

Assessing Person-Centered Health Outcomes in Chronic Obstructive Pulmonary Disease (COPD)

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 COPD

COPD is a common, chronic, and life-threatening condition that is most typically associated with reduced **physical functioning**, increased **dyspnea** (shortness of breath) and **fatigue**. Patient-centered health outcomes measures have been used successfully in observational studies and clinical trials to inform clinical decision making, to target healthcare resources and to enable accurate surveillance of and to quantify disease burden. Current guidelines from the Global Initiative for Chronic Obstructive Lung Disease (GOLD) for diagnostic and therapeutic interventions included patient-reported outcomes.

Suggested HealthMeasures for Primary Domains in COPD

Physical Function

Because COPD results in a significant compromise to the patient's overall ability to function physically, this domain is important to assess. We recommend the PROMIS® Physical Function computer adaptive test (4-12 questions). A CAT maximizes score precision for the most possible patients and minimizes how many questions a patient has to answer (but must be computer-administered). If CAT is not possible, the Physical Function V2.0 10a short form is available. The NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox®) also offers measures administered by a trained proctor to evaluate motor function. The full battery takes about 30 minutes.

Dyspnea

PROMIS offers two measures to assess dyspnea in the context of activities: PROMIS Dyspnea-Severity (V1.0) and PROMIS Dyspnea-Functional Limitations (V1.0). The two domains are highly correlated, so we recommend administering only one, depending on the primary interest. The measures have been validated in COPD but are not disease-specific. Both are available as 10-item short forms and as computer adaptive tests.

Fatigue

The PROMIS Fatigue CAT (4-12 questions) is relevant for patients with COPD, and the PROMIS Fatigue 13a short form is available if a CAT is not feasible. PROMIS Fatigue measures assess experience of fatigue (frequency, duration, and intensity) and the impact of fatigue on physical, mental, and social activities.

Summary

- Recommended primary domains for COPD include Physical Function, Dyspnea, and Fatigue.
- Recommended secondary domains for COPD include Depression, Anxiety, Sleep Disturbance, PROMIS 29 Profile, Global Health, Social Isolation, Satisfaction with Social Roles and Activities, and Ability to Participate in Social Roles and Activities.
- 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 COPD

COPD can impact other health domains as well. Thus, we recommend secondary domains that may be important to include in a comprehensive assessment of health outcomes.

Secondary HealthMeasures	Description
PROMIS Depression CAT or Depression 8a short form	Negative mood, negative views of self, negative social cognition, decreased positive affect and engagement
PROMIS Anxiety CAT or Anxiety 8a short form	Self-reported fear, anxious misery, hyperarousal, and somatic symptoms related to arousal
PROMIS Sleep Disturbance CAT or Sleep Disturbance 8a short form	PROMIS: Self-reported perceptions of sleep quality, sleep depth, and restoration associated with sleep, including difficulties and concerns with getting to sleep or staying asleep, as well as perceptions of the adequacy of and satisfaction with sleep.
PROMIS Social Isolation 8a short form; Satisfaction with Social Roles and Activities 8a short form; Ability to Participate in Social Roles and Activities 8a short form;	Isolation: Perceptions of being avoided, excluded, detached, disconnected from, or unknown by others; Satisfaction: Satisfaction with performing one's usual social roles and activities; Ability: Perceived ability to perform one's usual social roles and activities
PROMIS-29 Profile (29 questions)	Physical Function, Fatigue, Pain Interference, Pain Intensity, Sleep Disturbance, Depression, Anxiety, Ability to Participate in Social Roles and Activities, with scores produced for each domain and one pain intensity item
PROMIS Global Health Scale 10a	Global ratings of general health. Scores are produced for physical health and mental health.

Primary HealthMeasures for COPD Patients

- PROMIS Physical Function 10a or CAT
- PROMIS Dyspnea Severity or Dyspnea Functional Limitations measures 10a or CAT
- PROMIS Fatigue 13a or CAT

Learn More!

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

Assessment Times

Ideally, a pre-intervention (e.g., medication) assessment should be captured to serve as a reference point for monitoring response to treatment, with an additional follow-up assessment outside of the post-intervention period. Assessment can also be used longitudinally to measure decompensation, improvement, and stability in people experiencing COPD exacerbations.

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 healthmeasures@northwestern.edu.