SUMMARY
Kidney Care Quality Alliance Conference Call
August 23, 2016

A conference call of the Kidney Care Quality Alliance (KCQA) was convened on Tuesday, August 23, 2016. Representatives of the following organizations participated: AbbVie, American Kidney Fund, American Society of Nephrology, DaVita Healthcare Partners Inc., Dialysis Patient Citizens, Fresenius Medical Care North America, National Forum of ESRD Networks, National Kidney Foundation, National Nursing Certification Commission, Renal Physicians Association, Rogosin Institute, Satellite Healthcare.

OPENING REMARKS

Following the roll call, Dr. Allen Nissenson, KCQA Steering Committee Co-Chair, welcomed participants and noted that Dr. Ed Jones has stepped down from his role as Co-Chair. He commended Dr. Jones for his very significant contributions to KCQA over the past several years as Co-Chair. He then welcomed Dr. Paul Palevsky as the new Co-Chair. He noted that Dr. Palevsky is currently a Professor of Medicine in Clinical and Translational Science in the Renal-Electrolyte Division at the University of Pittsburgh School of Medicine and is Chief of the Renal Section at the VA Pittsburgh Healthcare System. Dr. Palevsky is actively involved in a number of research initiatives that have primarily focused on acute kidney injury and critical care nephrology, he was the inaugural associate editor for acute kidney injury and critical care nephrology for NephSAP, and is currently the deputy editor of the Clinical Journal of the American Society of Nephrology.

Dr. Palevsky hanked Dr. Nissenson and said he was pleased to assume the role of Co-Chair. He also thanked Dr. Jones for his work and dedication to KCQA, and remarked that he is looking forward to the work ahead.

AGENDA

Dr. Nishimi informed call participants that the focus of the call is to review the upcoming work plan landmarks for KCQA's patient-reported outcome focused initiative, as well as to provide a brief overview on the work conducted to date on the environmental scan. Next steps will also be outlined. There were no preliminary questions from participants.

BACKGROUND

Dr. Nishimi informed call participants that the KCP Operations Committee has approved moving forward with an initiative focused on a framework (e.g., principles, domains and subdomains, possible priorities, etc.) related to patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient reported outcome performance measures (PRO-PMs) for patients with ESRD.

Dr. Nishimi informed participants that measure development per se is not a focus at this time, nor is there a commitment by KCP to fund such. She noted the KCQA Steering Committee[1] has

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[1] Allen Nissenson (Co-Chair; DaVita), Paul Palevsky (Co-Chair; RPA), Scott Ash (FMC), Donna Bednarski (ANNA), Barbara Fivush (ASPN), Ray Hakim (ASN), Shari Ling (CMS), Chris Lovell (DCI), Tom Manley (NKF), Jason Spangler (Amgen), Gail Wick (AKF).

approved the proposed workplan that will be presented during the call.

WORKPLAN

Dr. Nishimi noted that the overall approach to the PRO initiative resembles many of the key components that were used for the *Blueprint* or for developing the KCQA's fluid management and medication reconciliation measures. She indicated that a high-level timeline is provided as Attachment B to the memo, and provided the following additional information:

Environment Scan

Dr. Nishimi informed participants that the initial pass for the environmental scan is largely complete. The scan focused on a review of the NQF's Quality Positioning System (QPS) and Patient- and Family-Centered Care (PFCC) projects (which will include measures not endorsed and so not in the QPS), Avalere's database (to which KCP has access because it grants permission for Avalere to publish KCQA specifications in full), AHRQ's National Quality Measures Clearinghouse, peer-reviewed literature, grey literature, material provided from KCQA members as they became aware of the initiation, and an increasing proliferation of proprietary entities (e.g., PROMIS, NQF's partnership with PatientsLikeMe, FasterCures' Framework for Patient Preferences into R&D Platforms, etc.).

Dr. Nishimi indicated that Attachment C to the memo summarizes the PROMs, PRO-PMs, and databases identified by the consultants to date. She noted the table focuses on titles and categorizing the items according to NQF's suggested domains in order to provide a sense of the current landscape, *regardless of patient population* (i.e., the vast majority of these are not specific to patients with ESRD). She informed participants that this scan will used as the starting point to identify an initial draft framework, which will include additional domains and/or parsing subdomains that are more relevant to ESRD, as well as for identifying gaps and priorities. She noted that Attachment D is the source file that contains more detailed descriptions for each item title found in Attachment C.

Dr. Nishimi noted that 128 instruments/PROMs/PRO-PMs have been identified in the current iteration of the environmental scan. The items are applicable to a wide variety of health diagnoses and conditions and are used to assess various health-relevant concepts, such as health-related quality of life, functional status, symptoms and symptom burden, health behaviors, and the patient's health care experience; these concepts are neither mutually exclusive nor exhaustive. She again noted the vast majority of the the items are not specific to patients with ESRD because the consultants cast the net broadly. The tables do not include all identified items, but rather presents the instruments/PROMs/ PRO-PMs that the consultants judged illustrated the current breadth and scope of measure types and constructs to provide information on instruments and measures that could be applicable to patients with ESRD or provide insight into constructing the framework.

Based on the NQF scheme, Dr. Nishimi indicated that the 128 items in the tables are distributed among the NQF domains, as follows:

- 4 Healthy Behavior items (2 of which are ESRD/transplant-related);
- 25 Experience with Care items (2 of which are ESRD/transplant-related);
- 51 Symptom/Symptom Burden (12 of which are ESRD/transplant-related);
- 58 Quality of Life (13 of which are ESRD/transplant-related); and

- 6 Unable to Classify due to insufficient information.

She noted in some cases more than one domain appeared to apply, as indicated in the table. Because such items were counted within each domain, the total is greater than 128.

Dr. Nishimi also noted that six registries/data platforms were were identified and are included in Attachment D; these will be further investigated as well to inform the framework.

Dr. Nishimi asked call participants to inform the consultants of any additional PROMs or PRO-PMs that they recommend be reviewed for possible inclusion and analysis in the scan. She indicated that the next step with respect to the environmental scan will be an analysis of the finer details of the items to draft a framework that goes beyond the NQF's four broad categories.

Commissioned Paper
Dr. Nishimi informed call participants that the initiative envisions a commissioned paper by a thought leader in PROs/PROMs/PRO-PMs who could apply it to the ESRD space or by an ESRD thought leader who could think about PROs/PROMs/PRO-PMs. She noted the consultants are currently working with the Co-Chairs and Steering Committee on candidate authors, but said if call participants had suggestions, the consultants would welcome them.

Structured Interviews of KCQA Members and Other Experts
Dr. Nishimi indicated that, as was done for the *Blueprint*, once KCQA has a better sense of the PROM/PRO-PM landscape that could be useful for patients with ESRD and a draft framework, the consultants will create a short background piece to use as the launching point for semi-structured interviews of KCQA members on what they view as important domains and subdomains (and likely specific PROM/PRO-PM types that members like, and dislike). Because it is important to adequately represent patient views, the consultants will work with KCQA's patient organization members and others on how best to expand interviews beyond the Lead and other representatives.

In-person Meeting
Dr. Nishimi indicated that the environmental scan, commissioned paper, and structured interviews, along with existing KCQA principles and the *Blueprint*'s goals (both modified in advance, if necessary, for this initiative) will provide the background for an in-person meeting in Washington, DC. As with the *Blueprint*, it is currently envisioned that this will again be limited to each member organization sending two individuals who will participate actively in the discussions. The target timeframe is February- March 2017.

Report
Dr. Nishimi informed participants that the initiative's output will be a report that identifies guiding principles, a framework, scope of, and ideally priorities for, PROs and PROMs for patients with ESRD. The timeline envisions a release around the time of KCP's June meeting.

Discussion
One call participant asked what degree of validation has been performed for each of the measures in the environmental scan tables, and asked if it would be possible to create a hierarchy depending on level of validation. Dr. Nishimi responded that that degree of teasing apart details will occur moving forward. She emphasized that, at this point, what is being

presented is strictly an environment survey to provide an idea of the types of instruments and measures currently in use. It was suggested that additional gaps may become evident once some of the measures are eliminated for lack of validation. Dr. Nishimi reminded the group that at this point the focus should not be on validity, but rather whether the measures contain the types of questions patients want and need to be asked, in particular because this initiative is not undertaking measure development.

Mr. Manley suggested that KCQA will be missing an important opportunity if there is not patient representation at the in-person meeting as well. Dr. Nishimi agreed, but noted that it will be important to think through how best to address the issue. She suggested the discussion could begin offline.

Mr. Jamgochian noted that DPC finalized its annual membership survey for the following week and expects to received between 600 and 800 responses. He reported thatthe survey asks questions about quality, and indicated there are both online and phone versions. He remarked that the survey is not at an advanced enough stage yet, but suggested that it be kept in mind for the future. He then indicated that DPC is strongly invested in and wants to support this work by way of patient advocate group and patient involvement. He asked Dr. Nishimi to keep DPC informed of what might be needed to assist. Dr. Nishimi expressed her appreciation. She indicated she is aware that DPC brings together focus group calls and noted that she will be contacting Mr. Jamgochian in that regard, perhaps after the DPC survey results are in.

Dr. Molony then noted that the Forum for ESRD Network's KPAC reaches hundreds of patients through the Networks. He indicated this route could be used to ask patients about the types of questions that would be important and meaningful to them for use in a PRO-PM. He noted that he, Maggie Carey, and Derek Forfang will facilitate the process and will send details upon completion. Dr. Nishimi thanked Dr. Molony and agreed that this would be useful.

Dr. Nishimi noted that NKF and perhaps DaVita, FMC, and DCI have patient councils. She suggested participants consider how to adapt existing online interview processes to some kind of survey. She remarked that such a survey could be fanned out and could be anonymous, giving each organization a code so results can be aggregated for analytic purposes. She asked participants to think about how to approach such an endeavor and about how to get initial input and prioritization in regards to what is important to patients to be asked about in terms of outcomes.

NEXT STEPS

Dr. Nishimi asked participants if there were any additional questions about the workplan components or timeline. No questions were raised. She again asked participants to forward to the consultants any additional items they would like to be included in the environmental scan.

With respect to next steps, Dr. Nishimi indicated that the consultants and Co-Chairs will work with the Steering Committee to further analyze the results of the scan and begin developing the materials for the structured interviews, draft principles, and framework.

Dr. Nishimi thanked participants for their thoughts and input, noting that this phase of KCQA's work is somewhat different from prior endeavors. She asked Drs. Nissenson and Palevsky if they had anything to add or any closing remarks. Drs. Nissenson and Palevsky thanked participants for their time and input, and the conference call was adjourned.

KIDNEY CARE
PARTNERS

TO: KCQA Members

FR: Robyn Y. Nishimi
Lisa McGonigal

RE: KCQA Patient-Reported Outcomes Initiative

DA: August 20, 2016

BACKGROUND

The Operations Committee has approved moving forward with an initiative focused on a framework (e.g., principles, domains and subdomains, possible priorities, etc.) related to patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient reported outcome performance measures (PRO-PMs) for patients with ESRD:[1]

- *Patient-Reported Outcome (PRO):* The concept of any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.
- *Patient-Reported Outcome Measure (PROM):* Instrument, scale, or single-item measure used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient to self-report (e.g., PHQ-9).
- *PRO-Based Performance Measure (PRO-PM):* A performance measure that is based on PROM data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved).

Measure development per se is not a focus at this time, nor is there a commitment by KCP to fund such. The KCQA Steering Committee[2] has reviewed the proposed workplan, and this memorandum summarizes the next steps for members' discussion.

WORKPLAN

The overall approach to this initiative resembles many of the key components we used for the *Blueprint* or for developing the KCQA's fluid management and medication reconciliation measures. A high-level timeline is provided as Attachment B, and the following sections provide additional information:

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[1] Attachment A sets out how PROs, PROMs, and PRO-PMs are referred to by NQF. Though we recognize the distinction in conversations often gets lost, we will endeavor to be more precise in the nomenclature used in KCQA's written documents.

[2] Allen Nissenson (Co-Chair; DaVita), Paul Palevsky (Co-Chair; RPA), Scott Ash (FMC), Donna Bednarski (ANNA), Barbara Fivush (ASPN), Ray Hakim (ASN), Shari Ling (CMS), Chris Lovell (DCI), Tom Manley (NKF), Jason Spangler (Amgen), Gail Wick (AKF).

- ***Environment Scan***. The initial pass for the environmental scan is largely complete and has focused on a review of the NQF's Quality Positioning System (QPS) and Patient- and Family-Centered Care (PFCC) projects (which will include measures not endorsed and so not in the QPS), Avalere's database (to which we have access because we grant permission for them to publish KCQA specifications in full), AHRQ's National Quality Measures Clearinghouse, peer-reviewed literature, grey literature, material provided from KCQA members as they became aware of the initiation, and an increasing proliferation of proprietary entities (e.g., PROMIS, NQF's partnership with PatientsLikeMe, FasterCures' Framework for Patient Preferences into R&D Platforms, etc.).

  Attachment C summarizes the PROMs, PRO-PMs, and databases we have identified to date. This table focuses on titles and categorizing the items according to NQF's suggested domains in order to provide a sense of the current landscape, *regardless of patient population* (i.e., the vast majority of these are not specific to patients with ESRD). We will use this as the starting point to identify an initial draft framework for additional domains and/or parsing subdomains that are more relevant to ESRD, as well as for identifying gaps and priorities. Attachment D is the source file that contains more detailed descriptions for each item title found in Attachment C.

  As Attachments C and D indicate, we identified 128 instruments/PROMs/PRO-PMs. Again, the vast majority of the items are not specific to patients with ESRD because we cast the net broadly—i.e., the items are applicable to a wide variety of health diagnoses and conditions and are used to assess various health-relevant concepts such as health-related quality of life, functional status, symptoms and symptom burden, health behaviors, and the patient's health care experience; these concepts are neither mutually exclusive nor exhaustive. The table presents those instruments/PROMs/PRO-PMs that we judged illustrated the current breadth and scope of measure types and constructs (not every single item we identified), so as to provide information on instruments and measures that could be applicable to patients with ESRD or provide insight into constructing the framework

  Based on the NQF scheme, the 128 items are distributed among the NQF domains, as follows:[3]

    - 4 Healthy Behavior items (2 of which are ESRD/transplant-related),
    - 25 Experience with Care items (2 of which are ESRD/transplant-related),
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  We also identified 6 registries/data platforms (Attachment D), and will further investigate these to inform the framework.

  Please let us know if there are any additional PROMs or PRO-PMs that you recommend we review for possible inclusion and analysis.

  The next step with respect to the environmental scan will be an analysis of the finer details of the items to draft a framework that goes beyond the NQF's four broad categories.

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[3] In some cases more than one domain appeared to apply, as indicated in the table. We counted that item within each domain, hence the total is >128.

- ***Commissioned Paper.*** The initiative envisions a commissioned paper by a thought leader in PROs/PROMs/PRO-PMs who could apply it to the ESRD space or by an ESRD thought leader who could think about PROs/PROMs/PRO-PMs. We are currently working with the Co-Chairs and Steering Committee on candidate authors.

- ***Structured Interviews of KCQA Members and Other Experts.*** As we did for the *Blueprint*, once we have a better sense of the PROM/PRO-PM landscape that could be useful for patients with ESRD and a draft framework, we will create a short background piece to use as the launching point for structured interviews of KCQA members on what they view as important domains and subdomains (and likely specific PROM/PRO-PM types that members like, and dislike). Because it is important to adequately represent patient views, we will work with KCQA's patient organization members and others on how best to expand interviews beyond the Lead and other representatives.

- ***In-person Meeting**.* The environmental scan, commissioned paper, and structured interviews, along with existing KCQA principles and the *Blueprint*'s goals (both modified in advance, if necessary, for this initiative) will provide the background for an in-person meeting in Washington, DC. As with the *Blueprint*, we currently envision this as again being limited to each member sending two individuals who will participate actively in the discussions. As noted in the workplan, the target timeframe is February-March 2017.

- ***Report.*** The initiative's output will be a report that identifies guiding principles, a framework, scope of, and ideally priorities for, PROs and PROMs for patients with ESRD. The timeline envisions a release around the time of KCP's June meeting.

NEXT STEPS/DISCUSSION
Are there any questions about the workplan components or timeline?

As indicated, please forward us any additional items you would like us to include in the environmental scan. With respect to next steps, we will work with the Steering Committee to further analyze the results of the scan and begin developing the materials for the structured interviews, draft principles, and framework.

Table 1. Distinctions among PRO, PROM, and PRO-PM: Two Examples

Concept	Patients With Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO (patient-reported outcome)	Symptom: depression	Functional Status-Role: employment
PROM (instrument, tool, single-item measure)	PHQ-9©, a standardized *tool* to assess depression	Single-item measure on National Core Indicators Consumer Survey: *Do you have a job in the community?*
PRO-PM (PRO-based performance measure)	Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711)	The proportion of people with intellectual or developmental disabilities who have a job in the community

SOURCE: National Quality Forum. Patient-Reported Outcomes (PROs) in Performance Measurement. January 10, 2013.

ATTACHMENT B

DRAFT TIMELINE/WORKPLAN FOR KCP PROM FRAMEWORK

Project initiation • Convene KCQA Co-Chairs • Convene KCQA Steering Committee o Review purpose of initiative and workplan o Discuss staff recommendations re: in-person meeting, pre-meeting work (e.g., commissioned paper, environmental scan, KCP member interviews with structured interview guidance) o Identify individuals other than KCQA Lead Representatives to be interviewed o Identify potential commissioned paper authors • Convene All-KCQA conference call to review initiative	Aug-Sep 2016
Identify commissioned paper author, let contract • Thought piece of how PROMs have evolved, what other fields are doing, and how the dialysis community might think about their application to ESRD. • See budget for additional details.	Aug-Sep
Environmental scan (consultants) • Do literature search for research in dialysis patient-reported items • Do NQF, AHRQ, and Avalere data base searches and catalog patient-reported items (generally and ESRD-specific) • Identify common themes/domains	Aug-Nov
Structured interviews of KCQA Lead Representatives and other experts (consultants) • In consultation with Steering Committee, create short, structured interview form as was done for *Blueprint* that elicits their perspectives on PROMs (e.g., scope, guiding principles, etc.) • Interview all KCQA Lead Representatives and/or their designees	Sep-Nov
Commissioned paper draft	Feb 2017
Co-Chair and Steering Committee calls • Review environmental scan • Review interview results • Review draft principles and framework • Review commissioned paper draft	Oct-Feb prn
All-KCQA conference call • Review environmental scan • Review interview results • Review draft principles and framework	Jan-Feb prn
In-person meeting to finalize draft principles and framework, as well as PROM priorities based on these. • As with *Blueprint*/Summit, use plenary as set-up and break-outs to discuss those issues needing in-person time vs. issues that can be handled with e-mail follow-up • As with Summit, limit participation to two individuals per KCP member; consider further limitation of Summit as one "speaking representative" and one "observer," excluding KCQA Steering Committee members, as was done for *Blueprint*, though I am inclined less toward that, though do feel at this time we should limit the number of individuals per KCQA member	Feb-Mar
Draft report (consultants)	Mar-Apr
Finalize report (consultants)	May
Co-Chair and Steering Committee calls prn re: meeting and report	Feb-May
Release report	June KCP mtg

TABLE 1. Working Environmental Scan Details of Instruments/PROMs and PRO-PMs[1] by Domain[2]

Healthy Behaviors = B

Ref	Instrument/PROM/PRO-PM	DOMAIN
9.	**Basel Assessment of Adherence with Immunosuppressive Medication Scales (BAASIS)** • Steward: University of Basel • Level: Not indicated	B
71.	**Immunosuppressant Therapy Adherence Scale (ITAS)** • Steward: University of Georgia College of Pharmacy Level: Not indicated	B
81.	**Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)** • Developer: De Geest et al. • Level: Not indicated	B
112.	**Self-Management Scale for Kidney Transplant Recipients** • Developer: S. Kosaka et al. • Level: Not indicated	B

Experience with Care = E

Ref	Instrument/PROM/PRO-PM	DOMAIN
1.	**NQF 0228: 3-Item Care Transition Measure (CTM)** • Steward: University of Colorado Denver Aschutz Medical Campus • Level: Hospital, Acute Care Facility	E
6.	**NQF 2789: Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Healthcare** • Steward: Center of Excellence for Pediatric Quality Measurement • Level: Clinician, Group/practice, Facility, Health Plan	E
12.	**NQF 0005: CAHPS Clinician & Group Survey (CG-CAHPS)—Adult, Child** • Steward: AHRQ	E

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[1] Gray cells indicate NQF endorsement. Yellow highlighted items are measures/instruments that reference patients with ESRD and/or kidney transplant recipients.

[2] For purposes of this initial scan, we have used the broad NQF domains (health behaviors, patient experience with care, symptom/symptom burden, and quality of life = B, E, S, Q respectively. Where there appeared to be both components or if the designation was not clear, two domains are indicated and place in both sections. Lastly, owing to the proprietary nature of some and/or lack of sufficient information, a few items are not characterized.

Ref	Instrument/PROM/PRO-PM	DOMAIN
	• Level: Clinician (group/practice, individual)	
13.	**NQF 0009: CAHPS Health Plan Survey v3.0 Children with Chronic Conditions Supplement** • Steward: AHRQ • Level: Health Plan • Note: Endorsement removed March 2016	E
14.	**NQF 0006: CAHPS Health Plan Survey, v5.0 (Medicaid and Commercial)** • Steward: AHRQ • Level: Health Plan	E
15.	**NQF 0517: CAHPS Home Health Care Survey** • Steward: CMS • Level: Facility	E
16.	**NQF 0258: CAHPS In-Center Hemodialysis Survey** • Steward: CMS • Level: Dialysis Facility	E
17.	**NQF 0691: CAHPS Nursing Home Survey—Discharged Resident Survey** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	E
18.	**NQF 0693: CAHPS Nursing Home Survey—Family Member Instrument** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	E
19.	**NQF 0692: CAHPS Nursing Home Survey—Long-Stay Resident Survey** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	E
23.	**NQF 2548: Child Hospital CAHPS** • Steward: Center for Quality Improvement and Patient Safety, AHRQ • Level: Facility	E
26.	**Consumer Quality Index for Chronic Dialysis Care** • Steward: University of Amsterdam • Level: Not indicated	E
37.	**DPC Patient Satisfaction and Priorities Survey** • Steward: DPC • Level: Not indicated	E
41.	**European Organization for Research and Treatment of Cancer (EORTC)-IN-PATSAT32** • Steward: European Organization for Research and Treatment of Cancer	E

Ref	Instrument/PROM/PRO-PM	DOMAIN
	• Level: Not indicated	
42.	**EORTC-QLQ-C15-PAL** • Steward: European Organization for Research and Treatment of Cancer • Level: Not indicated	E
47.	**NQF 0208: Family Evaluation of Hospice Care** • Steward: National Hospice and Palliative Care Organization • Level: Facility, Population (national)	E
67.	**HowRwe** • Steward: R-Outcomes Ltd. • Level: Not indicated	E
91.	**NKF's Patient-Centered Quality Measures Survey** • Steward: NKF • Level: Not indicated	E
92.	**NQF 0007: NCQA Supplemental Items for CAHPS 4.0 Adult Questionnaire** • Steward: NCQA • Level: Clinician (group/practice, individual, facility), Health Plan, Integrated Delivery System, Population (national, regional, state) • Note: Endorsement removed April 2014	E
94.	**OsteoARthritis Treatment Satisfaction (ARTS) Questionnaire** • Developer: Pouchet et al. • Level: Not indicated	E
95.	**Osteoporosis Patient Treatment Satisfaction Questionnaire (OPSAT-Q)** • Developer: Roche Laboratories, Inc. • Level: Not indicated	E
100.	**NQF 0726: Patient Experience of Psychiatric Care as Measure by the Inpatient Consumer Survey (ICS)** • Steward: National Association of State Mental Health Program Directors Research Institute (NRI) • Level: Facility, Population (national, regional, state)	E
101.	**NQF 1741: Patient Experience with Surgical Care Based on the CAHPS Surgical Care Survey** • Steward: American College of Surgeons, Division of Advocacy and Health Policy • Level: Individual Clinician, Group/Practice	E
106.	**Patient Satisfaction Questionnaire: PSQ-III** • Steward: RAND • Level: Not indicated	E
123.	**NQF 0725: Validated Family-Centered Questionnaire for Parents' and Patients' Experiences During Inpatient Pediatric Hospital Stay** • Steward: Boston Children's Hospital, Center for Patient Safety and Quality Research • Level: Facility • Note: Endorsement removed January 2015	E

Symptom/Symptom Burden = S

Ref	Instrument/PROM/PRO-PM	DOMAIN
8.	**Barthel's Index Rating Scale** • Steward: Public domain • Level: Not indicated	Q/S
10.	**Beck Depression Inventory (BDI)** • Steward: Public domain • Level: Not indicated	S
20.	**Center for Epidemiological Studies Depression (CES-D) Screen** • Steward: Public domain • Level: Not indicated	S
24.	**CHOICE Health Experience Questionnaire (CHEQ)** • Developer: AW Wu et al. • Level: Not indicated	Q/S
25.	**Comfort Questionnaire** • Developer: Katharine Kolcaba, PhD • Level: Healthcare Delivery Systems	S
27.	**Controlling the Impact of COPD on Health Status Measure** • Steward: Minnesota Community Measurement (MNCM) • Level: Individual Clinician	S
28.	**COPD Assessment Test (CAT)** • Steward: GlaxoSmithKline • Level: Not indicated	S
29.	**COPD Clinical Questionnaire (CCQ)** • Steward: University Medical Center Groningen • Level: Not indicated	Q/S
30.	**NQF 0711: Depression Remission at Six Months** • Steward: MN Community Measurement • Level: Clinician, Group/Practice, Facility	S
31.	**NQF 0710: Depression Remission at Twelve Months** • Steward: MN Community Measurement • Level: Clinician, Group/Practice, Facility	S
32.	**NQF 1884: Depression Response at Six Months—Progress Towards Remission** • Steward: MN Community Measurement • Level: Clinician, Group/Practice, Facility	S

Ref	Instrument/PROM/PRO-PM	DOMAIN
33.	**NQF 1885: Depression Response at Twelve Months—Progress Towards Remission** • Steward: MN Community Measurement • Level: Clinician, Group/Practice, Facility	S
35.	**Diabetes-39** • Steward: Public domain • Level: Not indicated	Q/S
36.	**Dialysis Symptom Index (DSI)** • Steward: University of Pittsburgh • Level: Not indicated	S
39.	**End Stage Renal Disease Severity Index (ESRD-SI)** • Steward: Not identified • Level: Not indicated	S
40.	**End-Stage Renal Disease Symptom Checklist–Transplantation Module (ESRD_SCLTM)** • Steward: University of Essen, Germany • Level: Not indicated	Q/S
44.	**EuroQOL: EQ5D** • Steward: EuroQOL Research Foundation • Level: Not indicated	Q/S
45.	**Fall Risk Assessment Scale for the Elderly (FRASE)** • Developer: G. Cannard (Ireland) • Level: Not indicated	Q/S
46.	**Falls Risk Assessment Tool (FRAT)** • Steward: Falls Prevention Group (Great Britain) • Level: Not indicated	Q/S
49.	**Fluid Management Survey** • Steward: Not identified • Level: Not indicated	S
59.	**General Health Questionnaire (GHQ)** • Steward: GL Assessments • Level: Not indicated	S
60.	**Generalized Anxiety Disorder Scale (GAD-7)** • Steward: Pfizer, Inc. • Level: Not indicated	S
61.	**Geriatric Depression Scale** • Steward: Public domain • Level: Not indicated	S

Ref	Instrument/PROM/PRO-PM	DOMAIN
62.	**Hamilton Rating Scale for Depression (HAM-D)** • Steward: Public domain • Level: Not indicated	S
64.	**Hemodialysis Stressor Scale (HSS)** • Developer: Baldriee et al. • Level: Not indicated	Q/S
65.	**Hospital Anxiety and Depression Scale (HADS)** • Steward: Participation and Quality of Life (PAR-QOL) Project • Level: Not indicated	S
66.	**Hospital-Level Risk-Standardized Patient-Reported Outcomes Following Primary Elective Total Hip and/or Total Knee Arthroplasty (THA/TKA)** • Steward: CMS (CMS pipeline) • Level: Hospital	Q/S
69.	**Identification of Seniors at Risk (ISAR)** • Steward: Not identified • Level: Not indicated	S
70.	**Illness Intrusiveness Ratings Scale (IIRS)** • Steward: Stanford Patient Education Research Center • Level: Not indicated	Q/S
73.	**Johns Hopkins Frailty Criteria** • Steward: Johns Hopkins University • Level: Clinician	Q/S
77.	**Kidney Transplant Recipient Stressor Scale (KTRSS)** • Steward: Not identified • Level: Not indicated	Q/S
83.	**Medical Outcomes Study Short Form 36-Item Health Survey (SF-36)** • Steward: RAND • Level: Not indicated	Q/S
87.	**Mental Health/Substance Abuse: Mean of Patients' Overall Change Scores on the Basis-24 Survey** • Developer: Susan V. Eisen, PhD • Level: Individual Clinician	Q/S
88.	**Mini-Nutritional Assessment (MNA)** • Steward: Nestle Nutrition Institute • Level: Not indicated	S
89.	**Modified Transplant Symptom Occurrence and Symptom Distress Scale-59 Items Revised (MTSOSD-59R)** • Steward: Universiteit Leuven • Level: Not indicated	S

Ref	Instrument/PROM/PRO-PM	DOMAIN
93.	**Optimal Asthma Care—Control Component** • Steward: MN Community Measurement • Level: Not stated	S
96.	**Pain Assessment Among Patients with Bone Metastases** • Steward: American Society of Clinical Oncology (ASCO) • Level: Clinician (group/practice)	S
97.	**Palfrey's Specific Health Questionnaire for ESRD Patients** • Steward: Not identified • Level: Not indicated	S
99.	**Patient Health Questionnaires (PHQ)** • Steward: Pfizer, Inc. • Level: Not indicated	S
102.	**Patient-Reported Health Status for Chronic Sinusitis—Completion of Validated Questionnaire of Health Status at Time of Diagnosis** • Steward: American Academy of Otolaryngology • Level: Hospital	S
105.	**Patient-Reported Outcomes Measures Information System (PROMIS) Measures** • Steward: HHS • Level: Not indicated	Q/S
107.	**Pediatric Comfort Assessment** • Developer: Ambuel et al. • Level: Not indicated	S
110.	**Physical Symptom Distress Scale** • Developer: CP Chiu • Level: Not indicated	S
111.	**Postchemotherapy Nausea** • Steward: ASCO • Level: Clinician (group/practice)	S
114.	**Sickness Impact Profile (SIP)** • Steward: Johns Hopkins University • Level: Not indicated	Q/S
115.	**Spence Children's Anxiety Scale (SCAS)** • Developer: Susan H. Spence, PhD • Level: Not indicated	S
121.	**Transplant Effects Questionnaire (TxEQ)** • Developer: Zeigelmann et al. • Level: Not indicated	S

Ref	Instrument/PROM/PRO-PM	DOMAIN
122.	**Transplant Symptom Frequency Questionnaire (TSFQ)** • Steward: Not identified • Level: Not indicated	S
124.	**PQRS 420: Varicose Veins Treatment with Saphenous Ablation—Outcomes Survey** • Steward: Society of Interventional Radiology • Level: Clinician	S
126.	**Wong-Baker FACES Pain Rating Scale** • Steward: Wong-Baker FACES • Level: Not indicated	S
128.	**Zung Self-Rating Depression Scale (ZSDS)** • Steward: Public domain • Level: Not indicated	S

Quality of Life = Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
2.	**100-Category Checklist** • Developer: H. Tsutsui et al. • Level: Not indicated	Q
3.	**Activity Measure for Post-Acute Care (AM-PAC)** • Steward: Boston University • Level: Not indicated	Q
7.	**NQF 2653: Average Change in Functional Status Following Total Knee Replacement Surgery** • Steward: MN Community Measurement • Level: Clinician (group/practice)	Q
8.	**Barthel's Index Rating Scale** • Steward: Public domain • Level: Not indicated	Q/S
11.	**Beth Israel/UCLA Functional Status Questionnaire (FSQ)** • Steward: Beth Israel/UCLA • Level: Not indicated	Q
21.	**NQF 0429: Change in Basic Mobility as Measured by the AM-PAC** • Steward: CREcare • Level: Individual Clinician, Facility	Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
22.	**NQF 0430: Change in Daily Activity Function as Measured by the AM-PAC** - Steward: CREcare - Level: Individual Clinician, Facility	Q
24.	**CHOICE Health Experience Questionnaire (CHEQ)** - Developer: AW Wu et al. - Level: Not indicated	Q/S
29.	**COPD Clinical Questionnaire (CCQ)** - Steward: University Medical Center Groningen - Level: Not indicated	Q/S
35.	**Diabetes-39** - Steward: Public domain - Level: Not indicated	Q/S
38.	**Edmonton Functional Assessment Tool (EFAT2)** - Steward: Not identified - Level: Not indicated	Q
40.	**End-Stage Renal Disease Symptom Checklist–Transplantation Module (ESRD_SCLTM)** - Steward: University of Essen, Germany - Level: Not indicated	Q/S
43.	**EORTC QLQ-C30** - Steward: European Organization for Research and Treatment of Cancer - Level: Not indicated	Q
44.	**EuroQOL: EQ5D** - Steward: EuroQOL Research Foundation - Level: Not indicated	Q/S
45.	**Fall Risk Assessment Scale for the Elderly (FRASE)** - Developer: G. Cannard (Ireland) - Level: Not indicated	Q/S
46.	**Falls Risk Assessment Tool (FRAT)** - Steward: Falls Prevention Group (Great Britain) - Level: Not indicated	Q/S
48.	**Ferrans and Powers Quality of Life Index of Dialysis (QLI)** - Steward: Ferrans and Powers - Level: Not indicated	Q
50.	**Functional Assessment of Chronic Illness Therapy (FACIT) Scales** - Developer: David Cella, Ph.D - Level: Not indicated	Q
51.	**NQF 2243: Functional Outcome Assessment**	Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
	• Steward: MN Community Measurement • Level: Clinician (group/practice)	
52.	**Functional Status Assessment and Goal Achievement for Patients with Congestive Heart Failure** • Steward: NCQA • Level: Hospital	Q
53.	**PQRS 377: Functional Status Assessment for Complex Chronic Conditions** • Steward: Mathmatica • Level: Clinician	Q
54.	**PQRS 282: Functional Status Assessment for Dementia** • Steward: American Academy of Neurology/American Psychiatric Association • Level: Clinician	Q
55.	**PQRS 375: Functional Status Assessment for Knee Replacement** • Steward: NCQA • Level: Clinician	Q
56.	**PQRS 178: Functional Status Assessment for Rheumatoid Arthritis** • Steward: American College of Rheumatology • Level: Clinician	Q
57.	**NQF 0423: Functional Status Change for Patients with Hip Impairments** • Steward: Focus on Therapeutic Outcomes (FOTO) • Level: Clinician (group/practice, individual, facility), Health Plan, Integrated Delivery	Q
63.	**Hemodialysis Quality of Life Questionnaire (HQL)** • Steward: Not identified • Level: Not indicated	Q
64.	**Hemodialysis Stressor Scale (HSS)** • Developer: Baldriee et al. • Level: Not indicated	Q/S
66.	**Hospital-Level Risk-Standardized Patient-Reported Outcomes Following Primary Elective Total Hip and/or Total Knee Arthroplasty (THA/TKA)** • Steward: CMS (CMS pipeline) • Level: Hospital	Q/S
68.	**HowRu** • Steward: R-Outcomes Ltd. • Level: Not indicated	Q
70.	**Illness Intrusiveness Ratings Scale (IIRS)** • Steward: Stanford Patient Education Research Center • Level: Not indicated	Q/S
72.	**NQF 2634: Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure—Change in Mobility Score for Medical Rehabilitation Patients** • Steward: CMS	Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
	• Level: Facility	
73.	**Johns Hopkins Frailty Criteria** • Steward: Johns Hopkins University • Level: Clinician	Q/S
74.	**Katz ADL** • Developer: S. Katz • Level: Not indicated	Q
75.	**KDQOL** • Steward: None (NQF 0260 is a structural reporting measure using KDQOL with Witten Assoc. as steward); the instrument was developed by RAND and is in the public domain • Level: Not a performance measure (i.e., is a PROM, not PRO-PM)	Q
76.	**Kidney Disease Questionnaire (KDQ)** • Steward: University of Calgary • Level: Not indicated	Q
77.	**Kidney Transplant Recipient Stressor Scale (KTRSS)** • Steward: Not identified • Level: Not indicated	Q/S
78.	**Kidney Transplant Questionnaire (KTQ)** • Developer: Laupacis et al. • Level: Not indicated	Q
79.	**Kurtzke Expanded Disability Status Scale (EDSS)** • Steward: Public domain • Level: Not indicated	Q
80.	**Life Satisfaction Index (LSI)** • Steward: Public domain • Level: Not indicated	Q
82.	**McGill Quality of Life Scale (MQOL)** • Developer: Robin Cohen • Level: Not indicated	Q
83.	**Medical Outcomes Study Short Form 36-Item Health Survey (SF-36)** • Steward: RAND • Level: Not indicated	Q/S
84.	**Medicare Health Outcomes Survey** • Steward: NCQA • Level: Managed Care Plans	Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
85.	**Medicare Health Outcomes Survey-Modified** • Steward: NCQA • Level: Managed Care Plans	Q
86.	**Medicare Health Outcomes Survey-Modified, General Comfort** • Developer: Katharine Kolcaba, PhD • Level: Healthcare Delivery System	Q
87.	**Mental Health/Substance Abuse: Mean of Patients' Overall Change Scores on the Basis-24 Survey** • Developer: Susan V. Eisen, PhD • Level: Individual Clinician	Q/S
90.	**National Institute of Diabetes and Digestive and Kidney Disease Transplantation Quality of Life Questionnaire (NIDDK-QOL)** • Steward: NIDDK • Level: Not indicated	Q
104.	**Patient Reported Outcome Indices for Multiple Sclerosis (PRIMUS)** • Steward: Galen Research Ltd. • Level: Not indicated	Q
105.	**Patient-Reported Outcomes Measures Information System (PROMIS) Measures** • Steward: HHS • Level: Not indicated	Q/S
108.	**Physical Functional Health Status** • Steward: Therapeutics Associates, Inc. • Level: Individual Clinician	Q
109.	**Physical Functional Status** • Steward: American Physical Therapy Association (APTA) • Level: Individual Clinician	Q
113.	**Short-Version Checklist** • Developer: H. Tsutsui et al. • Level: Not indicated	Q
114.	**Sickness Impact Profile (SIP)** • Steward: Johns Hopkins University • Level: Not indicated	Q/S
116.	**Spitzer Quality of Life Index** • Steward: Public domain • Level: Not indicated	Q
117.	**Stroke and Aphasia Quality of Life Scale-53 and -39 (SAQOL)** • Developer: Hilari et al. • Level: Not indicated	Q

Ref	Instrument/PROM/PRO-PM	DOMAIN
118.	**Stroke Impact Scale** • Steward: Public domain • Level: Not indicated	Q
119.	**Stroke-Specific Quality of Life Scale (SS-QOL)** • Developer: L.S. Williams et al. • Level: Not indicated	Q
120.	**Transplant Care Index (TCI)** • Steward: Not identified • Level: Not indicated	Q
125.	**Vulnerable Elders Scale-13 (VES-13)** • Steward: RAND • Level: Not indicated	Q
127.	**World Health Organization Quality of Life (WHOQOL) and WHOQOL-BREF** • Steward: WHO • Level: Not indicated	Q

Uncharacterized

Ref	Instrument/PROM/PRO-PM	DOMAIN
4.	**ACORN Adolescent (Youth) Outcome Questionnaire** • Steward: Center for Clinical Informatics • Level: Not stated	[3]
5.	**ACORN Adult Outcome Questionnaire** • Steward: Center for Clinical Informatics • Level: Not stated	[3]
34.	**NQF 0712: Depression Utilization of the PHQ-9 Tool** • Steward: MN Community Measurement • Level: Clinician, Group/Practice, Facility	[4]
58.	**NQF 2483: Gains in Patient Activation (PAM) Scores at 12 Months** • Steward: Insignia Health	[5]

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[3] ACORN is proprietary, so difficult to discern; also depends on specific instrument/combination of items, but appears to be Q, S.

[4] Structural process measure based on a patient-reported outcome tool, but not an outcome per se.

[5] Although often lumped with patient experience, engagement/activation is not precisely captured by that domain's overall focus and should perhaps be a separate domain.

Ref	Instrument/PROM/PRO-PM	DOMAIN
	• Level: Clinician (group/practice)	
98.	**Patient Activation Measure (PAM)** • Steward: Insignia Health • Level: Not indicated	[6]
103.	**Patient-Reported Outcomes Following Ilio-Femoral Stenting** • Steward: Society of Interventional Radiology • Level: Clinician	[7]

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[6] Although often lumped with patient experience, engagement/activation is not precisely captured by that domain's overall focus and should perhaps be a separate domain.

[7] No additional information available other than title.

TABLE 3. Working Environmental Scan Details of Instruments/PROMs, PRO-PMs, Registries/Data Platforms[1]

	MEASURE	DESCRIPTION	DOMAIN
1.	**NQF 0228: 3-Item Care Transition Measure (CTM)** • Steward: University of Colorado Denver Aschutz Medical Campus • Level: Hospital, Acute Care Facility	The CTM-3 is a hospital-level measure of performance that reports the average patient reported quality of preparation for self-care response among adult patients discharged from general acute care hospitals within the past 30 days.	E
2.	**100-Category Checklist** • Developer: H. Tsutsui et al. • Level: Not indicated	Developed to assess physical and psychosocial problems and functional and environmental factors affecting QOL in hemodialysis patients.	Q
3.	**Activity Measure for Post-Acute Care (AM-PAC)** • Steward: Boston University • Level: Not indicated	Outcome instrument that measures function in three domains: basic mobility, daily activities and applied cognitive. Can be used for quality improvement, outcomes monitoring, and research activities in inpatient and outpatient rehabilitation, home care, nursing homes and long-term acute care settings. Appropriate for functional assessment in adults with a wide range of diagnoses and functional abilities. Patients can respond to test items or the instrument can be completed by clinicians or family members. Available in two basic formats: a computer-based version and a short-form version.	Q
4.	**ACORN Adolescent (Youth) Outcome Questionnaire** • Steward: Center for Clinical Informatics • Level: Not stated	Not available.	[2]
5.	**ACORN Adult Outcome Questionnaire** • Steward: Center for Clinical Informatics • Level: Not stated	Not available.	[2]

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[1] Gray cells indicate NQF endorsement. Yellow highlighted items are measures/instruments that reference patients with ESRD and/or kidney transplant recipients. As noted in memo and Table 1 (Attachment C), "Domain" refers to those outlined in NQF's *Patient-Reported Outcomes in Performance Measurement* report.

[2] ACORN is proprietary, so difficult to discern; also depends on specific instrument/combination of items, but appears to be Q, S.

	MEASURE	DESCRIPTION	DOMAIN
6.	**NQF 2789: Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Healthcare** • Steward: Center of Excellence for Pediatric Quality Measurement • Level: Clinician, Group/practice, Facility, Health Plan	The Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care measures the quality of preparation for transition from pediatric-focused to adult-focused health care as reported in a survey completed by youth ages 16-17 years old with a chronic health condition. The ADAPT survey generates measures for each of the 3 domains: 1) Counseling on Transition Self-Management, 2) Counseling on Prescription Medication, and 3) Transfer Planning.	E
7.	**NQF 2653: Average Change in Functional Status Following Total Knee Replacement Surgery** • Steward: MN Community Measurement • Level: Clinician (group/practice)	For patients age 18 and older undergoing total knee replacement surgery, the average change from pre-operative functional status to one year (nine to fifteen months) post-operative functional status using the Oxford Knee Score (OKS) patient reported outcome tool.	Q
8.	**Barthel's Index Rating Scale** • Steward: Public domain • Level: Not indicated	Ordinal scale used to measure performance in activities of daily living (ADL). Each performance item is rated on this scale with a given number of points assigned to each level or ranking. It uses 10 variables describing ADL and mobility. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital.	Q/S
9.	**Basel Assessment of Adherence with Immunosuppressive Medication Scales (BAASIS)** • Steward: University of Basel • Level: Not indicated	4-item scale to assess recent (previous 4 weeks) immunosuppressive therapy (IST) adherence in adult renal transplant recipients, based on the dimensions of medication taking adherence (taking, timing, omitting / drug holidays, dose reduction).	B
10.	**Beck Depression Inventory (BDI)** • Steward: Public domain • Level: Not indicated	21-question multiple-choice self-report psychometric inventory for measuring the severity of depression. Noted in KCP Blueprint as a tool used to assess for depression in ESRD patients.	S
11.	**Beth Israel/UCLA Functional Status Questionnaire (FSQ)** • Steward: Beth Israel/UCLA • Level: Not indicated	Multidimensional self-report instrument used for assessing the physical, social, and psychological status of children and adults.	Q
12.	**NQF 0005: CAHPS Clinician & Group Survey (CG-CAHPS)—Adult, Child** • Steward: AHRQ • Level: Clinician (group/practice, individual)	The Consumer Assessment of Healthcare Providers and Systems Clinician & Group Survey (CG-CAHPS) is a standardized survey instrument that asks patients to report on their experiences with primary or specialty care received from providers and their staff in ambulatory care settings over the preceding 12 months. The survey includes standardized questionnaires for adults and children. All questionnaires can be used in both primary care and specialty care settings. The adult survey is administered to patients aged 18 and over. The child survey is administered to the parents or guardians of pediatric patients under the age of 18. Patients who have had at least one visit during the past 12-months are eligible to be surveyed.	E

	MEASURE	DESCRIPTION	DOMAIN
		The Adult CG-CAHPS Survey includes one global rating item and39 items in which 13 items can be organized into three composite measures and one global item for the following categories of care or services provided in the medical office: • Getting Timely Appointments, Care, and Information (5 items) • How Well Providers Communicate With Patients (6 items) • Helpful, Courteous, and Respectful Office Staff (2 items) • Overall Rating of Provider (1 item) The Child CG-CAHPS Survey includes one global rating item and 54 items in which 24 items can be organized into five composite measures and one global item for the following categories of care or services provided in the medical office: • Getting Timely Appointments, Care, and Information (5 items) • How Well Providers Communicate with Patients (6 items) • Helpful, Courteous, and Respectful Office Staff (2 items) • Overall Rating of Provider (1 item) • Provider´s Attention to Child´s Growth and Development (6 items) • Provider´s Advice on Keeping Your Child Safe and Healthy (5 items)	
13.	**NQF 0009: CAHPS Health Plan Survey v3.0 Children with Chronic Conditions Supplement** • Steward: AHRQ • Level: Health Plan • Note: Endorsement removed March 2016	31- questions that supplement the CAHPS Child Survey v 3.0 Medicaid and Commercial Core Surveys, that enables health plans to identify children who have chronic conditions and assess their experience with the health care system.	E
14.	**NQF 0006: CAHPS Health Plan Survey, v5.0 (Medicaid and Commercial)** • Steward: AHRQ • Level: Health Plan	The CAHPS Health Plan Survey is a standardized survey instrument which asks enrollees to report on their experiences accessing care and health plan information, and the quality of care received by physicians. The survey's target population includes individuals of all ages (18 and older for the Adult version; parents or guardians of children aged 0-17 for the Child version) who have been enrolled in a health plan for a specified period of time (6 months or longer for Medicaid version, 12 months or longer for Commercial version) with no more than one 30-day break in enrollment. The CAHPS Adult Health Plan Survey has 39 items, and the CAHPS Child Health Plan Survey has 41 core items. Ten of the adult survey items and 11 of the child survey items are organized into 4 composite measures, and each survey also has 4 single-item rating measures. Each measure is used to assess a particular domain of health plan and care quality from the patient's perspective. • Measure 1: Getting Needed Care (2 items) • Measure 2: Getting Care Quickly (2 items)	E

	MEASURE	DESCRIPTION	DOMAIN
		• Measure 3: How Well Doctors Communicate (4 items in Adult survey & 5 in Child survey) • Measure 4: Health Plan Information and Customer Service (2 items) • Measure 5: How People Rated Their Personal Doctor (1 item) • Measure 6: How People Rated Their Specialist (1 item) • Measure 7: How People Rated Their Health Care (1 item) • Measure 8: How People Rated Their Health Plan (1 item)	
15.	**NQF 0517: CAHPS Home Health Care Survey** • Steward: CMS • Level: Facility	The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Home Healthcare Survey is a standardized survey instrument and data collection methodology for measuring home health patients´ perspectives on their home healthcare in Medicare-certified home healthcare agencies. AHRQ and CMS supported the development of the Home Health CAHPS to measure the experiences of those receiving home health care with these three goals in mind: (1) to produce comparable data on patients´ perspectives on care that allow objective and meaningful comparisons between home health agencies on domains that are important to consumers, (2) to create incentives for agencies to improve their quality of care through public reporting of survey results, and (3) to enhance public accountability in health care by increasing the transparency of the quality of care provided in return for public investment.	E
16.	**NQF 0258: CAHPS In-Center Hemodialysis Survey** • Steward: CMS • Level: Dialysis Facility	Comparison of services and quality of care that dialysis facilities provide from the perspective of ESRD patients receiving in-center hemodialysis care. Patients will assess their dialysis providers , including nephrologists and medical and non-medical staff, the quality of dialysis care they receive, and information sharing about their disease. Three measures: • M1: Nephrologists' Communication and Caring • M2: Quality of Dialysis Center Care and Operations • M3: Providing Information to Patients Three global items: • M4: Rating of the nephrologist • M5: Rating of dialysis center staff • M6: Rating of the dialysis facility The first three measures are created from six or more questions from the survey that are reported as one measure score. The three global items use a scale of 0 to 10 to measure the respondent's assessment.	E

	MEASURE	DESCRIPTION	DOMAIN
17.	**NQF 0691: CAHPS Nursing Home Survey—Discharged Resident Survey** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	The CAHPS® Nursing Home Survey—Discharged Resident Instrument is a mail survey instrument to gather information on the experience of short stay (5 to 100 days) residents recently discharged from nursing homes. This survey can be used in conjunction with the CAHPS Nursing Home Survey—Family Member Instrument and the Long Stay Resident Instrument. The survey instrument provides nursing home level scores on 4 global items. In addition, the survey provides nursing home level scores on summary measures valued by consumers; these summary measures or composites are currently being analyzed. The composites may include those valued by long stay residents: (1) Environment; (2) Care; (3) Communication & Respect; (4) Autonomy and (5) Activities.	E
18.	**NQF 0693: CAHPS Nursing Home Survey—Family Member Instrument** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	The CAHPS Nursing Home Survey—Family Member Instrument is a mail survey instrument to gather information on the experiences of family members of long stay (greater than 100 days) residents currently in nursing homes. CMS requested development of this questionnaire, which is intended to complement the CAHPS Nursing Home Survey—Long-Stay Resident Instrument and the Discharged Resident Instrument. The Family Member Instrument asks respondents to report on their own experiences (not the resident's) with the nursing home and their perceptions of the quality of care provided to a family member living in a nursing home. The survey instrument provides nursing home level scores on 4 topics valued by patients and families: (1) Meeting Basic Needs—Help with Eating, Drinking, and Toileting; (2) Nurses/Aides´ Kindness/ Respect Towards Resident; (3)Nursing Home Provides Information/Encourages Respondent Involvement; and (4) Nursing Home Staffing, Care of Belongings, and Cleanliness. In addition, the survey provides nursing home scores on 3 global items including an overall Rating of Care.	E
19.	**NQF 0692: CAHPS Nursing Home Survey—Long-Stay Resident Survey** • Steward: AHRQ • Level: Facility • Note: Endorsement removed March 2016	The CAHPS® Nursing Home Survey—Long-Stay Resident Instrument is an in-person survey instrument to gather information on the experience of long stay (greater than 100 days) residents currently in nursing homes. This survey, and can be used in conjunction with the CAHPS Nursing Home Survey—Family Member Instrument and Discharged Resident Instrument. The survey instrument provides nursing home level scores on 5 topics valued by residents: (1) Environment; (2) Care; (3) Communication & Respect; (4) Autonomy and (5) Activities.	E
20.	**Center for Epidemiological Studies Depression (CES-D) Screen** • Steward: Public domain • Level: Not indicated	20-Item patient-reporting screening tool. Noted in KCP Blueprint as a tool used to assess for depression in ESRD patients.	S
21.	**NQF 0429: Change in Basic Mobility as Measured by the AM-PAC** • Steward: CREcare • Level: Individual Clinician, Facility	This measure is used to assess the mean change score in basic mobility of patients in a post-acute care setting as assessed using the "Basic Mobility" domain of the Activity Measure for Post-Acute Care (AM-PAC).	Q
22.	**NQF 0430: Change in Daily Activity Function as Measured by the AM-PAC** • Steward: CREcare • Level: Individual Clinician, Facility	This measure is used to assess the mean change score in daily activity function of patients in a post-acute care setting as assessed using the "Daily Activity" domain of the Activity Measure for Post-Acute Care (AM-PAC).	Q

	MEASURE	DESCRIPTION	DOMAIN
23.	**NQF 2548: Child Hospital CAHPS** • Steward: Center for Quality Improvement and Patient Safety, AHRQ • Level: Facility	The Consumer Assessment of Healthcare Providers and Systems Hospital Survey–Child Version (Child HCAHPS) is a standardized survey instrument that asks parents and guardians (henceforth referred to as parents) of children under 18 years old to report on their and their child's experiences with inpatient hospital care. The performance measures of the Child HCAHPS survey consist of 39 items organized by overarching groups into the following 18 composite and single-item measures: Communication with Parent 1. Communication between you and your child's nurses (3 items) 2. Communication between you and your child's doctors (3 items) 3. Communication about your child's medicines (4 items) 4. Keeping you informed about your child's care (2 items) 5. Privacy when talking with doctors, nurses, and other providers (1 item) 6. Preparing you and your child to leave the hospital (5 items) 7. Keeping you informed about your child's care in the Emergency Room (1 item) 8. Communication with Child 9. How well nurses communicate with your child (3 items) 10. How well doctors communicate with your child (3 items) 11. Involving teens in their care (3 items) Attention to Safety and Comfort 12. Preventing mistakes and helping you report concerns (2 items) 13. Responsiveness to the call button (1 item) 14. Helping your child feel comfortable (3 items) 15. Paying attention to your child's pain (1 item) Hospital Environment 16. Cleanliness of hospital room (1 item) 17. Quietness of hospital room (1 item) 18. Global Rating 19. Overall rating (1 item) 20. Recommend hospital (1 item) The measure timeframe is 12 months.	E

	MEASURE	DESCRIPTION	DOMAIN
24.	**CHOICE Health Experience Questionnaire (CHEQ)** - Developer: AW Wu et al. - Level: Not indicated	Developed to assess physical and psychosocial problems and functional and environmental factors affecting QOL in hemodialysis patients. Comprised of 2 parts, 9 general domains of SF-36 (physical function, role-physical, bodily pain, mental health, role-emotional, social function, vitality, general health, and report transition) and 16 dialysis-specific domains of the CHEQ (role-physical, mental health, general health, freedom, travel restriction, cognitive function, financial function, restriction diet and fluids, recreation, work, body image, symptoms, sex, sleep, access, and quality of life).	Q/S
25.	**Comfort Questionnaire** - Developer: Katharine Kolcaba, PhD - Level: Healthcare Delivery Systems	This measure assesses quality in terms of comfort using the General Comfort Questionnaire. The questionnaire, given to either patients or family members, measures the extent to which the responder is experiencing comfort at that point in time. The following variations on the General Comfort Questionnaires have been developed and are in use in various settings: - Shortened General Comfort Questionnaire - Comfort Behaviors Checklist - Comfort Daisies (pediatric) - Perianesthesia Comfort Questionnaire - Radiation Therapy Comfort Questionnaire - Urinary Incontinence and Frequency Comfort Questionnaire - End of Life Planning Comfort Questionnaire - End of Life Comfort Questionnaire, Patients - End of Life Comfort Questionnaire, Families - Hospice Comfort Questionnaire - Healing Touch Comfort Questionnaire - Advance Directives Comfort Questionnaire - Verbal Rating Scale Comfort Questionnaire - Verbal Rating Scale Comfort Questionnaire - Visual Discomfort Scale Comfort Questionnaire - Nurses Comfort Questionnaire	S
26.	**Consumer Quality Index for Chronic Dialysis Care** - Steward: University of Amsterdam - Level: Not indicated	71-item standardized patient survey combining the inventory of patient experiences with an assessment of their priority. Domains include provider care and communication with patient, communication and cooperation between providers, organization of care delivery, and environment during dialysis delivery.	E

	MEASURE	DESCRIPTION	DOMAIN
27.	**Controlling the Impact of COPD on Health Status Measure** - Steward: Minnesota Community Measurement (MNCM) - Level: Individual Clinician	COPD patient-reported outcome developed within the NQF Measure Incubator as a measure of physician practice outcomes. The measure quantifies the percentage of patients aged 50–80 years whose self-reported impact of COPD on their health status was low, stable or improved, as determined by the COPD Assessment Test (CAT) or COPD Clinical Questionnaire (CCQ).	S
28.	**COPD Assessment Test (CAT)** - Steward: GlaxoSmithKline - Level: Not indicated	8-item questionnaire designed to quantify the impact of COPD symptoms on the health status of patients. The CAT provides a score of 0–40 to indicate the impact of disease.	S
29.	**COPD Clinical Questionnaire (CCQ)** - Steward: University Medical Center Groningen - Level: Not indicated	10-item tool that focuses on the clinical status of the airways as well as functional limitations and psychosocial dysfunction. The CCQ consists of 3 separate domains (symptoms, functional state, and mental state); treatment in clinical practice can be aimed at these subdomains, which elaborates on tailor-made medicine in patients with COPD. The CCQ can also be used to evaluate the adequacy of clinical management and to assess functional performance.	Q/S
30.	**NQF 0711: Depression Remission at Six Months** - Steward: MN Community Measurement - Level: Clinician, Group/Practice, Facility	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate remission at six months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at six months (+/- 30 days) are also included in the denominator.	S
31.	**NQF 0710: Depression Remission at Twelve Months** - Steward: MN Community Measurement - Level: Clinician, Group/Practice, Facility	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate remission at twelve months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at twelve months (+/- 30 days) are also included in the denominator.	S
32.	**NQF 1884: Depression Response at Six Months—Progress Towards Remission** - Steward: MN Community Measurement - Level: Clinician, Group/Practice, Facility	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate a response to treatment at six months defined as a PHQ-9 score that is reduced by 50% or greater from the initial PHQ-9 score. This measure applies to both patients with newly diagnosed and existing depression identified during the defined measurement period whose current PHQ-9 score indicates a need for treatment. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at six months (+/- 30 days) are also included in the denominator.	S
33.	**NQF 1885: Depression Response at Twelve Months—Progress Towards Remission** - Steward: MN Community Measurement - Level: Clinician, Group/Practice,	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate a response to treatment at twelve months defined as a PHQ-9 score that is reduced by 50% or greater from the initial PHQ-9 score. This measure applies to both patients with newly diagnosed and existing depression identified during the defined measurement period whose current PHQ-9 score indicates a need for treatment. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at twelve months (+/- 30 days) are also included in the	S

	MEASURE	DESCRIPTION	DOMAIN
	Facility	denominator.	
34.	**NQF 0712: Depression Utilization of the PHQ-9 Tool** - Steward: MN Community Measurement - Level: Clinician, Group/Practice, Facility	Adult patients age 18 and older with the diagnosis of major depression or dysthymia who have a PHQ-9 tool administered at least once during the four-month measurement period. The Patient Health Questionnaire (PHQ-9) tool is a widely accepted, standardized tool that is completed by the patient, ideally at each visit, and utilized by the provider to monitor treatment progress.	[3]
35.	**Diabetes-39** - Steward: Public domain - Level: Not indicated	39-item diabetes-specific questionnaire assessing 6 categories: energy and mobility, diabetes control, anxiety and worry, social burden, sexual functioning, and diabetes medication.	Q/S
36.	**Dialysis Symptom Index (DSI)** - Steward: University of Pittsburgh - Level: Not indicated	30-item questionnaire developed to assess the physical and emotional symptom burdens of hemodialysis patients.	S
37.	**DPC Patient Satisfaction and Priorities Survey** - Steward: DPC - Level: Not indicated	Patient Satisfaction Survey assessing overall quality of the dialysis facility. Patient selects and responds to up to 5 of 19 questions they believe to be the most important when evaluating the overall quality of the facility. Domains include QOL, patient care experience (including with patient education, vascular access, transplant referral, mineral metabolism, adequacy, anemia, infections, and mortality and hospitalization).	E
38.	**Edmonton Functional Assessment Tool (EFAT2)** - Steward: Not identified - Level: Not indicated	UK instrument designed to evaluate functional performance of patients with advanced cancer over time and to document the degrees of functional performance of patients throughout the terminal phase. It assesses the status of 10 functions: communication, pain, mental status, dyspnea, sitting or standing balance, mobility, walk or wheelchair locomotion, ADLs, fatigue, and motivation. Each item is evaluated by a 4-point rating scale from 0 to 3, where 0 = functional independent performance and 3 = total loss of functional performance. A total possible score is 30.	Q
39.	**End Stage Renal Disease Severity Index (ESRD-SI)** - Steward: Not identified - Level: Not indicated	11-item index assessing the severity of ESRD-related symptoms (cardiovascular, cerebrovascular, bone disease, peripheral vascular disease, peripheral neuropathy, respiratory disease, deficient vision, autonomic neuropathy, gastrointestinal disease, dialytic access and events, diabetes, and an open category).	S
40.	**End-Stage Renal Disease Symptom Checklist–Transplantation Module (ESRD_SCLTM)**	43-item questionnaire that assesses the specific physical and psychological quality of life of renal transplant recipients, with a special focus on side effects of immune system suppression therapy. Contains 6 dimensions:	Q/S

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[3] Structural process measure based on a patient-reported outcome tool, but not an outcome per se.

	MEASURE	DESCRIPTION	DOMAIN
	- Steward: University of Essen, Germany - Level: Not indicated	1. Limited physical capacity (10 items) 2. Limited cognitive capacity (8 items) 3. Cardiac and renal dysfunction (7 items) 4. Side effects of corticosteroids (5 items) 5. Increased growth of gum and hair (5 items) 6. Transplantation-associated psychological distress (8 items) All questions are scored on a five-point Likert scale.	
41.	**European Organization for Research and Treatment of Cancer (EORTC)-IN-PATSAT32** - Steward: European Organization for Research and Treatment of Cancer - Level: Not indicated	32-item questionnaire developed to assess satisfaction with care in cancer patients.	E
42.	**EORTC-QLQ-C15-PAL** - Steward: European Organization for Research and Treatment of Cancer - Level: Not indicated	15-item palliative care questionnaire developed for use with cancer patients.	E
43.	**EORTC QLQ-C30** - Steward: European Organization for Research and Treatment of Cancer - Level: Not indicated	30-item questionnaire developed to assess the quality of life of cancer patients. Supplemented by disease-specific modules for e.g. breast, lung, head & neck, esophageal, ovarian, gastric, cervical cancer, multiple myeloma, esophago-gastric, prostate, colorectal liver metastases, colorectal and brain cancer.	Q
44.	**EuroQOL: EQ5D** - Steward: EuroQOL Research Foundation - Level: Not indicated	Standardized instrument for use as a measure of health status, applicable to a wide range of health conditions and treatments. Health status is measured in terms of five dimensions (5D): mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. There are currently 171 language versions of EQ-5D questionnaire available. EQ-5D is one of the most commonly used generic health status measurement instruments.	Q/S
45.	**Fall Risk Assessment Scale for the Elderly (FRASE)** - Developer: G. Cannard (Ireland) - Level: Not indicated	Assessment tool designed to predict patients' risk of falling.	Q/S
46.	**Falls Risk Assessment Tool (FRAT)** - Steward: Falls Prevention Group (Great Britain) - Level: Not indicated	Many versions in use. Assessment tool designed to predict patients' risk of falling.	Q/S

	MEASURE	DESCRIPTION	DOMAIN
47.	**NQF 0208: Family Evaluation of Hospice Care** • Steward: National Hospice and Palliative Care Organization • Level: Facility, Population (national)	Derived from responses to 17 items on the Family Evaluation of Hospice Care (FEHC) survey presented as a single score ranging from 0 to 100 and is an indication of the hospice´s overall performance on key aspects of care delivery. • Target Population: The FEHC survey is an after-death survey administered to bereaved family caregivers of individuals who died while enrolled in hospice. • Timeframe: The survey measures family member's perception of the quality of hospice care for the entire enrollment period, regardless of length of service. The computed hospice level performance score is calculated with once a quarter year.	E
48.	**Ferrans and Powers Quality of Life Index of Dialysis (QLI)** • Steward: Ferrans and Powers • Level: Not indicated	62-item instrument assessing the domains of QOL, health and function, social and economic, psychological spiritual and family).	Q
49.	**Fluid Management Survey** • Steward: Not identified • Level: Not indicated	Developed to assess hemodialysis patient–stated preferences regarding fluid management.	S
50.	**Functional Assessment of Chronic Illness Therapy (FACIT) Scales** • Developer: David Cella, Ph.D • Level: Not indicated	A collection of QOL questionnaires targeted to the management of chronic illness. The measurement system began with the creation of a generic CORE questionnaire called the Functional Assessment of Cancer Therapy-General (FACT-G), a 27-item compilation of general questions divided into 4 primary QOL domains: physical well-being, social/family well-being, emotional well-being, and functional well-being. It is considered appropriate for use with patients with any form of cancer, and has also been used and validated in other chronic illness condition (e.g., HIV/AIDS and multiple sclerosis) and in the general population (using a slightly modified version). Validation of a core measure allowed for the evolution of multiple disease, treatment, condition, and non-cancer-specific subscales. FACIT scales are constructed to complement the FACT-G, addressing relevant disease-, treatment-, or condition-related issues not already covered in the general questionnaire. Each is intended to be as specific as necessary to capture the clinically-relevant problems associated with a given condition or symptom, yet general enough to allow for comparison across diseases, and extension, as appropriate, to other chronic medical conditions There are over 50 different FACIT scales and symptom indexes. Equivalent foreign language versions of the FACIT questionnaires are now available in more than 50 different languages (for some scales), permitting cross-cultural comparisons of people from diverse backgrounds.	Q

	MEASURE	DESCRIPTION	DOMAIN
51.	**NQF 2243: Functional Outcome Assessment** • Steward: MN Community Measurement • Level: Clinician (group/practice)	Percentage of visits for patients aged 18 years and older with documentation of a current functional outcome assessment using a standardized functional outcome assessment tool on the date of the encounter AND documentation of a care plan based on identified functional outcome deficiencies on the date of the identified deficiencies.	Q
52.	**Functional Status Assessment and Goal Achievement for Patients with Congestive Heart Failure** • Steward: NCQA • Level: Hospital	Percentage of patients aged 65 years and older with congestive heart failure who had a target improvement goal defined after completing an initial patient-reported functional status assessment and met the goal after completing a follow-up functional status assessment.	Q
53.	**PQRS 377: Functional Status Assessment for Complex Chronic Conditions** • Steward: Mathmatica • Level: Clinician	Percentage of patients aged 18 years and older with complex chronic conditions who completed baseline and follow-up (patient-reported) functional status assessments.	Q
54.	**PQRS 282: Functional Status Assessment for Dementia** • Steward: American Academy of Neurology/American Psychiatric Association • Level: Clinician	Percentage of patients aged 18 years and older with a diagnosis of rheumatoid arthritis (RA) for whom a functional status assessment was performed at least once within 12 months.	Q
55.	**PQRS 375: Functional Status Assessment for Knee Replacement** • Steward: NCQA • Level: Clinician	Percentage of patients aged 18 years and older with primary total knee arthroplasty (TKA) who completed baseline and follow-up (patient-reported) functional status assessments.	Q
56.	**PQRS 178: Functional Status Assessment for Rheumatoid Arthritis** • Steward: American College of Rheumatology • Level: Clinician	Percentage of patients aged 18 years and older with a diagnosis of rheumatoid arthritis (RA) for whom a functional status assessment was performed at least once within 12 months.	Q
57.	**NQF 0423: Functional Status Change for Patients with Hip Impairments** • Steward: Focus on Therapeutic Outcomes (FOTO) • Level: Clinician (group/practice, individual, facility), Health Plan, Integrated Delivery	A self-report measure of change in functional status for patients 14 years+ with hip impairments. The change in functional status assessed using FOTO's (hip) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Q

	MEASURE	DESCRIPTION	DOMAIN
58.	**NQF 2483: Gains in Patient Activation (PAM) Scores at 12 Months** • Steward: Insignia Health • Level: Clinician (group/practice)	The Patient Activation Measure (PAM) is a 10 or 13 item questionnaire that assesses an individual´s knowledge, skill and confidence for managing their health and healthcare. The measure assesses individuals on a 0-100 scale. There are 4 levels of activation, from low (1) to high (4). The measure is not disease specific, but has been successfully used with a wide variety of chronic conditions, as well as with people with no conditions. The performance score would be the change in score from the baseline measurement to follow-up measurement, or the change in activation score over time for the eligible patients associated with the accountable unit. The outcome of interest is the patient's ability to self-manage. High quality care should result in gains in ability to self-manage for most chronic disease patients. The outcome measured is a change in activation over time. The change score would indicate a change in the patient´s knowledge, skills, and confidence for self-management. A positive change would mean the patient is gaining in their ability to manage their health. A "passing" score for eligible patients would be to show an average net 3-point PAM score increase in a 6-12-month period. An "excellent" score for eligible patients would be to show an average net 6-point PAM score increase in a 6-12-month period.	[4]
59.	**General Health Questionnaire (GHQ)** • Steward: GL Assessments • Level: Not indicated	Screening tool to detect those likely to have or be at risk of developing psychiatric disorders. Measure of the common mental health problems/domains of depression, anxiety, somatic symptoms and social withdrawal. Available in a variety of versions using 12, 28, 30 or 60 items (28-item version used most widely).	S
60.	**Generalized Anxiety Disorder Scale (GAD-7)** • Steward: Pfizer, Inc. • Level: Not indicated	Self-reported 7-item questionnaire for screening for GAD. Asks respondents over the last 2 weeks how frequently they have been bothered by the following problems: 1. Feeling nervous, anxious, or on edge 2. Not being able to stop or control worrying 3. Worrying too much about different things 4. Trouble relaxing 5. Being so restless that it's hard to sit still 6. Becoming easily annoyed or irritable 7. Feeling afraid as if something awful might happen Severity of symptoms are measured according to reported response categories with assigned points, as follows: not at all (0 points), several days (1 point), more than half the days (2 points), nearly every day (3 points). Assessment is indicated by the total score, which made up by adding together the scores for the scale all seven items.	S

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[4] Although often lumped with patient experience, engagement/activation is not precisely captured by that domain's overall focus and should perhaps be a separate domain.

	MEASURE	DESCRIPTION	DOMAIN
61.	**Geriatric Depression Scale** • Steward: Public domain • Level: Not indicated	15-item geriatric-specific depression screening tool.	S
62.	**Hamilton Rating Scale for Depression (HAM-D)** • Steward: Public domain • Level: Not indicated	20-item questionnaire used to provide an indication of depression and as a guide to evaluate recovery. The questionnaire is designed for adults and is used to rate the severity of their depression by probing mood, feelings of guilt, suicide ideation, insomnia, agitation or retardation, anxiety, weight loss, and somatic symptoms. Noted in KCP Blueprint as a tools used to assess for depression in ESRD patients.	S
63.	**Hemodialysis Quality of Life Questionnaire (HQL)** • Steward: Not identified • Level: Not indicated	Developed to assess hemodialysis patient QOL and physical and emotional symptoms.	Q
64.	**Hemodialysis Stressor Scale (HSS)** • Developer: Baldriee et al. • Level: Not indicated	Questionnaire developer to assess the burden of the following physiologic stressors in HD patients: fatigue, limited time and places for enjoyment, and physical activation limitation, fistula concerns, limitation of drinking water, low quality of life, travelling difficulties to the dialysis center, treatment cost, and low life expectancy.	Q/S
65.	**Hospital Anxiety and Depression Scale (HADS)** • Steward: Participation and Quality of Life (PAR-QOL) Project • Level: Not indicated	14-item instrument developed to determine the levels of anxiety and depression that a patient is experiencing while hospitalized. 7 items relate to anxiety and 7 to depression. The measure was specifically developed to avoid reliance on aspects of these conditions that are also common somatic symptoms of illness (e.g., fatigue, insomnia, or hypersomnia).	S
66.	**Hospital-Level Risk-Standardized Patient-Reported Outcomes Following Primary Elective Total Hip and/or Total Knee Arthroplasty (THA/TKA)** • Steward: CMS (CMS pipeline) • Level: Hospital	This outcome measure is currently under development. The measure will assess improvement in hospital-level, risk-standardized patient-reported outcomes following THA/TKA for Medicare fee-for-service (FFS) patients 65 years of age and older. The preoperative data collection timeframe will be 90 to 0 days before surgery and the postoperative data collection timeframe will be 270 to 360 days following surgery. The outcome will be defined using the Patient Reported Outcomes Measurement Information Systems (PROMIS)-Global or the Veterans Rand 12 Item Health Survey (VR-12), and/or the Hip dysfunction and Osteoarthritis Outcome Score/Knee injury and Osteoarthritis Outcome Score (HOOS/KOOS) instruments.	S/Q
67.	**HowRwe** • Steward: R-Outcomes Ltd. • Level: Not indicated	4-item generic patient questionnaire on patient satisfaction.	E
68.	**HowRu** • Steward: R-Outcomes Ltd. • Level: Not indicated	4-item generic patient questionnaire on quality of life.	Q
69.	**Identification of Seniors at Risk (ISAR)** • Steward: Not identified • Level: Not indicated	6-item risk-screening tool for elderly patients seen in the ED.	S

	MEASURE	DESCRIPTION	DOMAIN
70.	**Illness Intrusiveness Ratings Scale (IIRS)** • Steward: Stanford Patient Education Research Center • Level: Not indicated	13-item self-report instrument. The IIRS can be scored to generate a total score or three subscale scores: relationships and personal development, intimacy, and instrumental.	Q/S
71.	**Immunosuppressant Therapy Adherence Scale (ITAS)** • Steward: University of Georgia College of Pharmacy • Level: Not indicated	5-item scale asking respondents to indicate how often they were non-adherent to immunosuppressant therapy (IST) given a particular circumstance. The five items ask respondents how often they: (a) forgot to take their IST medications; (b) were careless about taking their IST medications; (c) stopped taking their IST medications because they felt better; (d) stopped taking their IST medications because they felt worse; and (e) missed taking their IST medications for any reason. Response options are A = ‘‘0% of the time (none)’’, B = ‘‘1–20% of the time’’, C = ‘‘21–50% of the time’’, and D = ‘‘greater than 50% of the time.	B
72.	**NQF 2634: Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure—Change in Mobility Score for Medical Rehabilitation Patients** • Steward: CMS • Level: Facility	Estimate of the risk-adjusted change in mobility score between admission and discharge among Inpatient Rehabilitation Facility (IRF) patients age 21 and older. The change in mobility score is calculated as the difference between the discharge mobility score and the admission mobility score.	Q
73.	**Johns Hopkins Frailty Criteria** • Steward: Johns Hopkins University • Level: Clinician	Popular approach to the assessment of geriatric frailty that encompasses the assessment of five dimensions hypothesized to reflect systems whose impaired regulation underlies the syndrome: unintentional weight loss, exhaustion, muscle weakness, slowness while walking, low levels of activity. Corresponding to these dimensions are five specific criteria indicating adverse functioning, which are implemented using a combination of self-reported and performance-based measures. Those who meet at least three of the criteria are defined as “frail”, while those not matching any of the five criteria are defined as “robust”.	Q/S
74.	**Katz ADL** • Developer: S. Katz • Level: Not indicated	Instrument to assess functional status as a measurement of the client’s ability to perform activities of daily living independently. The index ranks adequacy of performance in the 6 functions of bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yes/no for independence in each of the 6 functions; a score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.	Q
75.	**KDQOL** • Steward: None (NQF 0260 is a structural reporting measure using KDQOL with Witten Assoc. as steward); the instrument was developed by RAND and is in the public domain • Level: Not a performance measure (i.e., is a PROM, not PRO-PM)	36-item kidney disease-specific measure of HRQOL with five subscales: • **The SF-12 measure of physical (PCS) and mental (MCS) functioning (1-12)**, with items about general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities. • **Burden of Kidney Disease subscale (13-16)**, with items about how much kidney disease interferes with daily life, takes up time, causes frustration, or makes the respondent feel like a burden. • **Symptoms and Problems subscale (17-28b)**, with items about how bothered a respondent feels by sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness/dizziness,	Q

	MEASURE	DESCRIPTION	DOMAIN
		lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, or problems with dialysis access. - **Effects of Kidney Disease on Daily Life subscale (29-36)**, with items about how bothered the respondent feels by fluid limits, diet restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance.	
76.	**Kidney Disease Questionnaire (KDQ)** • Steward: University of Calgary • Level: Not indicated	Developed to assess disease-specific QOL for use in clinical trials of maintenance hemodialysis patients. Available in a 26-item version or as two parallel 13-item tests.	Q
77.	**Kidney Transplant Recipient Stressor Scale (KTRSS)** • Steward: Not identified • Level: Not indicated	44-item questionnaire assessing 4 domains: physical and psychological health problems, family relationships, employment and body image,	Q/S
78.	**Kidney Transplant Questionnaire (KTQ)** • Developer: Laupacis et al. • Level: Not indicated	25-item questionnaire addressing 5 domains: physical symptoms, fatigue, uncertainty/fear, appearance and emotions. Responses are obtained on a 7-point Likert scale, with the lowest score representing the lowest quality of life.	Q
79.	**Kurtzke Expanded Disability Status Scale (EDSS)** • Steward: Public domain • Level: Not indicated	Scale developed to measure the disability status of people with multiple sclerosis. The purpose was to create an objective approach to quantify the level of functioning that could be widely used by healthcare providers diagnosing MS. The EDSS is widely used and accepted as a valid tool to clinically measure and evaluate MS patients' level of functioning. The EDSS provides a total score on a scale that ranges from 0 to 10. The first levels 1.0 to 4.5 refer to people with a high degree of ambulatory ability and the subsequent levels 5.0 to 9.5 refer to the loss of ambulatory ability. The range of main categories include (0) = *normal neurologic exam*; to (5) = *ambulatory without aid or rest for 200 meters; disability severe enough to impair full daily activities*; to (10) = *death due to MS*. In addition, it also provides eight subscale measurements called Functional System (FS) scores assessing the eight functional systems affected by MS: 1. Pyramidal (motor function) (P) 2. Cerebellar (C11) 3. Brainstem (BS) 4. Sensory (S) 5. Bowel and Bladder (BB) 6. Visual (V) 7. Cerebral or Mental (Cb) 8. Other (O) The Functional Systems (FS) are scored on a scale of 0 (low level of problems) to 5 (high level of problems)	Q

	MEASURE	DESCRIPTION	DOMAIN
		to best reflect the level of disability observed clinically. The "Other" category is not rated numerically, but measures disability related to a particular issue, like motor loss. The total EDSS score is determined by two factors: gait and FS scores. EDSS scores below 4.0 are determined by the FS scores alone. People with EDSS scores of 4.0 and above have some degree of gait impairment. Scores between 4.0 and 9.5 are determined by both gait abilities and the FS scores. For simplicity, many experts gauge the EDSS scores between 4.0 and 9.5 entirely by gait, without considering the FS scores.	
80.	**Life Satisfaction Index (LSI)** • Steward: Public domain • Level: Not indicated	There are several versions of the LSI: the original (Life Satisfaction Index A [LSIA]) comprises 20 items; the LSIB contains 12 questions; the LSIZ contains 13 of the 20 items from the LSIA; the Life Satisfaction Index for the Third Age (LSITA), is a 35-item questionnaire created to measure successful aging in participants over 50 years of age. The LSI instruments cover general feelings of well–being among older people to identify "successful" aging by assessing 5 components of life satisfaction—zest (as opposed to apathy), resolution and fortitude, congruence between desired and achieved goals, positive self-concept, and mood tone. Positive well being is indicated by the individual taking pleasure in his daily activities, finding life meaningful, reporting a feeling of success in achieving major goals, a positive self image and optimism.	Q
81.	**Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)** • Developer: De Geest et al. • Level: Not indicated	27-item instrument measuring the strength dimension on a 5- point scale, ranging from "very little confidence" to "quite a lot of confidence" in adhering to an immunosuppressive regimen. Used by researchers in Europe and the USA in adherence studies in a number of chronic patient populations.	B
82.	**McGill Quality of Life Scale (MQOL)** • Developer: Robin Cohen • Level: Not indicated	18-item questionnaire relevant to all phases of the disease trajectory for people with a life-threatening illness. The questionnaire is unique in that it measures the existential domain, the physical domain is important but not predominant, and positive contributions to quality of life are measured. Principal components analysis suggests four subscales: physical symptoms, psychological symptoms, outlook on life, and meaningful existence.	Q

	MEASURE	DESCRIPTION	DOMAIN
83.	**Medical Outcomes Study Short Form 36-Item Health Survey (SF-36)** • Steward: RAND • Level: Not indicated	36-item, patient-reported survey of patient health consisting of 8 scaled scores, which are the weighted sums of the questions in their section. Each scale is directly transformed into a 0-100 scale on the assumption that each question carries equal weight. The lower the score the more disability, the higher the score the less disability—i.e., a score of zero is equivalent to maximum disability and a score of 100 is equivalent to no disability. The eight sections are: • vitality • physical functioning • bodily pain • general health perceptions • physical role functioning • emotional role functioning • social role functioning • mental health	S/Q
84.	**Medicare Health Outcomes Survey** • Steward: NCQA • Level: Managed Care Plans	This measure provides a general indication of how well a Medicare Advantage Organization (MAO) manages the physical and mental health of its members. The survey measures physical and mental health status at the beginning of a two-year period and again at the end of a two-year period, when a change score is calculated. Each member's health status is categorized as "better than expected," "the same as expected" or "worse than expected," accounting for death and risk-adjustment factors. MAO-specific results are assigned as percentages of members whose health status was better, the same or worse than expected.	Q
85.	**Medicare Health Outcomes Survey-Modified** • Steward: NCQA • Level: Managed Care Plans	The Medicare Health Outcomes Survey-Modified (HOS-M) is administered to vulnerable Medicare beneficiaries who are enrolled in Program of All-Inclusive Care for the Elderly (PACE) plans and are at greatest risk for poor health outcomes.	Q
86.	**Medicare Health Outcomes Survey-Modified, General Comfort** • Developer: Katharine Kolcaba, PhD • Level: Healthcare Delivery System	This measure assesses quality in terms of comfort using the General Comfort Questionnaire. The questionnaire, given to either patients or family members, measures the extent to which the responder is experiencing comfort at that point in time.	Q
87.	**Mental Health/Substance Abuse: Mean of Patients' Overall Change Scores on the Basis-24 Survey** • Developer: Susan V. Eisen, PhD • Level: Individual Clinician	This measure is used to assess the mean of patients' overall change scores on the BASIS-24 survey. The BASIS-24 survey is administered at the beginning of a treatment episode, with repeat assessments obtained at desired intervals to assess change during or following treatment. Six subscales are also calculated for the BASIS-24.	Q/S
88.	**Mini-Nutritional Assessment (MNA)** • Steward: Nestle Nutrition Institute • Level: Not indicated	Nutrition screening and assessment tool that can identify geriatric patients age 65 and above who are malnourished or at risk of malnutrition. Originally comprised of 18 questions, the current MNA now consists of 6 questions and streamlines the screening process. The current MNA retains the validity and accuracy of the original MNA in identifying older adults who are malnourished or at risk of malnutrition.	S?
89.	**Modified Transplant Symptom**	Updated 59-item version of the 45-item Modified Transplant Symptom Occurrence and Symptom Distress	S

	MEASURE	DESCRIPTION	DOMAIN
	Occurrence and Symptom Distress Scale-59 Items Revised (MTSOSD-59R) • Steward: Universiteit Leuven • Level: Not indicated	Scale (MDSOSD) to assess the transplant recipient's symptom experience (frequency and distress) with currently available immunosuppressive regimens. The self-reported scale assesses symptom frequency and symptom distress associated with the use of current immunosuppressive agents (e.g., cyclosporine, corticosteroids).	
90.	**National Institute of Diabetes and Digestive and Kidney Disease Transplantation Quality of Life Questionnaire (NIDDK-QOL)** • Steward: NIDDK • Level: Not indicated	63-item questionnaire which are organized into the domains of general health, personal function, psychological status, social and role function, and measures of disease. Items were drawn from multiple established general health questionnaires and a few instruments previously used in other transplant populations including kidney transplant recipients.	Q
91.	**NKF's Patient-Centered Quality Measures Survey** • Steward: NKF • Level: Not indicated	20-item questionnaire addressing a range of issues on care experiences and satisfaction.	E
92.	**NQF 0007: NCQA Supplemental Items for CAHPS 4.0 Adult Questionnaire** • Steward: NCQA • Level: Clinician (group/practice, individual, facility), Health Plan, Integrated Delivery System, Population (national, regional, state) • Note: Endorsement removed April 2014	This measure provides information on the experiences of Medicaid health plan members with the organization. Results summarize member experiences through composites and question summary rates. In addition to the 4 core composites from the CAHPS 4.0 Health Plan survey and two composites for commercial populations only, the HEDIS supplemental set includes one composite score and two item-specific summary rates: 1. Shared Decision Making Composite 2. Health Promotion and Education item 3. Coordination of Care item	E
93.	**Optimal Asthma Care—Control Component** • Steward: MN Community Measurement • Level: Not stated	Percentage of patients ages 5-50 (pediatrics ages 5-17) whose asthma is well-controlled as demonstrated by one of four age appropriate patient reported outcome tools: • Asthma Control Test (ACT) score of 20 or above - ages 12 and older • Childhood Asthma Control Test (C-ACT) score of 20 or above - ages 11 and younger • Asthma Control Questionnaire (ACQ) score of 0.75 or lower - ages 17 and older • Asthma Therapy Assessment Questionnaire (ATAQ) score of 0 – only applicable for children and adolescents	S
94.	**OsteoARthritis Treatment Satisfaction (ARTS) Questionnaire** • Developer: Pouchet et al. • Level: Not indicated	18-item questionnaire to assess patient satisfaction with osteoarthritis treatment.	E
95.	**Osteoporosis Patient Treatment**	Measure to assess satisfaction with bisphosphonate treatment in postmenopausal women. Contains 16	E

	MEASURE	DESCRIPTION	DOMAIN
	Satisfaction Questionnaire (OPSAT-Q) • Developer: Roche Laboratories, Inc. • Level: Not indicated	items in 4 subscales: convenience, confidence with daily activities, side effects, and overall satisfaction. All 4 subscale scores and an overall composite satisfaction score (CSS) can be computed.	
96.	**Pain Assessment Among Patients with Bone Metastases** • Steward: American Society of Clinical Oncology (ASCO) • Level: Clinician (group/practice)	Proportion of patients with radiographically detected metastatic disease in a given practice with worst pain >=4 using the Brief Pain Inventory (a score threshold associated with clinically meaningful pain that interferes with daily activities).	S
97.	**Palfrey's Specific Health Questionnaire for ESRD Patients** • Steward: Not identified • Level: Not indicated	Description not identified.	?
98.	**Patient Activation Measure (PAM)** • Steward: Insignia Health • Level: Not indicated	22-item measure that assesses patient knowledge, skill, and confidence for self-management. The measure was developed using Rasch analyses and is an interval level, unidimensional, Guttman-like measure.	[5]
99.	**Patient Health Questionnaires (PHQ)** • Steward: Pfizer, Inc. • Level: Not indicated	Multiple-choice self-report inventory used as a screening and diagnostic tool for mental health disorders of depression, anxiety, alcohol, eating, and somatoform. It is the self-report version of Pfizer's diagnostic tool, Primary Care Evaluation of Mental Disorders (PRIME-MD). Designed for use in the primary care setting, it lacks coverage for some disorders seen in psychiatric settings. It is a public domain resource available without cost in several languages. There are several versions: • PHQ-9 is a tool specific to depression that scores each of the 9 DSM-IV-related criteria based on the mood module from the original PRIME-MD. • The Patient Health Questionnaire-2 (PHQ-2) is a shorter version of the PHQ-9, with two screening questions to assess the presence of a depressed mood and a loss of interest or pleasure in routine activities. A positive response to either question indicates further testing is required. • The Generalized Anxiety Disorder (GAD-7) scores 7 common anxiety symptoms. • The PHQ-15 scores somatic symptoms. The PHQ-SADS screens for somatic, anxiety, and depressive symptoms using PHQ-9, GAD-7, and PHQ-15, plus the panic symptoms question from the original PHQ. The PHQ-9 is noted in the KCP Blueprint as a tool used to assess for depression in ESRD patients. PHQ-2 is under consideration within KCC for suitability as depression assessment tool to meet QIP's Depression Screening and Follow-Up Reporting Measure criteria.	S

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[5] Although often lumped with patient experience, engagement/activation is not precisely captured by that domain's overall focus and should perhaps be a separate domain.

	MEASURE	DESCRIPTION	DOMAIN
100.	**NQF 0726: Patient Experience of Psychiatric Care as Measure by the Inpatient Consumer Survey (ICS)** • Steward: National Association of State Mental Health Program Directors Research Institute (NRI) • Level: Facility, Population (national, regional, state)	The Patient Experience of Psychiatric Care as Measure by the Inpatient Consumer Survey (ICS) was developed to gather patient´s evaluation of their inpatient psychiatric care. The survey is composed of six individual measures or domains: • Measure #1—Outcome of Care. The receipt of mental healthcare services should enable patients to effectively deal with their illness and with social situations. Patient´s report of the effectiveness of the organization in enabling this improvement is an important dimension of the quality of care of the organization. • Measure #2—Dignity. The provision of mental healthcare services should be in an atmosphere where patients feel respected and treated with dignity. Patient´s report of the effectiveness of the organization in providing this respectful exchange is an important dimension of the quality of care of the organization. • Measure #3—Rights. The provision of mental healthcare services should be in an atmosphere where patients feel that they can express disapproval with conditions or treatment and receive an appropriate response from the organization. Patient´s report of the effectiveness of the organization in providing this respectful exchange is an important dimension of the quality of care of the organization. • Measure #4—Participation in Treatment. Patient´s involvement in the treatment process and the coordination of discharge planning with their doctors or therapist from the community are enabling activities that strengthen patient´s ability to care for themselves. Patient´s report of the effectiveness of the organization in supporting this level of involvement is an important dimension of the quality of care of the organization. • Measure #5—Hospital Environment. The provision of mental healthcare services should be in an environment conducive to patients feeling safe and enabling patients to focus on recovering from their illness. • Measure #6—Empowerment. The provision of mental healthcare services should be in an atmosphere where patients feel that they, interactively with their doctors and therapist, learn more about their illness and about their treatment options and are encouraged to determine their best plan to recovery. Patient´s report of the effectiveness of the organization in enabling this respectful, compassionate, and supportable encounter among patients and healthcare professionals is an important dimension of the quality of care of the organization. Question 28, "If I had a choice of hospitals, I would still choose this one", is considered as the anchor item utilized to measure overall satisfaction with the mental healthcare service received. This question does not pertain to any of the six measures/domains of the ICS. Each measure is scored as the percentage of patients (adolescents aged 13-17 and adults aged 18 and older) at time of discharge or at annual review who respond positively to the domain on the survey for a given month. Survey questions are based on a standard 5-point Likert scale, evaluated on a scale from	E

	MEASURE	DESCRIPTION	DOMAIN
		strongly disagree to strongly agree.	
101.	**NQF 1741: Patient Experience with Surgical Care Based on the CAHPS Surgical Care Survey** • Steward: American College of Surgeons, Division of Advocacy and Health Policy • Level: Individual Clinician, Group/Practice	The following 6 composites and 1 single-item measure are generated from the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surgical Care Survey. Each measure is used to assess a particular domain of surgical care quality from the patient's perspective. • Measure 1: Information to help you prepare for surgery (2 items) • Measure 2: How well surgeon communicates with patients before surgery (4 items) • Measure 3: Surgeon's attentiveness on day of surgery (2 items) • Measure 4: Information to help you recover from surgery (4 items) • Measure 5: How well surgeon communicates with patients after surgery (4 items) • Measure 6: Helpful, courteous, and respectful staff at surgeon's office (2 items) • Measure 7: Rating of surgeon (1 item) The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surgical Care Survey is administered to adult patients (age 18 and over) having had a major surgery as defined by CPT codes (90-day globals) within 3 to 6 months prior to the start of the survey.	E
102.	**Patient-Reported Health Status for Chronic Sinusitis—Completion of Validated Questionnaire of Health Status at Time of Diagnosis** • Steward: American Academy of Otolaryngology • Level: Hospital	Percentage of patients, aged 18 years and older, with a diagnosis of chronic sinusitis who completed a questionnaire about their symptoms of chronic sinusitis and health status at the time of diagnosis using a validated tool or instrument and had the results documented in the medical record.	S
103.	**Patient-Reported Outcomes Following Ilio-Femoral Stenting** • Steward: Society of Interventional Radiology • Level: Clinician	Not available.	[6]
104.	**Patient Reported Outcome Indices for Multiple Sclerosis (PRIMUS)** • Steward: Galen Research Ltd. • Level: Not indicated	Disease-specific patient questionnaire which measures the quality of life of patients suffering from Multiple Sclerosis. The measure comprises 3 scales—quality of life, activity limitations, and symptoms—which are designed to be used together or as standalone measures. A higher score on any or all of these scales indicates a lower quality of life due to the disease.	Q
105.	**Patient-Reported Outcomes Measures Information System (PROMIS) Measures** • Steward: HHS	Set of person-centered measures that evaluates and monitors physical, social, and emotional health in adults and children. Can be used with the general population and with individuals living with chronic conditions. The following areas are of particular relevance to patients with renal disease: • Overall symptom burden	Q/S

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[6] No additional information available other than title.

	MEASURE	DESCRIPTION	DOMAIN
	• Level: Not indicated	• CKD uncertainty • Fatigue • Depression • Anxiety • Mobility • ADLs • Symptoms: o Pain o Itching o Skin changes o Loss of appetite o GI symptoms (nausea, vomiting) o Shortness of breath o Sleep disorders o Restless legs o Sexual dysfunction	
106.	**Patient Satisfaction Questionnaire: PSQ-III** • Steward: RAND • Level: Not indicated	50-item survey that taps global satisfaction with medical care as well as satisfaction with six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care. An older version of the questionnaire (the PSQ) consists of 80 items, and a short form survey (PSQ-18) that retains many characteristics of its full-length counterpart. The PSQ sub-scales show acceptable internal consistency reliability. As corresponding PSQ-18 and PSQ-III subscales are substantially correlate with one another, the PSQ-18 may be appropriate for use in situations where the need for brevity precludes administration of the full-length PSQ-III.	E
107.	**Pediatric Comfort Assessment** • Developer: Ambuel et al. • Level: Not indicated	Comfort care assessment of physical, psychospiritual, environmental, environmental, sociocultural aspects of care.	S
108.	**Physical Functional Health Status** • Steward: Therapeutics Associates, Inc. • Level: Individual Clinician	This measure is used to assess the average change in patient functional status among patients receiving outpatient rehabilitation services as measured by the CareConnections Outcomes System Functional Index. CareConnections Outcomes System is a system that measures the efficacy of intervention of rehabilitation (physical therapy and occupational therapy) services in the outpatient setting. Patient data collected on the first visit is compared to data collected on the last visit.	Q
109.	**Physical Functional Status** • Steward: American Physical Therapy Association (APTA) • Level: Individual Clinician	This measure is used to assess the mean change score in patients' mobility following physical therapy intervention as assessed using the Outpatient Physical Therapy Improvement in Movement Assessment Log (OPTIMAL) Instrument.	Q

	MEASURE	DESCRIPTION	DOMAIN
110.	**Physical Symptom Distress Scale** • Developer: CP Chiu • Level: Not indicated	Developed to estimate the degree of symptom distress experienced by ESRD patients.	S
111.	**Postchemotherapy Nausea** • Steward: ASCO • Level: Clinician (group/practice)	Proportion of patients receiving moderately or highly emetogenic systemic cancer treatment (on the basis of ASCO and Multinational Association of Supportive Care in Cancer guideline criteria) who experience moderate or worse nausea within a week. The workgroup selected the National Cancer Institute's PRO-CTCAE nausea items to serve as the assessment instrument.	S
112.	**Self-Management Scale for Kidney Transplant Recipients** • Developer: S. Kosaka et al. • Level: Not indicated	24-item scale within four subscales (self-monitoring, self-care behavior in daily living, early detecting and coping with abnormalities after kidney transplantation, and stress management) developed to assess patients' self-management practices and skills.	B
113.	**Short-Version Checklist** • Developer: H. Tsutsui et al. • Level: Not indicated	Developed as a shortened version of the 100-Category Checklist to assess physical problems and functional and environmental factors affecting QOL in hemodialysis patients.	Q
114.	**Sickness Impact Profile (SIP)** • Steward: Johns Hopkins University • Level: Not indicated	136-item generic questionnaire.	Q/S
115.	**Spence Children's Anxiety Scale (SCAS)** • Developer: Susan H. Spence, PhD • Level: Not indicated	45-item psychological questionnaire designed to identify symptoms of various anxiety disorders, specifically social phobia, obsessive-compulsive disorder, panic disorder/agoraphobia, and other forms of anxiety in children and adolescents between ages 8 and 15. Test can be filled out by the child or by the parent. There is also a 34 question version of the test specialized for children in preschool between ages 2.5 and 6.5.	S
116.	**Spitzer Quality of Life Index** • Steward: Public domain • Level: Not indicated	Quality of life index that covers five dimensions—activity, daily living, health, support of family and friends, and outlook. Differs from performance status measures in that it also measures aspects of quality of life such as social support and outlook, although scores on it have been shown to be determined mainly by aspects of performance status, such as ability to perform activities of daily living, activity levels, and health. It can be rated by both clinicians and patients. Not suitable for measuring or classifying the quality of care of life of ostensibly healthy people.	Q
117.	**Stroke and Aphasia Quality of Life Scale-53 and -39 (SAQOL)** • Developer: Hilari et al. • Level: Not indicated	SS-QOL modified for use in people with aphasia. 53- and abbreviated 39-item interview-administered self-report scale grouped into 12 subdomains based on the SS-QOL: self-care, mobility, upper-extremity function, work, vision, language, thinking, personality, mood, energy, and family and social roles. The SAQOL has 2 response formats, both based on a 5-point scale: 1= could not do it at all to 5 = no trouble at all and 1 = definitely yes to 5 = definitely no. Overall and subdomain scores can range from 1 to 5; the overall SAQOL score is calculated by summing across the items and dividing by the number of items; subdomain scores are calculated the same way.	Q
118.	**Stroke Impact Scale** • Steward: Public domain • Level: Not indicated	59-item scale that measures the aspects of stroke recovery found to be important to patients and caregivers as well as stroke experts. Questions are broken down into eight domains: strength, hand function, mobility, activities of daily living, emotion, memory, and communication.	Q

	MEASURE	DESCRIPTION	DOMAIN
119.	**Stroke-Specific Quality of Life Scale (SS-QOL)** • Developer: L.S. Williams et al. • Level: Not indicated	49-items assessed on 5-point Guttman-type scales. Each item is answered using 1 of 3 different response sets. 12 domains include: mobility, energy, upper extremity function, work and productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality. May be used with proxies.	Q
120.	**Transplant Care Index (TCI)** • Steward: Not identified • Level: Not indicated	6-item questionnaire designed to serve as single composite measure to track transplant-specific quality of life and several issues related to graft care.	Q
121.	**Transplant Effects Questionnaire (TxEQ)** • Developer: Zeigelmann et al. • Level: Not indicated	Condition-specific patient questionnaire to assess the effects of organ transplantation with 24-items clustered around 5 conceptual coherent factors: worry about transplant, guilt regarding donor, disclosure, medication adherence, and responsibility.	S
122.	**Transplant Symptom Frequency Questionnaire (TSFQ)** • Steward: Not identified • Level: Not indicated	Designed to measure the frequency and severity of 33 symptoms falling within 6 domains: affective distress, neurocognitive symptoms, physical appearance changes, gastrointestinal distress, appetite/weight changes, and miscellaneous symptoms.	S
123.	**NQF 0725: Validated Family-Centered Questionnaire for Parents' and Patients' Experiences During Inpatient Pediatric Hospital Stay** • Steward: Boston Children's Hospital, Center for Patient Safety and Quality Research • Level: Facility • Note: Endorsement removed January 2015	This family-centered survey questionnaire consists of 68 questions that assess various aspects of care experiences during inpatient pediatric hospital stays. Questions can be used individually to measure specific performance but 35 rating questions can also be summarized into domain scores. The 68 questions of the survey can be divided into 4 groups: • 26 background questions that provide information for comparisons across different demographic and patient groups; • 35 questions that are part of 8 domains; • 5 overall rating questions to be used individually; and • 2 open-ended questions allowing parents to write individual comments Type of Score: The majority of the survey questions are categorical in nature. Ordinal measures enable the rating of experiences, dichotomous measures are used to assess if subsequent questions apply to the experiences of parents and the patient but a small number of questions are open-ended to allow any additional or more detailed comments. Domain scores are calculated as the percentage of domain questions answered in the most positive response category, the top-box, of all the domain questions the respondent answered. Target Population: The target population is one of the parents, 18 years or older, of a child that stayed for at least one day in an inpatient unit at the hospital and was discharged during the previous time period, e.g. the last month or the last quarter. Timeframe: Monthly or Quarterly.	E

	MEASURE	DESCRIPTION	DOMAIN
124.	**PQRS 420: Varicose Veins Treatment with Saphenous Ablation—Outcomes Survey** • Steward: Society of Interventional Radiology • Level: Clinician	Percentage of patients treated for varicose veins (CEAP C2-S) who are treated with saphenous ablation (with or without adjunctive tributary treatment) that report an improvement on a disease specific patient reported outcome survey instrument after treatment.	S
125.	**Vulnerable Elders Scale-13 (VES-13)** • Steward: RAND • Level: Not indicated	13-item screening tool that is based upon age, self-rated health, and the ability to perform functional and physical activities to identify populations of community-dwelling elders at increased risk for functional decline or death over a five-year period. The VES-13 can be self-administered or administered by nonmedical personnel over the telephone or at an office visit.	Q
126.	**Wong-Baker FACES Pain Rating Scale** • Steward: Wong-Baker FACES • Level: Not indicated	Pain scale that shows a series of faces ranging from a happy face at 0, "No hurt" to a crying face at 10 "Hurts worst". The patient must choose the face that best describes how they are feeling. Originally created for children to help them communicate about their pain, now the scale is used around the world with people ages 3 and older to facilitate communication and improve pain assessment. (Under consideration within KCC for suitability as pain assessment tool to meet QIP's Pain Assessment and Follow-Up Reporting Measure criteria.)	S
127.	**World Health Organization Quality of Life (WHOQOL) and WHOQOL-BREF** • Steward: WHO • Level: Not indicated	International cross-culturally comparable quality of life assessment instrument that assesses the individual's perceptions in the context of their culture and value systems and their personal goals, standards, and concerns. The instrument comprises 26 items measuring the following domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical trials.	Q
128.	**Zung Self-Rating Depression Scale (ZSDS)** • Steward: Public domain • Level: Not indicated	Self-reported 20-item measure of the symptoms of depression. Items responses are ranked from 1 to 4, with higher scores corresponding to more frequent symptoms.	S
PROM REGISTRIES/PLATFORMS			
1.	**Evaluating the Measurement of Patient-Reported Outcomes (EMPRO)**	A 39-item tool for the standardized assessment of patient-reported outcome measures. Consists of 8 key attributes: conceptual and measurement model, reliability, validity, responsiveness, interpretability, burden, alternative modes of administration, and cross-cultural and linguistic adaptations.	NA
2.	**Patient Outcomes Registry for Transplant Effects on Life (PORTEL)**	Nationwide patient registry established to evaluate QOL and determine the effects of transplant and immunosuppressive regimens on patient outcomes. Patients complete a 100-item self-administered questionnaire consisting of questions about patient demographics, organ functioning, and other post-transplant outcomes. General QOL was measured by the Short Form-12 (SF-12). The Memphis Survey, an instrument developed and psychometrically validated at the University of Tennessee, was administered to patients to evaluate side-effects associated with immunosuppression.	NA
3.	**PatientsLikeMe Open Research Exchange**	PatientsLikeMe is building the Open Research Exchange platform that engages patients in developing new patient-reported health outcome measures that capture and report on what is meaningful to patients in the	NA

	MEASURE	DESCRIPTION	DOMAIN
		real world and better reflect patients' experiences with a disease and how it is affecting their health and quality of life. Access to the new platform is free, and all instruments and items developed on the platform will be made openly available for free, unlimited use and further development with no commercial restrictions. Researchers and PatientsLikeMe members are currently collaborating to develop measures for hypertension and Type 2 diabetes, as well as tools to capture patient perspectives on end-of-life care and the burden of treatment regimens.	
4.	**PatientViewpoint**	Website for patient-reported outcomes assessment. The purpose of the website is to improve patients' experience of care in real-time by facilitating doctor-patient communication, which can then improve patient care and outcomes. The target audience includes both patients and clinicians, and the website is designed to allow both patients and clinicians to track changes in status. To facilitate interpretability of the data, the website includes alerts for scores or changes in scores that exceed pre-set thresholds. Any generic or disease-specific PRO can be programmed into the website, enabling its use in a broad range of patient populations.	NA
5.	**Patient-Reported Outcomes Measures Information System (PROMIS)** • Steward: HHS • Level: Not indicated	Set of person-centered measures that evaluates and monitors physical, social, and emotional health in adults and children. Can be used with the general population and with individuals living with chronic conditions. See measures section above, Row 93, for additional details.	NA
6.	**RPA Kidney Quality Improvement Registry**	CMS-approved qualified clinical data registry (QCDR) designed for nephrology practitioners to foster performance improvement and improve outcomes in the care of patients with kidney disease. The registry collects data for the purpose of patient and disease tracking to foster improvement in the quality of care provided to patients. As the only nephrology-specific QCDR, RPA indicates the registry will have the data with which to develop and test measures. Not limited to PQRS measures.	NA