

SUPPLEMENTAL MATERIAL

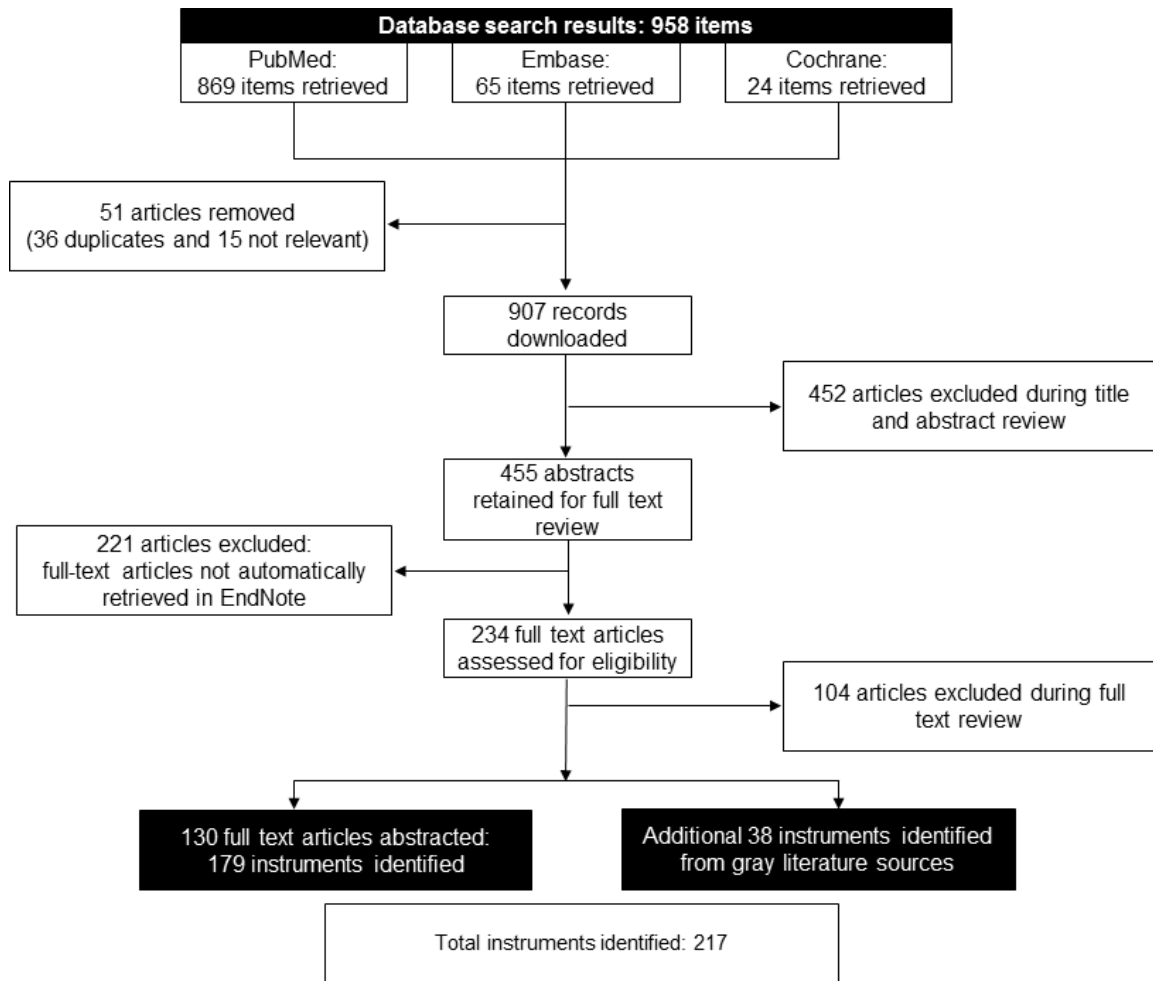
Supplemental Materials 1. Targeted literature search to identify existing PROMs.

We conducted a comprehensive, targeted search of published and gray literature to identify existing PROMs used in CKD/kidney failure and other chronic conditions with similar disease profiles and symptom burdens. We initiated our search of published literature using PubMed, followed by Embase, and Cochrane Library, combining search strings to identify relevant PROMs. We conducted the search with the terms:

Search terms

1. "chronic kidney disease" OR "end-stage renal disease" OR "kidney failure" OR "dialysis"
2. "patient-reported outcome measure" OR "patient-centered measurement" OR "assessment tool" OR "assessment tools" OR "surveys and questionnaires" OR "questionnaires" OR "questionnaire" OR "self-report" OR "patient experience" OR "instrument" OR "scale" OR "outcome assessment (health care)"
3. ("sickle cell anemia" OR "cancer" OR "polycystic liver disease" OR "heart failure") AND ("insomnia" OR "fatigue" OR "muscle cramps" OR "pain" OR "depression" OR "anxiety" OR "mental distress" OR "quality of life" OR "return to function")
4. "devices" OR "drugs" OR "left ventricular assist device" OR "LVAD"

Supplemental Figure 1. Flow chart of article and instrument selection.



We supplemented these searches with a review of primary articles cited within the systematic reviews for specific data and additional citations. In addition, we reviewed and included measures suggested by the Steering Committee that did not emerge from our other searches. Finally, we conducted targeted internet searches for relevant gray literature. We conducted Google searches using similar combinations of search strings to identify articles, reports, and websites with information on relevant PROMs and their characteristics. We also reviewed several websites known to include information on PROMs:

- [HealthMeasures: includes four comprehensive measurement systems \(PROMIS®, Neuro-QOL, ASCQ-Me®, and NIH Toolbox®\)](#)
- [Centers for Medicare and Medicaid Services \(CMS\) Measures Inventory](#)
- [National Quality Forum](#)
- [Rehabilitation Measures Database](#)
- [Mapi Research Trust](#)
- [OMERACT—Outcome Measures in Rheumatology](#)
- [GEM Grid-Enabled Measures Database](#)
- [Medical Device Innovation Consortium](#)
- [Medical Device Development Tool \(MDDT\) Program](#)

Two trained research staff independently screened abstracts for further review. The research staff used a set of guiding rules to determine abstracts for exclusion. In cases of uncertainty, both independent screeners needed to agree that an abstract was potentially applicable or not applicable. Research staff then applied the below exclusion criteria to the articles that were identified for further review based on the abstract.

Exclusion criteria

Exclusion criteria for abstracts:

- Not written in English
- Not published within the last 5 years (or 10 years, if necessary)
- Not relevant to most adult patients with CKD/kidney failure or an adult population with a chronic debilitating condition
- Does not report on PROMs (e.g., process or performance measures)
- Not a review, systematic review, or meta-analysis (clearly an editorial or commentary)
- Full text article not available

Additional exclusion criteria applied to full texts:

- PROM data are not presented in a usable form
- Does not focus on CKD/kidney failure or related conditions/symptoms or medical devices

After excluding appropriate articles, we abstracted relevant content from the identified materials as available (published and gray literature, or web copy about PROMs for which there were no publications) and created an annotated inventory of existing PROMs (Excel database, attached).

Relevant Content Abstracted (as available)

Measure name
Measure steward, publisher, or source
Type of Measure (i.e., general, CKD/kidney failure specific, other health condition, symptom-specific)
Purpose of the measure (e.g., rationale for development, applicable populations)
Concepts addressed by the measure (e.g., domains)
Description of the measure (e.g., items)
Modes of data collection (e.g., in-person, mail, web, phone) available
Methods of administration available (e.g., paper, electronic, interactive voice response or interactive voice response)
Respondent and administrative burden
Scoring information
Scientific acceptability including psychometric properties (e.g., validity, reliability, responsiveness, acceptability)
Exclusions or exceptions of the measure
Whether the tool is proprietary or publicly available, or if unclear
Whether Spanish or other language translations are available
Weblink to measure

Supplemental Table 1. PROMs identified in the targeted literature search (****bolding** identifies the 27 instruments reviewed in detail and considered for prioritization by the steering committee).^a

Measure name	Brief description
Health-related quality of life (HRQOL) measures	
Kidney-disease specific	
1. 100 Category Checklist (+ Short-Version Checklist)	A 100-item instrument developed to assess physical and psychosocial problems as well as functional and environmental factors affecting QOL in hemodialysis patients.
2. Agarwal self-administered CKD symptom assessment instrument	A 37-item instrument for use in non-dialysis patients including questions regarding both mental and physical health.
3. Autosomal dominant polycystic kidney disease (ADPKD) Impact Scale (ADPKD-IS)	A 14-item instrument developed to assesses HRQOL in patients with ADPKD.
4. Chinese Dialysis Quality of Life Scale (CDQOL)	A 29-item instrument designed to measure the QOL of Chinese dialysis patients.
5. CHOICE Health Experience Questionnaire (CHEQ)** (fatigue, freedom subscales)	An 83-item instrument developed to complement the generic 36-Item Short Form Health Survey (SF-36). It assesses physical and psychosocial problems, functional, and environmental factors affecting QOL among patients receiving hemodialysis.
6. Ferrans and Powers Quality of Life Index of Dialysis**	A 62-item instrument that assesses domains of QOL including health, function, social, economic, psychological, spiritual and family.
7. Gastrointestinal Quality of Life Index (GIQLI)	A 36-item instrument that focuses on the impact GI complaints on the HRQOL of kidney transplant patients.
8. HEMO Questionnaire (fatigue subscale)**	A 46-item instrument that contains modified versions of the kidney disease QOL (KDQOL) and index of wellbeing (IWB); developed for use in a multi-center randomized clinical trial in dialysis.
9. Hemodialysis Quality of Life Questionnaire (HQL)	A 26-item instrument developed to assess hemodialysis patient QOL and physical and emotional symptoms.
10. Hemodialysis Stressor Scale (HSS)	A 29-item instrument developed to assess the burden of physiologic stressors in hemodialysis patients.
11. Kidney Disease Quality of Life (KDQOL), multiple versions- KDQOL-SF; KDQOL-36)**	A 134-item instrument designed for use in patients with kidney disease undergoing dialysis; encompasses both generic (SF-36) and disease-specific elements. Several shortened/modified versions available.
12. Kidney Disease Questionnaire (KDQ)** (fatigue subscale)	A 26-item instrument designed to assess the effects of interventions on the QOL of patients undergoing hemodialysis.
13. Kidney Transplant Recipient Stressor Scale (KTRSS)	A 44-item instrument assessing 4 domains: physical and psychological health problems, family relationships, employment and body image.
14. Kidney Transplant Questionnaire (KTQ)	A 25-item instrument for use in kidney transplant patients.
15. National Institute of Diabetes and Digestive and Kidney Disease Transplantation Quality of Life Questionnaire (NIDDK-QOL)	A 63-item instrument organized into the domains of general health, personal function, psychological status, social and role function, and measures of disease.
16. National Kidney Dialysis and Kidney Transplantation Study (NKDKTS)	A 16-item instrument developed as part of government-commissioned study to investigate QOL, quality of care, rehabilitation, and health status of US patients undergoing dialysis.
17. Parfrey Symptom Assessment	An instrument developed to measure QOL among kidney failure patients.
18. Recovery Time from Dialysis	A single-item open-ended measure: "How long does it take you to recover from a dialysis session?"
19. Renal Dependent Individualized Quality of Life Questionnaire (RDI-QLQ)	A 21-item instrument of the impact of chronic kidney failure on QOL.
20. Renal Quality of Life Profile (RQLP)	A 43-item instrument that covers five dimensions: Eating and drinking, Physical activities, Leisure time, Psychosocial activities and Impact of treatment.
21. ReTransQOL (RTQ, 2 versions)	A 45-item (version 1) and 32-item (version 2) instrument with 5 dimensions designed to assess QOL in kidney transplant patients.

22. Transplant Care Index (TCI)	A 6-item instrument designed to serve as a single composite measure to track transplant-specific QOL and several issues related to graft care.
23. Transplant Effects Questionnaire (TxEQ)	A 24-item instrument that assesses the effects of organ transplantation related to 5 factors: worry about transplant, guilt regarding donor, disclosure, medication adherence, and responsibility.
24. Vascular Access Questionnaire (VAQ)	A 17-item instrument designed to assess symptoms, QOL, and adverse events associated with vascular access in chronic dialysis patients at a single center in Toronto, Canada.
Other condition-specific	
Diabetes	
25. Audit of Diabetes-Dependent Quality of Life (ADDQOL)	A 19-item instrument that measures the impact of diabetes on QOL.
26. Diabetes Specific Quality of Life Scale (DSQL)	A 64-item instrument of individual treatment goals among patients with type 1 diabetes.
27. Diabetes-39	A 39-item instrument assessing 6 categories: energy and mobility, diabetes control, anxiety and worry, social burden, sexual functioning, and diabetes medication.
Cancer	
28. Body Image Scale	A 10-item instrument to evaluate body image in cancer patients with good structural validity, internal consistency, and test-retest reliability.
29. Cancer Assessment for Young Adults-Testicular (CAYA-T)	A 90-item instrument of HRQOL among young adults with cancer.
30. Cancer Problems in Living Scale	A 31-item instrument of problems faced by individuals with cancer.
31. Cancer Rehabilitation Evaluation System (CARES)	A 139-item instrument (short-form=59 items) used to understand, document and assess the needs of patients with cancer.
32. Cancer-related Health Worries Scale or Lerman Cancer Worry Scale	A 6-item instrument designed to measure worry about the risk of developing cancer and the impact of worry on daily functioning.
33. Edmonton Functional Assessment Tool (EFAT2)	A 10-item instrument designed to evaluate functional performance of patients with advanced cancer over time.
34. European Organization for Research and Treatment of Cancer (EORTC) EORTC-QLQ-C30 (Multiple instruments for various forms of cancer and associated symptoms)	A 30-item instrument developed to assess HRQOL of cancer patients in clinical trials; multidimensional across multiple cancer diagnoses and cultural settings.
35. Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System (Multiple instruments, including fatigue)** Derived from the Functional Assessment of Cancer Therapy (FACT) series of questionnaires for various forms of cancer, including kidney cancer	A collection of HRQOL measures targeted to the management of chronic illness. The FACIT Measurement System now includes over 400 questions; multiple modules and instruments.
36. Functional Living Index-Cancer (FLIC-Index)	A 22-item functionally oriented QOL instrument.
37. Impact of Cancer Scale (IOC)	An 82-item instrument that assesses the impact of cancer on the QOL and other aspects of long-term cancer survivors.
38. Impact of Events scale (IES) and Impact of Events Scale-Revised (IES-R)	A 15-item instrument of lung cancer-specific distress.
39. Linear Analogue Self-Assessment Scale	A single-item measure of overall QOL initially developed to measure the subjective effects of treatment in women with advanced breast cancer.
40. Lung Cancer Symptom Scale (LCSS)	A 9-item instrument particularly for use in clinical trials of lung cancer that evaluates six major symptoms and their effect on overall symptomatic distress, functional activities, and global QOL.
41. Multidimensional Quality of Life Scale-Cancer (MQOLS-CA) or Quality of Life Scale-Cancer (QOL-CA)	A 30-item instrument developed to assess QOL among patients with cancer; a 28-item version is also available.

42. Novel Scale for Assessing Quality of Life of Prostate Cancer Patients Receiving Androgen Deprivation Therapy (ADT)	A 22-item instrument to measure QOL for prostate cancer patients receiving ADT.
43. Prostate Cancer Specific Quality of Life Instrument (PROSQOLI)	A 10-item instrument evaluating pain, fatigue, appetite, constipation and other symptoms, and overall well-being among patients with prostate cancer.
44. Quality of Life in Adult Cancer Survivors (QLACS)	A 41-item instrument measuring four domains of QOL among patients with cancer, including physical well-being, psychological well-being, social well-being, and spiritual well-being QOL for individual survivors of cancer who are 5 or more years past their cancer diagnosis.
45. Trial-specific QOL module (QLM-P14)	A 14-item instrument assessing symptoms specific for metastatic castration-resistant prostate cancer.
46. University of Washington Quality of Life Questionnaire (UWQOL)	A 12-item instrument that captures basic QOL data on the physical, functional, emotional QOL of the head and neck cancer patient.
Skin Conditions	
47. Dermatology Life Quality Index (DLQI)	A 10-item instrument assessing symptoms, feelings, daily activities, etc. among patients with different skin diseases.
48. Skindex-10; Skindex-16; Skindex-29	Instruments that assess impacts on QOL from side effects related to skin conditions; multiple versions available.
Heart Failure	
49. European Heart Failure Self-Care Behavior Scale (EHFScBS)	A 9-item (originally 12 items) instrument used to measure behaviors performed by heart failure patients to maintain life, healthy functioning, and wellbeing.
50. Kansas City Cardiomyopathy Questionnaire (KCCQ)	A 23-item, self-administered instrument for heart failure used to quantify physical functions, symptoms, social function, self-efficacy, and knowledge and QOL.
51. Minnesota Living with Heart Failure Questionnaire (MLHFQ)	A 21-item instrument of the adverse life effects of heart failure.
Urinary/Pelvic/Bowel Conditions	
52. Incontinence Quality of Life Questionnaire (IQOL)	A 22-item instrument with subscales to assess behavior, psychosocial impact, and social embarrassment relating to urinary incontinence in both women and men.
53. Pelvic Floor Distress Inventory-Short Form (PFDI-20)	A 20-item instrument that assesses the impact of pelvic floor disorders on HRQOL in women including urinary, prolapse, and gastrointestinal dysfunction.
54. Pelvic Floor Impact Questionnaire-Short Form (PFIQ-7)	A 7-item instrument that assesses the extent to which bladder, bowel, and vaginal symptoms affect women's activities, relationships, and feelings.
55. Rome II/Rome III Modular Questionnaire for Irritable Bowel Syndrome	Measures assessing effects of bowel disease; Rome II: for functional bowel disorders; Rome III: for irritable bowel syndrome.
Arthritis	
56. Patient Global Assessment of Quality of Life (PGA)	A single item instrument assessing global health and overall disease activity among individuals with arthritis.
57. Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)	A 24-item instrument that assesses pain (WOMAC A), stiffness (WOMAC B), and physical function (WOMAC C) in patients with hip/knee osteoarthritis.
Multiple Sclerosis	
58. Patient Reported Outcome Indices for Multiple Sclerosis (PRIMUS)	A 59-item instrument that assesses QOL in multiple sclerosis patients.
Osteoporosis	
59. Quality of Life Questionnaire of the European Foundation for Osteoporosis (QUALEFFO)	A 41-item instrument of QOL in osteoporosis patients.
Stroke	
60. Stroke and Aphasia Quality of Life Scale-53 and -39 (SAQOL)	A 53-item instrument of QOL modified for use with aphasia.
61. Stroke Impact Scale	A 59-item instrument that measures the aspects of stroke recovery found to be important to patients, caregivers, and stroke experts.

62. Stroke-Specific Quality of Life Scale (SS-QOL)	A 49-item instrument assessing 12 domains of function and QOL related to stroke.
Spinal Stenosis	
63. Zurich Claudication Questionnaire (ZCQ)	An 18-item instrument to evaluate symptom severity, physical function, and surgery satisfaction in lumbar spinal stenosis.
Esophageal	
64. Swallowing Quality of Life Questionnaire (SWAL QOL)	A 44-item instrument used to measure of QOL and quality of care for patients with oropharyngeal dysphagia.
Generic	
65. Barthel activity of daily living index (ADL)	A 10-item instrument that assesses ten variables of daily living.
66. Brief Illness Perception Questionnaire (B-IPQ), Illness Perception Questionnaire (IPQ) and Revised Illness Perception Questionnaire (R-IPQ)	A 9-item instrument that measures illness perception.
67. Center for Disease Control and Prevention HRQOL-14** (Activity limitations module)	A 4-item instrument of HRQOL.
68. Comfort Questionnaire	A 49-item instrument measuring the extent to which the patient is experiencing comfort at that point in time.
69. Dartmouth Primary Care Cooperative Research Network (CO-OP) Functional Health Assessment Charts/ World Organization of National Colleges, Academies, and Academic Associations of General Practices/Family Physicians (WONCA) (COOP/WONCA charts)	The COOP-WONCA charts include 6, single-item instruments of different aspects of functional health status designed for use in primary care.
70. Decision Regret Scale (DRS)	A 5-item instrument that measures distress or remorse after a health care decision.
71. General Health Questionnaire	A screening tool to detect those likely to have or be at risk of developing psychiatric disorders. Measures common mental health problems/domains of depression, anxiety, somatic symptoms and social withdrawal; multiple versions available.
72. Groningen Frailty Indicator (GFI)	A widely used self-report screening instrument developed in the Netherlands for identifying frail older adults.
73. Health Assessment Questionnaire-Disability Index (HAQ-DI)	One of the first instruments deliberately designed to capture the long-term influence of multiple chronic illnesses.
74. HowRu Questionnaire	A 4-item generic instrument on QOL.
75. Illness Effects Questionnaire (IEQ)	A 4-item instrument that assesses the effects of illness.
76. Illness Impact Scale (IIS)**	A 9-item instrument of the extent to which an illness (mental or physical) has adversely affected a person's life.
77. Illness Intrusiveness Ratings Scale (IIRS)	A 13-item instrument measuring the degree to which a person's illness and/or treatment interferes with life.
78. Katz Index of Independence in Activities of Daily Living (ADL)	A 6-item instrument used to assess functional status as a measurement of the person's ability to perform activities of daily living independently.
79. Late Life Function and Disability Instrument (Late-Life FDI)	A 48-item instrument assessing function and disability among community-dwelling older adults.
80. Life Attitude Profile-Revised (LAP-R)	A 48-item self-report multidimensional instrument of discovered meaning and purpose in life and the motivation to find meaning and purpose in life.
81. McGill Quality of Life Questionnaire (MQOL) and McGill Pain Questionnaire; Short Form	An 18-item instrument developed to assess general domains of QOL in patients at all stages of life-threatening illnesses from diagnosis to cure or death.
82. MD Anderson Symptom Inventory-core or MDASI	A 19-item instrument used to assess QOL and symptom impact on daily activities.
83. Medical Outcomes Study (MOS) 36-Item Short-Form Health Survey or SF-36 and multiple versions (SF-12, SF-20, Mental Health Index (MHI-5 and MHI-17), Vitality subscale**	A 36-item instrument that assesses non-condition-specific functional health that was originally validated in patients with chronic conditions; multiple versions.

84. Nottingham Health Profile (NHP)**	A 38-item generic instrument developed to assess an individual's perception of his or her own health status.
85. Patient-Reported Outcomes Measurement Information System (PROMIS)—Multiple Instruments including reviewed item banks for fatigue, physical function, satisfaction with participation in social roles, ability to participate in social roles and activities, mobility, and the 29-profile	A set of instruments that evaluate and monitor a range of physical, social, and emotional health aspects in adults and children.
86. Paulson-Lichtenberg Frailty Index (PLFI)	A 5-item frailty instrument developed to incorporate Health and Retirement Study (HRS) data into frailty research.
87. Personal Adjustment to Chronic Illness Scale (PACIS)	A single-item indicator of the adjustment to chronic illness process.
88. Profile of Mood States (POMS)	A 65-item instrument used to measure six identifiable moods or affective states. A 35-item short form is also available.
89. Psychological General Well-Being Index (PGWBI)	A 22-item instrument used to measure self-representations of intrapersonal affective or emotional states reflecting a sense of subjective well-being or distress.
90. Psychological Wellbeing Scale (PWBS)	A 42-item instrument used to measure six aspects of wellbeing and happiness: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance; 18-item version available.
91. Psychosocial Response to Illness Scale; also Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR)	A 46-item instrument used to evaluate seven domains of functioning related to adjustment to illness: health care orientation (attitudes, perceptions, and expectations regarding one's health care), vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress.
92. Quality of Life at the End of Life (QUAL-E)	A 25-item instrument developed to assess QOL at the end of life in a range of diseases and degrees of illness across care settings.
93. Quality of Life Index (QLI) 3.0	A 68-item instrument measuring satisfaction with various domains of life and importance of the domain to the individual.
94. Schedule for the evaluation of individual Quality of life (SEIQoL-DW, SEIQoL)	A structured interview tool in which patients list five areas of life, which are most important to them concerning QOL.
95. Sickness Impact Profile**	A 136-item generic instrument used to evaluate the impact of disease on both physical and emotional functioning.
96. Spiritual Well-Being Scale (SWBS)	A 20-item general indicator of perceived well-being used for the assessment of individual and congregational spiritual well-being.
97. Spitzer Quality of Life Index	A 5-item instrument used to assess health outcomes among persons with cancer and other chronic disease covering five dimensions—activity, daily living, health, support of family and friends, and outlook.
98. World Health Organization Quality of Life Assessment-WHOQOL-100; WHOQOL-BREF (Multiple Instruments); World Health Organization Quality of Life Assessment-WHOQOL-BREF (Dialysis)	A 100-item instrument measuring the following domains: physical health, psychological health, social relationships, and environment. The 26-item WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical trials. The WHOQOL-BREF (Dialysis) is a 32-item HRQOL instrument with 5 domains modified for use in patients receiving dialysis.
99. Women's Health Questionnaire	A 36-item instrument of mid-aged women's emotional and physical health.
Specific symptom/ functioning^b	
Kidney-disease specific	
General	
100. CKD-Symptom Burden Index (CKD-SBI)	A 32-item indicator of symptom burden derived from the dialysis symptom index (DSI); developed for use in patients with CKD stages IV and V.
101. End Stage Renal Disease Severity Index (ESKD-SI)	An 11-item instrument assessing the severity of kidney failure-related symptoms.

102. Physical Symptom Distress Scale (PSDS)	A 16-item instrument developed to estimate the degree of symptom distress experienced by kidney failure patients.
Dialysis	
103. Dialysis Symptom Index (DSI)	A 30-item instrument developed to assess the physical and emotional symptom burdens of hemodialysis patients.
104. Edmonton Symptom Assessment System (ESAS) and Modified Edmonton Symptom Assessment System	A 10-item instrument of physical and emotional symptom burdens for the dialysis population.
105. Fluid Management Survey	An instrument developed to assess hemodialysis-patient-stated preferences regarding fluid management.
106. Uraemic Pruritus in Dialysis Patients (UP-Dial)	A 14-item instrument deemed valid and reliable for assessing UP among patients on dialysis.
Transplant	
107. End-Stage Renal Disease Symptom Checklist-Transplantation Module (ESKD-SCL-TM)	A 43-item symptom-specific QOL instrument designed for use in kidney transplant patients on immunosuppression therapy.
108. Modified Transplant Symptom Occurrence and Symptom Distress Scale (MTSOSD)	A 29-item instrument designed to assess side effects of immunosuppression therapy in kidney transplant patients.
109. Transplant Symptom Frequency Questionnaire (TSFQ)	A 33-item instrument designed to measure the frequency and severity of symptoms falling within 6 domains: affective distress, neurocognitive symptoms, physical appearance changes, gastrointestinal distress, appetite/weight changes, and miscellaneous symptoms.
Focal Segmental Glomerulosclerosis (FSGS)	
110. FSGS Symptom Diary	A 23-item PROM designed to assess symptoms and symptom impact in adults with FSGS.
111. FSGS Symptom Impact Questionnaire	A 17-item PROM designed to assess symptoms and symptom impact in adults with FSGS.
Palliative	
112. Palliative Care Outcome Symptom Scale (POS-S Renal)	An 18-item instrument evaluating outcomes in palliative care for patients with advanced disease; + disease-specific modules.
Other condition-specific (cancer)	
113. International Prostate Symptom Score (I-PSS)	A 7-item instrument for use with devices used to treat benign prostatic hyperplasia (BPH).
114. Schwartz Cancer Fatigue Scale	A 28-item instrument used to assess fatigue in cancer patients.
115. Rotterdam Symptom Checklist (RSCL)	A 39-item instrument developed to measure the symptoms reported by cancer patients participating in clinical research.
116. Symptom Experience Scale	A 24-item instrument designed to measure women's experience of symptoms associated with treatment for breast cancer.
117. Memorial Symptom Assessment Scale (MSAS)	A 32-item instrument of physical and emotional symptoms experienced by patients with cancer.
Generic	
General Symptom	
118. Brief Symptom Inventory-18 (BSI-18)	An 18-item instrument measuring general psychological distress.
119. Symptom Distress Scale (SDS)	A 13-item instrument measuring symptom distress from the specific symptoms experienced as reported by the patient.
Fatigue	
120. Brief Fatigue Inventory (BFI)**	A 9-item instrument assessing the severity of fatigue and the impact of fatigue on daily functioning.
121. Chalder Fatigue Scale (CFS)**	An 11-item instrument used to measure the severity of tiredness in fatiguing illnesses.
122. Modified Fatigue Impact Scale (FIS)**	A 40-item instrument that assesses the problems in patients' QOL that they attribute to their symptoms of fatigue.
123. Fatigue Severity Scale (FSS)**	A 9-item instrument measuring the severity of fatigue and its effect on person's activities and lifestyle.
124. Fatigue Symptom Inventory (FSI)**	A 14-item instrument that assesses the severity, frequency, and diurnal variation of fatigue, and its interference with QOL.

125. Multidimensional Assessment of Fatigue (MAF)**	A 16-item instrument measuring fatigue in adults with chronic illness; the original purpose of the MAF was to evaluate self-reported fatigue in patients with rheumatoid arthritis (RA).
126. Multidimensional Fatigue Inventory (MFI-20)**	A 20-item instrument covering the following dimensions: general fatigue, physical fatigue, mental fatigue, reduced motivation, and reduced activity.
127. Piper Fatigue Scale (Revised)**	A 27-item instrument of fatigue.
128. Rhoten Fatigue Scale	A single-item subjective rating scale established to measure a patient's level of fatigue.
129. Visual Analogue Scale to Evaluate Fatigue Severity (VAS-F)**	A measure of fatigue that includes items asking respondents to place an "X," representing how they currently feel, along a visual analogue line that extends between two extremes (e.g., from "not at all tired" to "extremely tired").
Depression	
130. Beck Depression Inventory (BDI)	A 21-item multiple choice self-report inventory that measures characteristic attitudes and symptoms of depression. the severity of depression. Noted in KCP Blueprint as a tool used to assess for depression in kidney failure patients.
131. Center for Epidemiologic Studies Depression Scale (CES-D); Revised (CESD-10)	A 20-item patient-reported screening tool for depression and a 10-item version.
132. Depression Screening Instrument (DSI)	A 16-item instrument assessing depression for use in community surveys carried out in general practice.
133. Geriatric Depression Scale (GDS)	A 15-item geriatric-specific screening tool for depression.
134. Hamilton Depression Scale (HAMD-17)	A 17-item instrument that assesses severity of, and change in, depressive symptoms.
135. Hospital Anxiety and Depression Scale (HADS)	A 14-item instrument developed to determine levels of anxiety and depression experienced by hospitalized patients.
136. Patient Health Questionnaire (PHQ)	A 9-item instrument for screening, diagnosing, monitoring and measuring the severity of depression.
137. Quick Inventory of Depressive Symptomatology (QIDS)	A 16-item instrument measuring the severity of a patient's depression.
138. Self-Rating Depression scale (SDS)	A 20-item instrument assessing the level of depression for patients diagnosed with depressive disorder.
139. Symptom Checklist-Core Depression Scale (SCL-CD6)	A 6-item instrument covering the core symptoms of depression.
140. Zung Self-Rating Depression Scale (ZSDS)	A 20-item instrument of the symptoms of depression.
Anxiety	
141. Generalized Anxiety Disorder Scale (GAD-7)	A 7-item instrument for screening for generalized anxiety disorder.
142. Hamilton Anxiety Rating Scale (HAMA)	A 14-item instrument used to assess the severity of anxiety.
143. State Anxiety Inventory (SAI) and State-Trait Anxiety Inventory (STAI)	A 20-item instrument that asks how a person feels now and about situational factors that may influence anxiety levels. A 40-question instrument used to quantify anxiety and to simplify the separation between state anxiety and trait anxiety, feelings of anxiety and depression.
144. Zung Self-Rating Anxiety Scale (SAS)	A 20-item instrument used to evaluate anxiety.
Insomnia	
145. Calgary Sleep Apnea Quality of Life Index (SAQLI)	A 35-item instrument to measure within-subject change in response to a therapeutic intervention.
146. Daytime Insomnia Symptom Scale (DISS)	A 20 visual analog scale instrument presenting adjectives or brief phrases designed to capture the subjective experience of insomnia patients across the course of a day.
147. Epworth Sleepiness Scale (ESS)	An 8-item instrument that asks the respondent to rate their usual chances of having dozed off or fallen asleep while engaged in eight different activities.
148. Functional Outcomes of Sleep Questionnaire (FOSQ)	A 30-item instrument assessing the impact of disorders of excessive sleepiness on multiple activities of everyday living.
149. Insomnia Severity Index (ISI)	A 7-item instrument assessing the nature, severity, and impact of insomnia.

150. Pittsburgh Sleep Quality Index (PSQI)	A 19-item instrument assessing sleep quality and disturbances over a 1-month time.
Itching	
151. Brief Itching Inventory (BII)	A 6-item instrument assessing interference of itching with: Mood, Normal Work (includes both work outside the home and housework, Relations with other people, Sleep, Enjoyment of Life.
Sexual Functioning	
152. Female Sexual Functioning Index (FSFI)	A 19-item instrument of sexual functioning in women assessing sexual arousal, orgasm, satisfaction, pain for use in clinical trials.
153. International Index of Erectile Function (IIEF)	A 15-item instrument assessing erectile function.
154. Medical Outcomes Study Sexual Functioning Scale (MOS-SF)	A 4-item scale assessing sexual problems that are part of the core MOS instruments of QOL.
155. Sexual Activity Questionnaire (SAQ)	A 14-item instrument assessing the impact of long-term tamoxifen on the sexual functioning of women at high risk of developing breast cancer.
Gastrointestinal	
156. Gastrointestinal Symptom Rating Scale (GSRS)	A 15-item instrument assessing important gastrointestinal side effects of immunosuppressive therapy in kidney transplant patients
157. Rhodes Index for Nausea, Vomiting, and Retching	An 8-item instrument used to assess nausea, vomiting, and retching (NVR) from patient's perspective; originally developed for use in cancer patients undergoing chemotherapy.
158. Assessment of Late Effects of RadioTherapy-Bowel (ALERT-B) Questionnaire	A 3-item simple screening tool to detect common gastrointestinal symptoms in outpatient clinics.
159. Bowel Disease Questionnaire	An instrument developed to elicit gastrointestinal symptoms relevant to functional disorders.
Pain	
160. Amsterdam Pain Management Index	An instrument designed to evaluate the adequacy of cancer pain treatment and capture pain intensity to determine a patients' tolerable level of pain.
161. Brief Pain Inventory (BPI)	A 9-item instrument that captures pain severity and pain interference with common dimensions of feeling and function.
162. Dallas Pain Questionnaire (DPQ)	Assesses four aspects of daily living affected by chronic back pain.
163. Multidimensional Pain Inventory Pain Severity scale (MPI-PS)	A 52-item instrument assessing chronic pain.
164. Wong-Baker FACES Pain Rating Scale	A single item instrument that uses a visual analog scale to rate pain.
165. Oswestry Disability Index (ODI)	A 10-item instrument to measure disability for low back pain.
166. Roland-Morris Low Back Pain and Disability Questionnaire (RMQ)	A 24-item instrument to measure low back pain and related disability.
Urinary	
167. American Urological Association Symptom Index (AUA-SI)	A 7-item instrument assessing urinary urgency, frequency, and voiding symptoms.
168. International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF)	A 5-item instrument assessing the frequency and amount of urinary incontinence well as the QOL impact.
Other	
169. Cambridge-Hopkins diagnostic questionnaire for Restless Leg Syndrome (RLS)	A 13-item instrument covering the basic diagnostic features of RLS.
170. Foot Function Index (FFI)	A 23-item instrument measuring the impact of foot pathology on function in terms of pain, disability and activity restriction.
171. Patient Care Monitor™ (PCM)	A proprietary web-based technology platform that collects data from patients at the point of care and includes a symptom survey.
172. Perceived Symptoms Associated with Antihypertensive Drugs (PERSYVE)	An instrument measuring patients' issues regarding adherence, adverse drug events, communication, among other constructs relating to antihypertensive drugs.
173. The Parathyroidectomy Assessment of Symptoms (PAS)	A 13-item instrument measuring hyperparathyroidism-related symptoms.
Technology/ Device	

Kidney disease-specific	
None	
Other condition-specific (diabetes)	
174. Diabetes Injection Device Experience Questionnaire (DID-EQ) and Diabetes Injection Device Preference Questionnaire (DID-PQ)	A 20-item instrument assessing patients' experiences with a single injection device and a 20-item instrument that asks patients to indicate their preference between two injection devices.
175. Insulin Delivery System Rating Questionnaire (IDSRQ) and The Insulin Delivery System Questionnaire (IDSQ)	An instrument assessing the impact of different insulin delivery systems.
176. Insulin Injection Preference Questionnaire (IIP-Q)	An instrument assessing expectations of and preference for the insulin injection pen compared with the vial and syringe.
177. Insulin Pens Questionnaire – Evaluation (IPQ-E)	A 26-item instrument assessing features of insulin delivery devices for prandial use.
178. Treatment-Related Impact Measures for Diabetes and Diabetes Devices (TRIM-D and TRIM-D Device)	Instruments measuring treatment-related impacts of diabetes medications and diabetes devices.
Generic	
179. Assistive Technology Device Predisposition Assessment- (ATDPA) Device Form	A tool that targets the evaluation of overall user experience with assistive technology.
180. Psychosocial Impact of Assistive Devices Scale (PIADS)	An instrument assessing the psychosocial impact of assistive devices on QOL.
181. PYTHEIA: A Scale for Assessing Rehabilitation and Assistive Robotics	A 15-item scale measuring individual functionalities of rehabilitation or assistive robot devices.
182. Technology Acceptance Model (TAM)	A 6-item instrument measuring the extent to which prospective customers perceive usefulness and ease of a new technology.
183. Technology Readiness Index (TRI)	A 26-item instrument of assessing prospective customers' acceptance and use of a new technology.
Satisfaction	
Kidney disease-specific	
184. Questionnaire for Acceptance of and Satisfaction with Implanted Central Venous Catheter (QASICC)	A 22-item instrument assessing patient satisfaction with, and acceptance of a totally implanted central venous catheter.
185. Renal Treatment Satisfaction Questionnaire (RTSQ)	An 11-item instrument assessing satisfaction with treatment for patients with CKD for use in clinical trials or routine clinical care.
Other condition-specific	
186. Insulin Treatment Satisfaction Questionnaire (ITSQ)	A measure of insulin treatment satisfaction, applicable to a wide range of insulin therapies.
187. Patient Satisfaction with Insulin Therapy (PSIT)	A measure of patient satisfaction with insulin (injected and inhaled) treatment in adult patients with either type1 or type 2 diabetes.
188. Cancer Therapy Satisfaction Questionnaire (CTSQ)	An instrument assessing satisfaction with and preference for chemotherapy and biological therapy in pill or IV form.
189. Diabetes Treatment Satisfaction Questionnaire (DTSQ)	An 8-item instrument assessing patients' satisfaction with their diabetes treatment.
Generic	
190. Life Satisfaction Index (LSI)	A 35-item instrument measuring successful aging in participants over 50 years of age.
191. Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q - SF)	A 14-item instrument evaluating general activities (e.g., physical health, feelings, work, and household duties).
192. Satisfaction with Life Scale (SWLS)	A 5-item instrument measuring global cognitive judgments of satisfaction with one's life.
193. Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) 2.0	A standardized satisfaction assessment tool designed for assistive technologies.
Utility	
Kidney disease-specific	
194. Modified Time Trade-Off (TTO)	A utility measure for assessing QOL in dialysis and kidney transplant.
Other condition-specific	

None	
Generic	
195. Assessment of Quality of Life instrument (AQOL)	A 35-item instrument measuring HRQOL (multiple versions).
196. European QOL 5-Dimensions (EQ-5D or EuroQOL-5D)	A 6-item instrument assessing HRQOL in terms of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression; also used as a utility measure.
197. Health and Activities Limitation Index	An 8-item instrument that offers a method of utility assessment using existing values from the National Health Interview Survey (NHIS) and a utility algorithm to derive preferences.
198. Health Utilities Index (HUI) and Health Utilities Index Mark 3 (HUI3)	A generic preference-based measure used to describe health status, measure morbidity and HRQOL, and produce utility scores.
199. Quality of Well Being Self-Administered Scale (QWB-SA)	A cost utility analysis metric developed to estimate QOL adjusted years.
200. Short Form 6 Dimension (SF-6D)	A 6-item instrument for HRQOL (derived from SF-36).
201. The 15-D Measure of Health-Related Quality of Life (15-D)	A generic, 15-dimension HRQOL instrument that can be used both as a profile and as a single index score measure.
Other	
Kidney disease-specific	
202. Standardized Outcomes in Nephrology-Hemodialysis and Peritoneal Dialysis (SONG-HD and SONG-PD) SONG-Fatigue; in development	The SONG initiative has developed a core set of priority outcomes for trials in patients on hemodialysis and is developing an analogous set of outcomes for patients on peritoneal dialysis. A 3-item instrument to assess fatigue/energy in dialysis patients. To date, no information has been published on this measure.
203. Surveying Patients Experiencing Young Adult Kidney Failure Study (SPEAK)	A single cross-sectional online survey for 16- to 30-year-olds receiving kidney replacement therapy in United Kingdom.
Other condition-specific	
204. Mini-Mental State Examination (MMSE); Modified MMSE (3MS)	Dementia screening tools.
205. Mood Disturbance Scale	A 13-item instrument for bipolar disorder screening.
206. Consequences of screening and consequences of screening in Lung Cancer (COS-LC)	A multi-scale instrument assessing psychosocial consequences of screening for cancer (specifically lung cancer).
207. COST Measure: A Financial Toxicity Patient-Reported Outcome in Cancer	An 11-item instrument used to describe the financial distress experienced by patients with cancer.
208. Social Difficulties Inventory (SDI-21)	A 21-item instrument assessing social well-being in the oncology setting.
209. Supportive Care Needs Survey (SCNS)	An instrument assessing generic needs of patients with cancer.
Generic	
210. Basel Assessment of Adherence Scale (BAAS); Basel Assessment of Adherence with Immunosuppressive Medication Scales (BAASIS)	A 4-item instrument measuring dosing, timing and frequency adherence; and a visual analog scale to capture self-assessment of overall medication adherence. Multiple versions available.
211. Beliefs About Medicines Questionnaire (BMQ)	An 18-item instrument measuring necessity for and concerns about medication.
212. Immunosuppressant Therapy Adherence Scale (ITAS)	A 5-item instrument assessing non-adherence to immunosuppressant therapy (IST) given a particular circumstance.
213. Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)	A 27-item instrument measuring the strength dimension on a 5-point confidence scale.
214. Medication Adherence Rating Scale (MARS)	A 10-item instrument evaluating attitudes about medications and actual medication-taking behavior.
215. Morisky Medication Adherence Scale (MMAS)	A 4-item instrument designed to estimate the risk of medication non-adherence.
216. Healthy Days/Health-Related Quality of Life measure	A 5-item instrument used to monitor population health levels in support of epidemiologic and prevention research.

217. Vulnerable Elders Survey or VES-13	A 13-item instrument assessing functional and physical health to identify community-dwelling elders at risk for functional decline or death.
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^a Instruments identified by the search process described in the **Supplemental Materials 1**.

^b The symptom-specific PROM search was not exhaustive. Targeted literature searches for specific symptoms of interest are needed to identify additional symptom-specific PROMs for consideration.

Supplemental Table 2. In-person meeting attendees (March 2019, Washington, DC).

Name	Organization/ Affiliation
Fraser Bocell, PhD	CDRH, FDA
Jennifer E. Flythe, MD, MPH	University of North Carolina at Chapel Hill
Debbie S. Gipson, MD, MS	University of Michigan Mott Children's Hospital
Amanda Grandinetti, MPH	Kidney Health Initiative Patient and Family Partnership
Tandrea Hilliard, PhD	American Institutes for Research
Frank Hurst, MD	CDRH, FDA
Kourtney Ikeler, BA	American Institutes for Research
San Keller, PhD	American Institutes for Research
Robert Nordyke, PhD	Beta 6 Consulting, LLC
Kathryn O'Callaghan, PhD	CDRH, FDA
Ronald Perrone, MD	Tufts Medical Center
Prabir Roy-Chaudhury, MD, PhD	University of North Carolina at Chapel Hill and W.G. (Bill) Hefner Veterans Affairs Medical Center
Grace Squillaci	Kidney Health Initiative /American Society of Nephrology
Michelle Tarver, MD, PhD	CDRH, FDA
Mark Unruh, MD, MS	University of New Mexico
Melissa West	Kidney Health Initiative /American Society of Nephrology

Abbreviations: CDRH: Center for Devices and Radiological Health; FDA, Federal and Drug Administration.