Assessing Person-Centered Health Outcomes in Adults with Chronic Kidney Disease (CKD)

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 Chronic Kidney Disease
Because kidney function affects many bodily systems, Chronic Kidney Disease (CKD) has a wide variety of symptoms. CKD and its treatments can have a significant impact on an individual’s global health, including: fatigue, physical function, sleep, psychological stress, life satisfaction, depression, anxiety, and cognitive function. Patient-reported assessments can be used in both clinical care and clinical research for monitoring and characterizing symptom burden and functional impact from Chronic Kidney Disease.

Suggested HealthMeasures for Primary Domains in Chronic Kidney Disease

Fatigue
Persistent and chronic fatigue is common in CKD 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 computerized adaptive testing (CAT).

Physical Function
Physical function often limited in persons with CKD. 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. It is available as a 10-item short form or CAT. PROMIS Upper Extremity Function is a useful addition for patients with concerns specific to the upper body (e.g., hand, wrist, shoulder, elbow). It is available as a 7-item short form or CAT.

Sleep Disturbance
Many patients with CKD also have difficulty sleeping. The PROMIS Sleep Disturbance 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.

Global Health Scale
The PROMIS Global Health measure is a general health assessment that includes ratings of general physical and mental health as well as ability to participate in social roles and daily tasks. It is available via a 10-item scale.
Suggested Health Measures for Secondary Domains in Chronic Kidney Disease

Chronic Kidney Disease 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 8-item short form or CAT</td>
<td>Assesses negative mood, views of self, and social cognition, as well as decreased positive affect and engagement.</td>
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<tr>
<td>PROMIS Anxiety 8-item 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 Sexual Function and Satisfaction: Erectile Function 11-item scale</td>
<td>Ability to achieve and maintain an erection for sexual activity.</td>
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<td>PROMIS Sexual Function and Satisfaction: Interest in Sexual Activity 2-item scale</td>
<td>Conscious awareness of wanting to engage in sexual activity.</td>
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<td>PROMIS Life Satisfaction 5-item short form or CAT</td>
<td>Assesses one’s cognitive evaluation of life experiences and whether one likes his/her life or not.</td>
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<tr>
<td>PROMIS Cognitive Function 8-item short form or CAT</td>
<td>Assesses mental acuity, concentration, verbal and nonverbal memory, verbal fluency, the extent to which cognitive impairments interfere with daily functioning, whether other people observe cognitive impairments, and the impact of cognitive dysfunction on quality of life.</td>
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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.

Primary HealthMeasures for Chronic Kidney Disease Patients

- PROMIS Fatigue 13-item short form or CAT
- PROMIS Physical Function 10-item short form or CAT
- PROMIS Physical Function Upper Extremity 7a short form or CAT
- PROMIS Sleep Disturbance 8-item short form or CAT
- PROMIS Global Health 10-item scale

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