depression is common in the HIV-infected population. The PROMIS Depression measure assesses affective symptoms of sadness, loneliness, unhappiness, and inability to enjoy usual activities. It is available as an 8-item short form or via CAT.

Anxiety

People living with HIV may additionally experience anxiety. The PROMIS Anxiety measure assesses fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms related to arousal (racing heart, dizziness). It is available as an 8-item short form or via CAT.

Summary

- Recommended primary domains for HIV research or care include fatigue, cognitive function, depression, and anxiety.
- Recommended secondary domains for HIV research or care include pain, social satisfaction, and stigma.
- HealthMeasures offers brief, psychometrically sound measures for these domains.
- Recommended assessment times include pre-treatment (baseline) and post-treatment.

Suggested HealthMeasures for Secondary Domains in HIV

HIV may impact many aspects of a person’s physical, emotional and social functioning. This means that other health status and quality of life domains can also be significantly impacted and represent secondary domains worth assessing:

Secondary HealthMeasures	Description
PROMIS Pain Intensity 3-item short form*	Chronic pain is not uncommon in HIV-infected individuals, often due to infection- or treatment-related distal peripheral sensory neuropathy. This PROMIS measure assesses how much a person is hurting.
NIH Toolbox Social Relationships measures: Perceived Rejection, Perceived Hostility, Friendship, Loneliness, Emotional Support, and Instrumental Support (most available as an 8-item short form)	The NIH Toolbox Social Relationships measures may reveal difficulties experienced by HIV-infected individuals in the social domain and include surveys of: Friendship, Emotional Support, Instrumental Support, and reverse-coded Perceived Rejection, Perceived Hostility, and Loneliness.
Neuro-QoL Stigma 8-item short form	Assesses perceptions of self and publicly enacted negativity, prejudice, and discrimination as a result of disease-related manifestations.
PROMIS Scale 2.0 – Neuropathic Pain Quality 5a	Caused by damage to the peripheral somatosensory nervous system, part of the nervous system involved in bodily feelings. This damage can be caused by an abnormality, trauma or disease.

Primary HealthMeasures for HIV Patients

- PROMIS Fatigue 13-item short form (FACIT-Fatigue) or CAT
- PROMIS Cognitive Function 8-item short form or CAT
- PROMIS Depression 8-item short form or CAT
- PROMIS Anxiety 8-item short form
- PROMIS Global Health 10-item short form

Learn More!

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

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 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.