PATIENT-REPORTED OUTCOMES FOR END-STAGE RENAL DISEASE:

A FRAMEWORK & PRIORITIES FOR MEASUREMENT

KIDNEY CARE QUALITY ALLIANCE

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CONTENTS

EXECUTIVE SUMMARY

Each year in the United States, more than 118,000 Americans are diagnosed with kidney failure (or End Stage Renal Disease [ESRD]) – an irreversible condition that is fatal without a kidney transplant or life-sustaining dialysis treatments. Currently, more than 660,000 Americans suffer from ESRD and approximately 468,000 are on dialysis, a number that is expected to double over the next decade.

For more than a decade, Kidney Care Partners (KCP), a coalition of patient advocates, dialysis professionals, care providers and manufacturers, has provided community-wide leadership in kidney care quality. In 2005, KCP convened the Kidney Care Quality Alliance (KCQA), which represents the full range of stakeholders, to develop performance measures. Most recently, KCQA recognized the increasing importance of patient-reported outcomes (PROs) to improving care for patients with ESRD. In July 2016, KCQA launched its Patient-Reported Outcomes Initiative to:

- identify guiding principles for measure development in this area;
- establish a framework for what should be measured; and
- recommend priorities for patient-reported outcome measure development.

KCQA adopted a systematic, multi-faceted approach to this work, which included an environmental scan, semi-structured interviews, a prioritization survey, commissioned papers, and an in-person meeting. Based on these efforts, KCQA recommends adopting a comprehensive framework for patient-reported outcome measurement for patients with ESRD that encompasses four categories, each with several domains and subdomains (Figure A); of highest priority are patient experience with care and health-related quality of life (HRQOL).

All KCQA stakeholders view patient-reported outcome measures (PROMs) and patient-reported outcome performance measures (PRO-PMs) as valuable tools that provide different and important information as compared to traditional clinical and structural reporting measures. KCQA's recommendations focus on four areas: 1) patient experience with care and In-Center Hemodialysis (ICH) CAHPS; 2) KDQOL as a PROM/PRO-PM; 3) HRQOL and PROM/PRO-PM development; and 4) overarching issues.

Patient Experience with Care and ICH CAHPS

CMS has adopted ICH CAHPS as the PROM to assess facility-level *Patient Experience with Care* for both payment (QIP) and public reporting (e.g., Dialysis Five-Star) purposes. Abandoning this metric in favor of a new, shorter survey is unlikely, so KCQA makes the following findings and recommendations specific to ICH CAHPS:

- ICH CAHPS is viewed more favorably than KDQOL and aspects can be actionable at the facility level.
- **Administration of the ICH CAHPS survey and survey burden—both the length and frequency of administration—are highly problematic and need significant improvement. A shorter, but valid, instrument should be a high priority.** The validity of ICH CAHPS results is increasingly threatened with decreasing response rates due to the high frequency of administration and survey length. Dialysis patients, in particular, experience a high degree of survey burden and fatigue—e.g., in addition to twice yearly ICH CAHPS, they may well receive Hospital CAHPS from hospitalization(s), and Clinician and Group CAHPS.
    - Consideration should be given to an approach that requires patients to respond to a randomly assigned, single ICH CAHPS composite (nephrologists communication and caring, quality of dialysis center care and operations, and providing information to patients) or the global rating questions for a given measurement period, thereby shortening any one person's burden.
    - If CMS continues to require the whole survey, the number of items should be significantly reduced.

  - The twice yearly frequency is becoming untenable and should be reduced while maintaining validity of the score.
  - CMS, in particular, as well as providers and patient organizations, should enhance general outreach that emphasizes to patients the importance of completing the survey.
- **ICH CAHPS is deficient in representing patient experience for home dialysis patients. Development of a valid patient experience PROM for home dialysis should be a priority.**
  - KCQA should support ongoing private-sector efforts to develop a home dialysis patient experience with care measure.
  - CMS and the Agency for Healthcare Quality Research should provide additional funding to accelerate the ongoing private-sector effort to address the lack of a home dialysis PROM/PRO-PM.

KDQOL as a PROM/PRO-PM

The Conditions for Coverage encourage use of KDQOL for purposes of patient-specific, individual quality of life assessment; though other instruments may be deployed, as a practical matter they are not. KCQA makes the following findings specific to KDQOL:

- KDQOL is an individual patient assessment tool for which scores should not be aggregated to measure facility quality.
- **KCQA recognizes the importance and priority of HRQOL PROMs/PRO-PMs, but KDQOL is not an appropriate starting point for a facility-level, HRQOL-related PROM/PRO-PM.**

Health-Related Quality of Life and PROM/PRO-PM Development

KCQA's interviewees and survey respondents view HRQOL as a priority for PROM development. At the same time, HRQOL for patients with ESRD is multi-factorial and varies significantly over time, even for an individual patient. Accordingly, the overall HRQOL of a facility's patient population is not a valid endpoint to represent the quality of care at a facility. KCQA makes the following findings and recommendations for HRQOL-related PROM/PRO-PM measure development:

- **Broadly measuring global HRQOL of a facility's patient population for the purpose of facility-level accountability is problematic because of limits to facility control of many aspects, complexity of individual assessments being attributed as group characteristics, and case mix.** A global index also has the potential to divert resources that would be best served by targeted, specific HRQOL-related PROMs/PRO-PMs and a potential to lead to cherry-picking of patients.
- **Specific subdomains of HRQOL appear amenable for near-term PROM/PRO-PM measure development. Specifically, KCQA supports initial HRQOL-related measure development that focuses on an aspect of HRQOL that occurs during, or in the immediate aftermath, of treatment.** For example, a scientifically valid PROM/PRO-PM to assess "recovery time after dialysis," a subdomain of the HRQOL Energy and Vitality domain, could address a common patient concern about post-dialysis fatigue. Similarly, intradialytic symptoms or experiences with treatment that have a significant impact on HRQOL (e.g., cramping, nausea, lightheaded-ness, falls, or modality education, respectively) could similarly be priority areas for PROM/PRO-PM measure development.
- Regardless of the specific aspect of HRQOL that is being measured, any measure should be constructed to acknowledge that patients can be satisfied without complete resolution of a given issue, and that there are issues they do not want addressed, which will vary by patient. Patients should be asked about x and

whether the matter is even of concern to them. Only if it is, should they be queried as to whether the concern has been addressed.

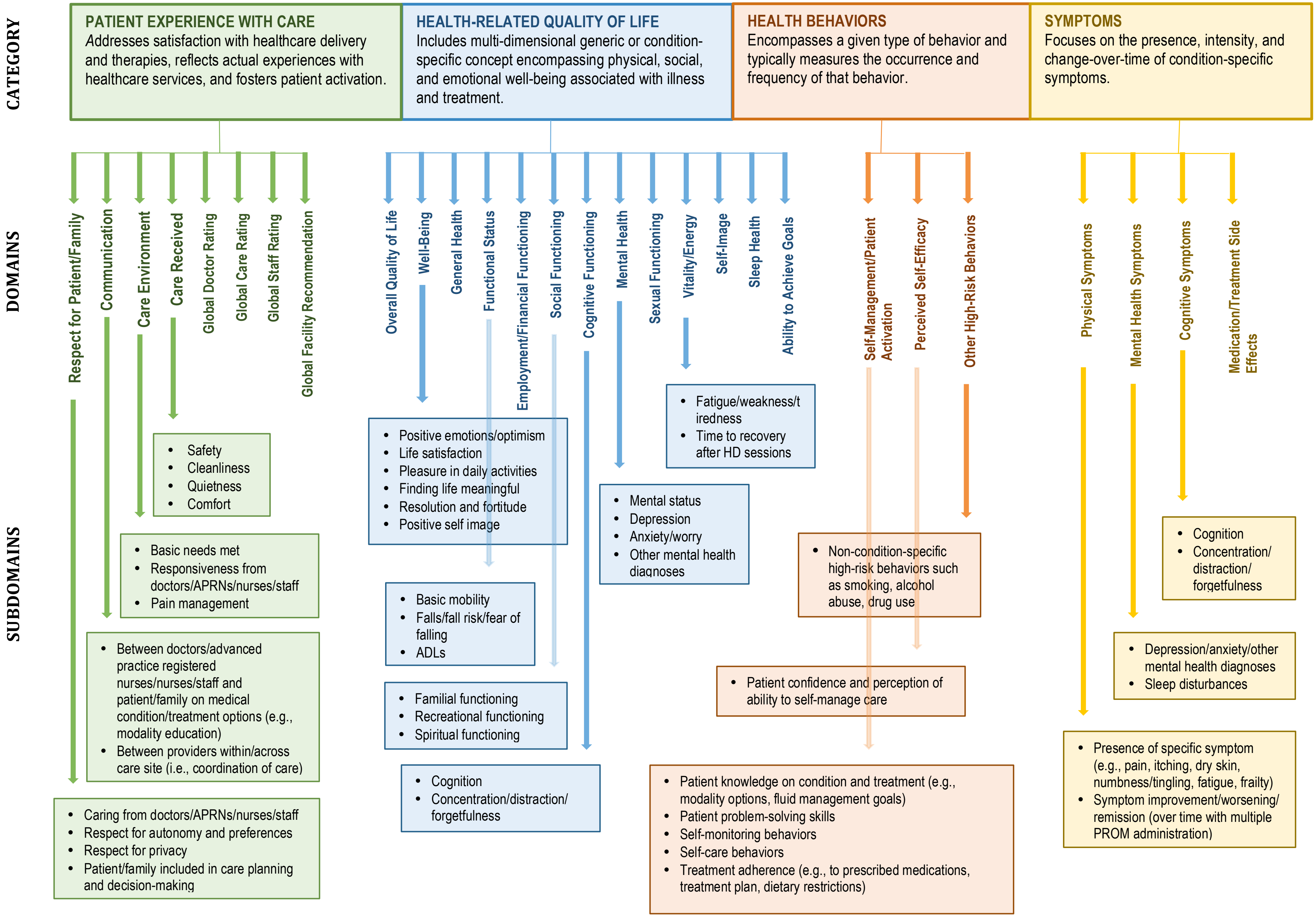
- Even as it is not appropriate as a facility-level HRQOL PROM/PRO-PM, KDQOL also is not state-of-the art for assessing the HRQOL of individual patients, whereas PROMIS is. PROMIS should be considered as an updated mechanism for individual assessment, as well as how it might be leveraged for any new, targeted HRQOL-related PROM/PRO-PM development.
- **Any new HRQOL-related measure development by CMS should be a multi-stakeholder process that relies on the state-of-the art science and technology and reduces redundancy and burden at both the individual assessment and facility accountability levels, be meaningful for patients, and be actionable by providers.**
- **Given the significant hurdles for patients new to dialysis and the overall trajectory of the disease, it is important that HRQOL-related measures account for these factors (e.g., through risk adjustment or stratifying incident vs. prevalent populations).**

Overarching Findings and Recommendations

Over the course of this Initiative, several observations were made during the interviews, through survey comments, and at the in-person meeting about PROMs and PRO-PMs that were not specific to a category, but were overarching to patient-reported outcomes. KCQA makes the following findings and recommendations on these themes:

- **Survey fatigue and survey burden impact both patients and providers and is in urgent need of improvement.** CMS should work with KCQA and others to significantly reduce the burden of existing PROMs/PRO-PMs, regardless of adding new PROMs/PRO-PMs to this area.
- **Approximately 70 percent of patients interviewed indicated a reluctance to be honest about complaints because of mistrust and fear of retribution.** In contrast, many providers indicated providing flexibility in choosing survey mode and place of administration, specifically at the facility, could improve opportunities to act specifically and immediately about concerns. **Ultimately, the use of PROMs/PRO-PMs should address patients' concerns for privacy: Patients must be comfortable answering honestly if the measures are to drive improved quality. Increased attention by facility personnel and physicians needs to regularly ensure that patients understand why they are surveyed, and patients need to know about the specific actions that have been taken to enhance care because of survey responses.**
- **New PRO instruments must be shorter and simpler, and must be validated before deployment. Patients must resonate with any new PRO survey; they must be asked about matters important and meaningful to them. At the same time, dialysis facilities and health care professionals must be able to deploy evidence-based interventions that impact scores from any new PROMs/PRO-PMs and improve quality in as real-time as possible.**
    - Any new instrument must balance other quality priorities against the burden of time on patients to participate and the resources (cost and time) on facilities to administer and intervene to improve outcomes.
    - Implementation of any new instrument must ensure receipt of a sufficient number of timely responses, from which meaningful statistical analyses can be conducted and improved outcomes can be achieved.
- **New PROMs/PRO-PMs should be reviewed and endorsed by NQF prior to implementation.**

FIGURE A: A FRAMEWORK FOR MEASURING ESRD PATIENT- REPORTED OUTCOMES



PATIENT EXPERIENCE WITH CARE
Addresses satisfaction with healthcare delivery and therapies, reflects actual experiences with healthcare services, and fosters patient activation.

Domains:
- Respect for Patient/Family
- Communication
- Care Environment
- Care Received
- Global Doctor Rating
- Global Care Rating
- Global Staff Rating
- Global Facility Recommendation

Subdomains:
- Safety
- Cleanliness
- Quietness
- Comfort

- Basic needs met
- Responsiveness from doctors/APRNs/nurses/staff
- Pain management

- Between doctors/advanced practice registered nurses/nurses/staff and patient/family on medical condition/treatment options (e.g., modality education)
- Between providers within/across care site (i.e., coordination of care)

- Caring from doctors/APRNs/nurses/staff
- Respect for autonomy and preferences
- Respect for privacy
- Patient/family included in care planning and decision-making

HEALTH-RELATED QUALITY OF LIFE
Includes multi-dimensional generic or condition-specific concept encompassing physical, social, and emotional well-being associated with illness and treatment.

Domains:
- Overall Quality of Life
- Well-Being
- General Health
- Functional Status
- Employment/Financial Functioning
- Social Functioning
- Cognitive Functioning
- Mental Health
- Sexual Functioning
- Vitality/Energy
- Self-Image
- Sleep Health
- Ability to Achieve Goals

Subdomains:
- Positive emotions/optimism
- Life satisfaction
- Pleasure in daily activities
- Finding life meaningful
- Resolution and fortitude
- Positive self image

- Basic mobility
- Falls/fall risk/fear of falling
- ADLs

- Familial functioning
- Recreational functioning
- Spiritual functioning

- Cognition
- Concentration/distraction/forgetfulness

- Mental status
- Depression
- Anxiety/worry
- Other mental health diagnoses

- Fatigue/weakness/tiredness
- Time to recovery after HD sessions

HEALTH BEHAVIORS
Encompasses a given type of behavior and typically measures the occurrence and frequency of that behavior.

Domains:
- Self-Management/Patient Activation
- Perceived Self-Efficacy
- Other High-Risk Behaviors

Subdomains:
- Non-condition-specific high-risk behaviors such as smoking, alcohol abuse, drug use

- Patient confidence and perception of ability to self-manage care

- Patient knowledge on condition and treatment (e.g., modality options, fluid management goals)
- Patient problem-solving skills
- Self-monitoring behaviors
- Self-care behaviors
- Treatment adherence (e.g., to prescribed medications, treatment plan, dietary restrictions)

SYMPTOMS
Focuses on the presence, intensity, and change-over-time of condition-specific symptoms.

Domains:
- Physical Symptoms
- Mental Health Symptoms
- Cognitive Symptoms
- Medication/Treatment Side Effects

Subdomains:
- Cognition
- Concentration/distraction/forgetfulness

- Depression/anxiety/other mental health diagnoses
- Sleep disturbances

- Presence of specific symptom (e.g., pain, itching, dry skin, numbness/tingling, fatigue, frailty)
- Symptom improvement/worsening/remission (over time with multiple PROM administration)

INTRODUCTION

Health Care Quality. *The degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.*[1]

Patient-Reported Outcome. *A report of the status of a patient's health condition, health behavior, or experience with care that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.*[2]

Medicine and health care have always sought to improve the health and well-being of patients. It wasn't until the late 1960s, however, that a systematic assessment of care to improve its quality took root.[3] The emphasis on evidence-based medicine, incorporation of clinical guidelines, and use of performance measures are now widely deployed drivers[4,5] to improve health care quality, as are public reporting of performance and value-based purchasing programs. In particular, clinical performance measures have proliferated rapidly for the full range of care settings and for myriads of disease, health promotion, and prevention purposes.[6,7]

How health care quality is specifically measured also has rapidly advanced. Most recently, the full range of stakeholders—patients, health care professionals, and providers—have begun to recognize that measuring a patients' own perceptions of their experiences and symptoms is a central component to improving and delivering high-quality, patient-centered care,[8,9,10] including dialysis care.[11,12,13,14 ,15]

THE KIDNEY CARE QUALITY ALLIANCE AND CONTEXT FOR THIS REPORT

Each year in the United States, more than 118,000 Americans are diagnosed with kidney failure (or End Stage Renal Disease [ESRD]) – an irreversible condition that is fatal without a kidney transplant or life-sustaining dialysis treatments. Currently, more than 660,000 Americans suffer from ESRD and approximately 468,000 are on dialysis, a number that is expected to double over the next decade.[16]

For more than a decade, Kidney Care Partners, a coalition of patient advocates, dialysis professionals, care providers and manufacturers, has provided community-wide leadership in kidney care quality through several proactive initiatives. Initially, it convened the Kidney Care Quality Alliance (KCQA) in 2005 to develop performance measures, work with the Centers for Medicare and Medicaid Services (CMS) to harmonize like measures, and receive National Quality Forum (NQF) endorsement. From 2014-2016, KCQA lead multi-stakeholder, consensus-based development of performance measures for fluid management and medication reconciliation, both of which were endorsed by NQF.

Most recently, KCQA recognized the increasing importance of patient-reported outcomes to improving care for patients with ESRD, yet acknowledged that measure development in this area was premature until a full understanding of the potential opportunities and pitfalls had been examined. Accordingly, in July 2016, KCQA launched its Patient-Reported Outcomes Initiative to:

- identify guiding principles for measure development in this area;
- establish a framework for what should be measured; and
- recommend priorities for patient-reported outcome measure development.

This document summarizes the results of an environmental scan (Appendix F), semi-structured interviews and an on-line prioritization survey, and input from two commissioned papers (Appendix G) discussed at an in-person meeting held in Washington, DC, on May 16, 2017. It reports on the KCQA Initiative's deliberations, presenting findings and recommendations to advance the development and implementation of ESRD-specific patient-reported outcome measures—important, but nascent tools to improve the quality of care for patients with ESRD.

WHAT ARE "PROS, PROMS, AND PRO-PMS"?

As noted earlier, a **patient-reported outcome (PRO)** is, simply put, information provided by the patient without interpretation by other parties. To be useful beyond an individual patient, however, requires gathering such information through a standardized data collection vehicle (a measure) that has been tested to ensure that it is scientifically robust—e.g., mis-intepretation is minimized so that the results are valid. Such data collection tools are referred to as **patient-reported outcome measures (PROMs).** Finally, in order for health care providers or professionals to gain an understanding of the overall performance on the input provided by a group of patients, experts construct **PRO-based performance measures (PRO-PMs)**. More formally, KCQA uses NQF's nomenclature:[17]

- **Patient-Reported Outcome (PRO):** The concept of any report of the status of a patient's health condition, health behavior, or experience with care that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else[18] (e.g., reporting on depression).
- **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, which measures depression).
- **PRO-Based Performance Measure (PRO-PM):** A performance measure that is based on PROM data aggregated for an accountable health care entity (e.g., percentage of patients in a health plan whose depression score, as measured by the PHQ-9, improved).

Currently, for example, the Centers for Medicare and Medicaid Services (CMS) requires dialysis facilities to survey patients about their experience with care (the PRO) using the In-Center Hemodialysis (ICH)-CAHPS (the PROM). Aggregate results for a facility are reported in three domains, as well as an overall score (the PRO-PM).

A FRAMEWORK FOR MEASURING ESRD PATIENT-REPORTED OUTCOMES

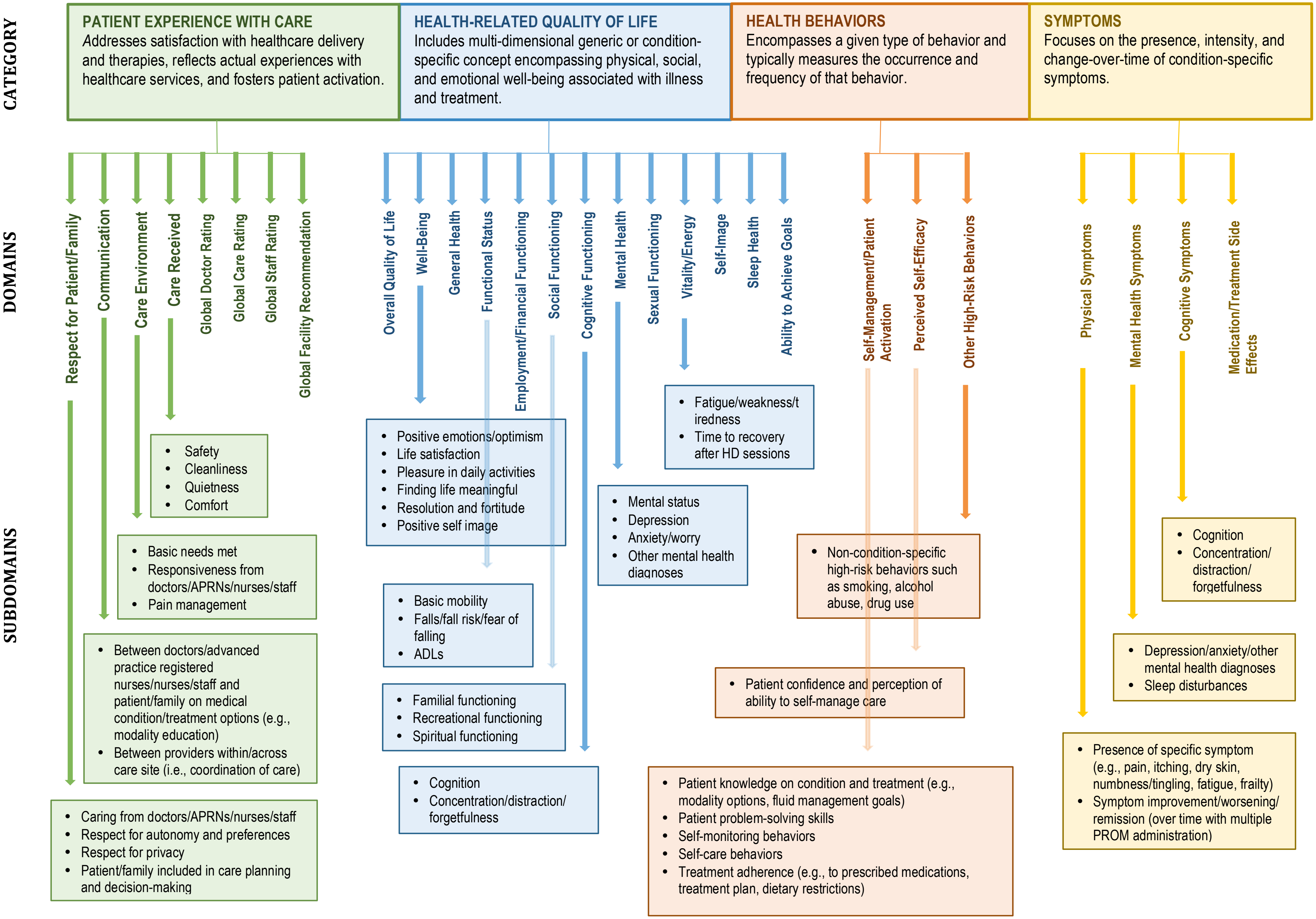
Prioritizing what aspects of care for patients with ESRD could be evaluated through PROs first required identifying the topics—categories, domains, and subdomains—around which measures could be developed and then organizing the topics in a comprehensive framework for measurement. KCQA recognized that not all topics will be important to measure (e.g., may not have evidence to support them, may not be actionable), but adopted a wide-ranging, systematic approach to identify the overall framework.

KCQA used the NQF's four broad categories for PROs—health behaviors, health-related quality of life (HRQOL), patient experience with care, and symptoms/symptom burden—as the starting point to build the framework, then drew upon the results of an environmental scan (Appendix F) that identified 150 PROMs and six PROM-related registries/platform to identify candidate domains (and subdomains) for each of the four high-level categories. All publicly available PROMs and PRO-PMs in the environmental scan were reviewed, and the domains and subdomains for each were evaluated as candidates for KCQA's ESRD PRO measurement framework. KCQA's Guiding Principles, updated in 2017 for this Initiative, also informed this work, as did KCP's *A Strategic Blueprint for Advancing Kidney Care Quality*.[19] Interviews with KCQA members, patients, and additional experts who reviewed a draft framework and discussion at the in-person meeting refined the final framework, which is illustrated in Figure A and summarized below.

KCQA's framework for measuring PROs for patients with ESRD is organized around four categories: health behaviors, HRQOL, patient experience with care, and symptoms.#

During the interviews and discussions with stakeholders, it became clear that "symptom burden" introduced ambiguity in its overlap, and a potential for confusion, with HRQOL, so KCQA's framework modifies the NQF rubric.

FIGURE A: A FRAMEWORK FOR MEASURING ESRD PATIENT- REPORTED OUTCOMES



CATEGORY

PATIENT EXPERIENCE WITH CARE
*A*ddresses satisfaction with healthcare delivery and therapies, reflects actual experiences with healthcare services, and fosters patient activation.

HEALTH-RELATED QUALITY OF LIFE
Includes multi-dimensional generic or condition-specific concept encompassing physical, social, and emotional well-being associated with illness and treatment.

HEALTH BEHAVIORS
Encompasses a given type of behavior and typically measures the occurrence and frequency of that behavior.

SYMPTOMS
Focuses on the presence, intensity, and change-over-time of condition-specific symptoms.

DOMAINS

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Global Facility Recommendation

Overall Quality of Life
Well-Being
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Vitality/Energy
Self-Image
Sleep Health
Ability to Achieve Goals

Self-Management/Patient Activation
Perceived Self-Efficacy
Other High-Risk Behaviors

Physical Symptoms
Mental Health Symptoms
Cognitive Symptoms
Medication/Treatment Side Effects

SUBDOMAINS

- Safety
- Cleanliness
- Quietness
- Comfort

- Basic needs met
- Responsiveness from doctors/APRNs/nurses/staff
- Pain management

- Between doctors/advanced practice registered nurses/nurses/staff and patient/family on medical condition/treatment options (e.g., modality education)
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- Patient confidence and perception of ability to self-manage care

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- Sleep disturbances

- Presence of specific symptom (e.g., pain, itching, dry skin, numbness/tingling, fatigue, frailty)
- Symptom improvement/worsening/ remission (over time with multiple PROM administration)

- *Health Behaviors* measures encompass a given type of behavior (e.g., smoking) and typically measures the occurrence and frequency of that behavior. (3 domains)
- *Health-Related Quality of Life* can be generic or condition-specific, and measures encompass physical, social, and emotional well-being associated with illness and its treatment. (13 domains)
- *Patient Experience with Care* measures satisfaction with care delivery and therapies, reflects actual experiences with services to foster patient engagement. (9 domains)
- *Symptoms* measures focus on the presence, intensity, and change-over-time of condition-specific symptoms. (4 domains)

The framework is intended as a comprehensive roadmap of the areas around which PROMs and PRO-PMs could be developed for patients with ESRD. KCQA recognizes that specific PROMs or PRO-PMs may overlap certain domains, or in particular, subdomains. Similarly, specific PROMs may measure multiple categories, with some items related to symptoms and others to health behaviors. Finally, KCQA recognizes that not all domains and subdomains necessarily lend themselves to measure development for accountability purposes (i.e., public reporting and payment); some may be limited and best suited to internal quality improvement or development of instruments/PROMs for individual patient assessment.

PRIORITIES FOR MEASURING ESRD PATIENT-REPORTED OUTCOMES: INTERVIEW AND SURVEY RESULTS

Prioritizing potential PRO measure development was a key component of KCQA's Initiative, given the potential breadth of domains and subdomains for ESRD PROMs and PRO-PMs. Toward this end, KCQA used two methods to prioritize the domains/subdomains. First, the semi-structured interviews to refine the framework also asked interviewees for their initial priorities. Second, KCQA conducted a formal on-line prioritization. Results from both approaches are summarized in this section.

Methodology and Sample

From late October 2016 through early January 2017, semi-structured interviews of 52 KCQA members, patients, and other experts (Appendix C) were conducted. The on-line survey resulted in 50 completed surveys from representatives of KCQA organizations, KCQA Steering Committee members, and patients; 42 individuals participated in both the interview and survey. Additionally:

- Of the 42 individuals, 21 were from KCQA organizations, 5 were KCQA Steering Committee members,[*] and 16 were patients.
- To ensure patients were adequately represented, the American Kidney Fund, Dialysis Patient Citizens, National Forum of ESRD Networks, and National Kidney Foundation provided the names of 28 patients willing to be interviewed and interested in participating in the KCQA Initiative; 19 patients were interviewed, and 9 did not respond to our outreach. Of the 19 interviewed, 16 (84.2%) also completed the survey; 3 additional patients who did not respond to the request for an interview completed the survey. Additionally, 2 patients who are also KCQA member representatives are included in the interview and survey calculations for both groups.
- For the interviews, 27 individuals from the 32 KCQA member organizations participated; 21 (80.8%) also completed the survey, as did an additional 5 who did not respond to requests for an interview.
- Ten of 12 Steering Committee members were interviewed, 9 (75%) of whom also completed the survey.

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[*] Steering Committee members who also serve as their organization's Lead Representative are counted in the KCQA members group.

Overall Prioritization

Prioritization for the categories differed between the interview and survey groups. Specifically, in the initial interviews, *Patient Experience with Care* was identified as the highest priority by both the patient and non-patient cohorts. For the online survey, however, both groups identified *Health-Related Quality of Life* as the highest priority. This shift appears due to a variety of factors, including that the interview and survey populations did not overlap entirely, shifting of priorities among categories by those who participated in both the interview and survey, and the different approach between the modalities (interviewees were asked only for their highest priority, the survey asked for a ranking of 1-4).

Additional analyses of the means and relative rankings by KCQA member and patient groups, summarized in the following sections, also provide insight into differences in emphasis by the two groups, even though the overall rankings appear similar. For example, examining the subcategory domains within both *Health-Related Quality of Life* and *Patient Experience with Care* identified differences in priorities between KCQA members and patients: Patients place a greater priority on *Mental Health* and *Communication* for these two categories, respectively, than did KCQA members.

Themes from the Interviews and Survey

Several themes emerged from the interviews and surveys:

- Appropriateness of the high-level PRO categories (*Health-related Quality of Life [HRQOL]*, *Symptoms*, *Patient Experience with Care*, and *Health Behaviors*);
- Priorities for PRO measurement;
- Barriers to collecting meaningful PRO information;
- Experience with ICH CAHPS and KDQOL;
- Other issues and concerns.

Each of these themes is discussed in the sections that follow, based on both interview information and survey data (and survey comments), as appropriate.

Appropriateness of the PRO Categories

Overall, the vast majority of interviewees felt the four major PRO categories in the framework comprehensively described the potential areas for PROM and PRO-PM development for patients with ESRD. A few interviewees, however, offered commentary about one or more of the categories that provide insights into how PROM and PRO-PM development might be viewed in the future.

- One KCQA member suggested that *HRQOL* should be removed from the list, as the issues do not fall within the dialysis facility's realm of influence and there is a lack of funding to appropriately address those issues.
- Several KCQA members indicated that *Patient Experience with Care* is highly subjective and variable, and one suggested that it is the least helpful of the PRO categories in the day-to-day management of the dialysis unit. None, however, believed the category should be removed.
- Another member questioned whether the *Health Behaviors* category is truly an outcome and how measurement in this area would be used to assess quality or improve care, but agreed it is nevertheless important to address.

Priorities for PRO Measurement

Information from the interviews and surveys was analyzed in three groups: All interviewees/respondents, KCQA members only, and patients only.[##] Interviewees were asked for their

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[##] The "KCQA Members" analyses limit input to that from one individual per KCQA member organization; the net result is four more individuals (other experts and Steering Committee members who are not also the representative for their organizations) in the "All Respondents" analyses than the sum of the "KCQA Members" and "Patients" analyses.

preliminary input[**] on which of the four high-level PRO categories they believe should be the highest priority in ESRD PRO measurement; subsequently, survey respondents were asked to formally rank the categories according to what they feel is most important for patients with ESRD (1 = highest priority, 4 = lowest).[^]

Highest Priority, Interviews vs. Survey

Despite the fact that 42 individuals who participated in the interviews also completed the survey (80.8% overlap), the prioritization ranking between the two modalities was not congruent. Specifically, 15 of the 42 (35.7%) individuals who participated in both modalities modified their #1 ranking from that which he/she named in the interview. The net effect of these changes was a reversal of the two top priorities—from *Patient Experience with Care* in the interviews to *HRQOL* in the survey. Figure 1 and Figure 2 illustrate this shift.

FIGURE 1: Percentage of All Interviewees (n=52) Ranking Each PRO Category #1

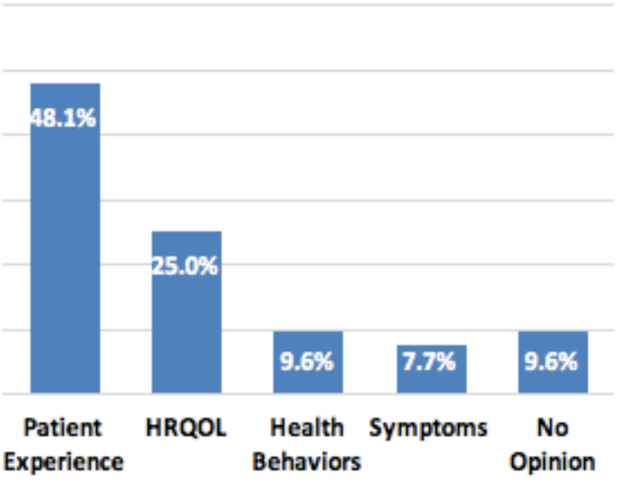
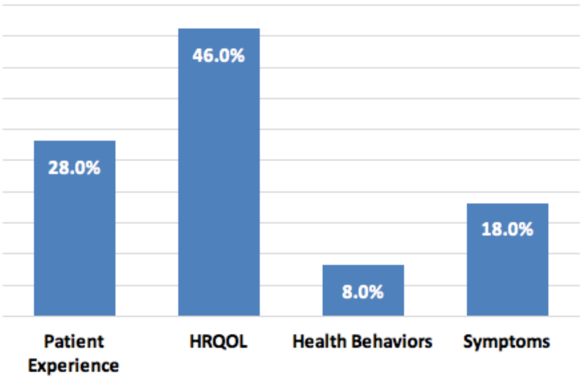


FIGURE 2: Percentage of All Survey Respondents (n=50) Ranking Each PRO Category #1



Analysis of Interview-Survey Incongruence

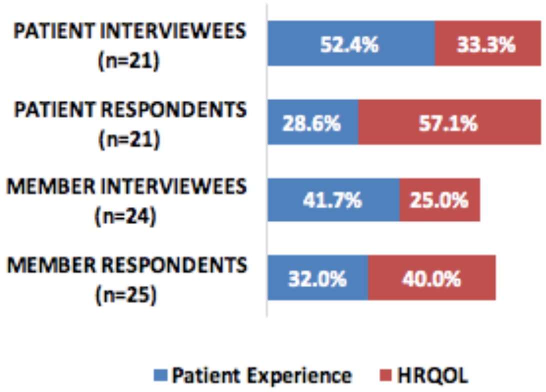
A detailed comparison of the interview and survey responses revealed that the net shift towards *HRQOL* resulted from 15 interviewees changing their highest priority when subsequently completing the survey and the addition of input from 6 survey respondents who had declined to participate in the preceding interviews.

Figure 3 illustrates the impact of these shifts on the percentages of members and patients ranking *Patient Experience* and *HRQOL* as #1 in the interviews, as compared to the surveys.

[**] Interviewees were advised that their response could be revised, if desired, when later completing the survey.

[^] Survey respondents who were interviewed were not reminded of their previously-noted priority.

FIGURE 3: Patients and Members Ranking *Patient Experience* and *HRQOL* #1 in the Interviews and Survey[&,^^]



As can be seen, there was a substantial reversal in priorities in the patient group, with 52.4% and 33.3% of interviewees ranking *Patient Experience* and *HRQOL* #1, respectively, and 28.6% ranking *Patient Experience* and 57.1% ranking *HRQOL* #1 in the surveys. KCQA members also reversed their top priority from *Patient Experience* to *HRQOL* in the survey, but the shift was more modest than was seen with patients.

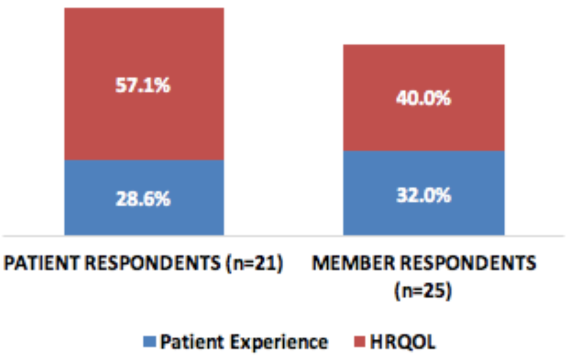
Understanding the Incongruence

The above analyses offer no insight into why relevant survey respondents revised their top priority from that identified in the interview, resulting in the net shift from *Patient Experience* to *HRQOL*. However, an evaluation of the mean survey rankings for the high-level PRO categories, an analysis of modes, and a review of voting patterns potentially provide some information.[***]

Specifically, mean rankings demonstrate a much narrower margin between *HRQOL* and *Patient Experience* than can be discerned from the ranking percentages above—suggesting that perhaps respondents find both categories similarly compelling and struggled with the pointed request in the survey to prioritize one above the other; during the interview, respondents were asked only for their top category. Similarly, examining the modes also provided additional insight into how the groups voted. Notably, as many KCQA member respondents ranked *HRQOL* #3 as #1 (40% each), with a majority (52%) ranking *Symptoms* as #2. Conversely, a clear majority (57.1%) of patients ranked *HRQOL* #1, while the most frequent ranking for *Symptoms* among patients was #3. In short, while *HRQOL* was the clear priority for patient respondents, the spread between *HRQOL* and *Patient Experience* was much narrower for members, with 40% prioritizing the former and 32% the latter (Figure 4). Also of note, the patient subgroup's rankings for the high-level categories suggest that patients place less focus on *Symptoms* as a priority for PRO measurement than do KCQA members. Appendix H provides additional details on these analyses.

Overall, the survey findings conclude that both KCQA members and patients place high priority on *HRQOL* and *Patient Experience*, but that the relative "strength" of those views about the categories.

FIGURE 4: Percentage Ranking *Patient Experience* and *HRQOL* #1 by Survey Subgroup



[&] All patient analyses displayed in this document include only patient interviewees/survey respondents; individuals from patient organizations who were not, themselves, patients, are not included in this cohort for these analyses. NOTE: The patient subgroup also was analyzed with the addition of responses from KCQA's patient organization representatives who were not also patients, with no appreciable change in priorities/rankings.

[^^] As previously noted, "Members" analyses limit input to that from one individual per KCQA member organization.

[***] Comparable data are not available for the interviews, as interviewees were asked only to identify their highest priority.

Rationales for Category Prioritization

Interviewees were asked for their rationale for selecting their highest priority. Similarly, the survey provided space for respondents to provide commentary on their rankings. In summary:

- *HRQOL:* Both during the interviews and in comments submitted with the surveys, rationales for prioritizing *HRQOL* centered around a "downstream" effect—i.e., improving patients' quality of life would be expected to have a positive impact on *Symptoms* and *Patient Experience*, and perhaps even *Health Behaviors*. One patient survey respondent noted that overall well-being and good health is the most important thing to dialysis patients; a KCQA member similarly indicated that *HRQOL* measures are the best metrics to guide specific patient care. However, during the interviews several individuals remarked that *HRQOL* is a complex concept that is difficult to effectively and measurably impact. Some also noted the inverse correlation between *HRQOL* and disease burden (i.e., quality of life inherently declines as ESRD vintage progresses) compromises its potential value for use in performance measurement. Still others noted that aspects of *HRQOL* are already addressed through screening mandated by the Conditions for Coverage. None of these concerns were explicitly reiterated in the survey comments, however, nor was there any explanation from relevant survey respondents as to why they had changed their top priority from *Patient Experience* to *HRQOL* in the interim between the interview and survey.

- *Patient Experience with Care:* Several interviewees and survey respondents opined that *Patient Experience* is the top priority to patients, is relatively actionable, and that a more positive interaction between patients and providers would ultimately impact the other three PRO areas. The subdomain of *Communication*, in particular, was highly prioritized among those favoring *Patient Experience*, with one patient remarking that good communication builds a foundation upon which all other PRO categories can more readily be addressed and improved upon. One KCQA member noted that patients are chronically fearful about their dialysis treatments and that providers need to be cognizant of this fact; much can be done to intervene and put the patient at ease, but facilities are not taking the necessary steps to improve on this most basic and achievable of goals.

- *Symptoms:* As noted earlier, *Symptoms* was ranked as #2 by a substantial number of respondents. Provided rationales included that *HRQOL* and *Symptoms* are inextricably linked and that gaining a better sense of *Symptoms* might provide insight into how to more directly improve quality of life for patients.

- *Health Behaviors:* As previously noted, one member questioned whether *Health Behaviors* is a true outcome and how metrics addressing this topic could be used to assess quality or improve care. Likewise, one patient commented that patients' health-related behaviors aren't truly reflective of a dialysis facility's quality. While two other KCQA members noted that increased focus on *Health Behaviors* could "trickle down" to impact the three other PRO categories, they acknowledged that patient behavior is notoriously difficult to address and that "lower hanging fruit" should receive priority.

Focus on HRQOL and Patient Experience Domain Priorities

As the interviews and survey reveal, the top high-level categories were *HRQOL* and *Patient Experience with Care*. To gain additional insight into what aspects of each category were most important, the on-line survey asked respondents to rank the domains (but not subdomains) for each. This section examines the highest ranked domains (of 13) for HRQOL and the four domains of *Patient Experience with Care*. Appendix H provides full data for all 13 domains under *HRQOL*, as well as the domain rankings for *Symptoms* and *Health Behaviors.*

- *HRQOL:* Survey respondents were asked to rank the 13 *HRQOL* domains according to what they felt was most important for patients with ESRD; 1=highest and 13=lowest. Subcategories were: *Overall Quality of Life, Well-Being, General Health, Functional Status, Employment/Financial Functioning, Social Functioning* [spiritual, familial, recreational], *Mental Functioning/Cognition, Mental Health/Emotional Functioning, Sexual Functioning, Vitality/Energy, Self-Image, Sleep Health,* and *Ability to Achieve Desired Goals.* Figure 4 illustrates the mean rankings for respondents' four highest HRQOL priorities.

FIGURE 5: Mean Ranking, Top 4 *HRQOL* Subcategories, All Respondents (n=49[$])

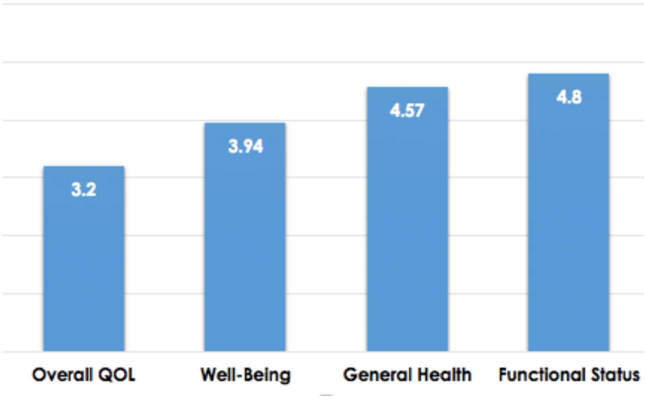
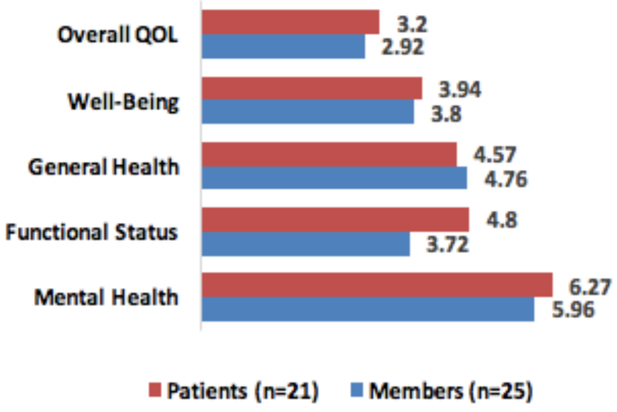


Table 1 demonstrates that **the *HRQOL* domain priorities are largely consistent across both respondent subgroups, with *Overall QOL* being the top domain priority; *Well-Being* and *General Health* rank in the Top 3 for both groups, although the placement differs. Of note, however, patients ranked *Mental Health* over *Functional Status in* their Top 4 priorities.**

Table 1: Ranking of *HRQOL* Subcategories by Survey Group

Ranking	All Respondents	KCQA Members	Patients
#1	Overall QOL	Overall QOL	Overall QOL
#2	Well-Being	Functional Status	Well-Being
#3	General Health	Well-Being	General Health
#4	Functional Status	General Health	Mental Health

FIGURE 6: Mean Ranking of *HRQOL* Subcategories by Respondent Subgroup (lower values [closer to 1] are more highly prioritized)



- *Patient Experience with Care:* Respondents were asked to rank the four *Patient Experience* subcategories (*Respect for Patient/Family*, *Communication* [with patient/family and between providers], *Care Environment* [safety, cleanliness, quietness, comfort], and *Care Received* [basic needs met, responsiveness from providers, pain management); 1=highest and 4=lowest priority. Figure 7 demonstrates that **rankings for Patient Experience with Care domains again were consistent overall across the two respondent subgroups, except patients place a higher priority on *Communication* and KCQA members on *Care Received*** (Table 2, Figure 8).

[$] One patient respondent only completed the high-level categories and the *Patient Experience* subcategories rankings, such that n=49 for the *HRQOL* "All Respondents" analysis and n=20 for the patient subgroup *HRQOL* analysis.

FIGURE 7: Mean Ranking, *Patient Experience* Subcategories, All Respondents (n=50)

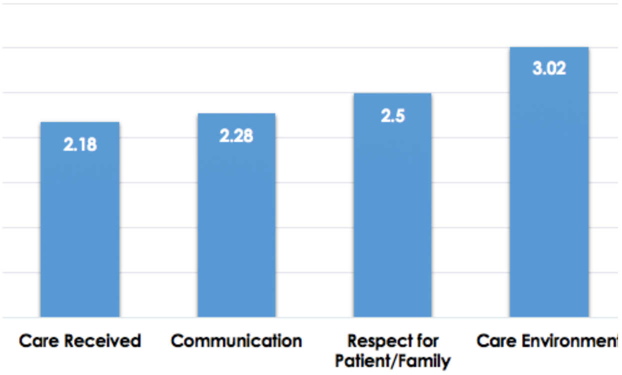
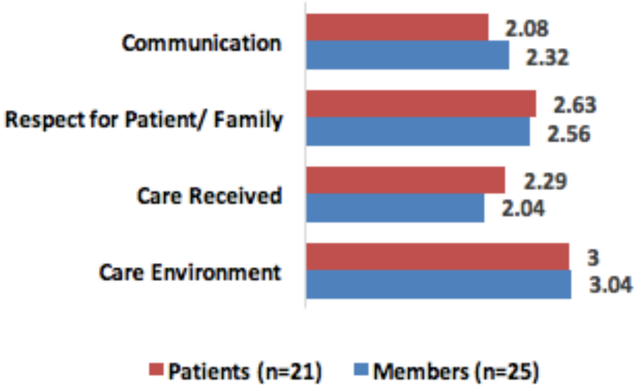


Table 2: Ranking of *Patient Experience* Subcategories by Survey Group

Rank	All Respondents	KCQA Members	Patients
#1	Care Received	Care Received	Communication
#2	Communication	Communication	Care Received
#3	Respect for Patient/Family	Respect for Patient/Family	Respect for Patient/Family
#4	Care Environment	Care Environment	Care Environment

FIGURE 8: Mean Ranking of *Patient Experience* Subcategories by Respondent Subgroup (lower values are more highly prioritized)



Not surprisingly, the survey findings conclude KCQA members and patients prioritize the specific domains for *HRQOL* and *Patient Experience* differently. Of particular note, *Mental Health* is prioritized as #4 by patients but does not appear in the KCQA members Top 4. For *Patient Experience*, *Communication* as an area for PROM/PRO-PM development is ranked #1 by patients, but #2 by KCQA members.

Barriers to Collecting Meaningful Patient-Reported Outcome Information

Input on perceived barriers to collecting meaningful PRO information was obtained through the interviews:

- **A majority of patients (52 percent) identified patient survey fatigue as the single greatest barrier to the collection of PRO data.** Distraction with more pressing concerns, feeling too ill to participate, and the perception that the information gleaned from the surveys is not used in any meaningful manner and does not result in appreciable changes in care also were frequently mentioned.

- **A significant proportion of the patients interviewed (approximately 70 percent) indicated that mistrust and a reluctance to be honest for fear of retribution by staff are barriers, particularly among elderly patients.**

- In contrast to patients' fear of retaliation for submitting a critical evaluation of their health care providers, several **KCQA member interviewees noted that anonymized blanket scores are not useful in a routine care setting, wherein the provider is seeking to investigate specific issues to improve care and outcomes for the individual patients who identified those issues.**

- **KCQA member organizations and Steering Committee members agreed with patients that survey fatigue is a significant issue (68 percent), as are patient literacy issues, the substantial administrative burden on providers, and the necessarily subjective nature of patient responses that make determining how best to respond challenging.**

- Recommendations on how to overcome these barriers varied widely and were oftentimes contradictory. Some believe electronic survey administration would improve response rates, while others prefer in-person interviews, paper-and-pencil administration, or use of a trusted third-party vendor. Some non-patient interviewees noted that reimbursement for the collection of PRO data would ease facility burden, with one interviewee suggested that limiting survey response options would simplify PRO surveys and improve completion rates; another recommended somehow incentivizing patient participation during in-center dialysis sessions. Patient interviewees in particular suggested that treating patients with respect, making them feel safe while in the dialysis facility, and following up on the survey data would reduce patient reluctance to complete the questionnaires.

Experience with ICH CAHPS and KDQOL

Two PRO instruments are widely used by dialysis clinics. CMS requires ICH CAHPS as part of both the Quality Incentive Program and the Dialysis Five-Star Program, and KDQOL Is deployed based on requirements under the Conditions for Coverage. KCQA asked interviewees for their familiarity with and perspectives on these instruments.

- Nearly all interviewees with prior experience with the ICH CAHPS and KDQOL do not view these surveys as effective instruments that provide meaningful patient-reported information on patients' experiences and/or quality of life.
- **For ICH CAHPS, the most commonly cited concern by patients and KCQA members is the burden associated with both the length of the survey and the twice-yearly administration. Significant concern also was expressed that home dialysis patients' experiences are completely unassessed, since ICH CAHPS is used only for patients receiving in-center hemodialysis.** Several members noted there are gaps in the instrument and that the low response rates raise concerns about response bias—a much simpler process is needed to glean more useful, well-rounded information. **Patient interviewees, in particular, indicated that the categorical responses with no space for additional comments limit their ability to provide meaningful information. Several patients opined that the survey is administered merely to "check off" a facility requirement, and felt that responses are not actually reviewed or acted upon.**
- **As compared to ICH CAHPS, several interviewees (n=13) had a more favorable impression of the KDQOL, indicating the survey is briefer, more user-friendly, asks more meaningful questions, and provides more actionable information.** Nevertheless, some Steering Committee and KCQA members noted that the survey was developed more than 20 years ago and was tested in a small group of patients in California[+] and might not appropriately translate to the contemporary, national dialysis population. **Importantly, however, it was emphasized that the KDQOL has not been specifically tested nor validated for use as a performance measure: It is an individual patient assessment tool, not an instrument valid for facility-level accountability.** One KCQA member pointed out that the KDQOL provides no guidance on specific interventions for identified issues, and voiced substantial concern about attempts to tie the instrument to a PROM or PRO-PM.

Other Issues and Concerns About PROs

Interviewees were offered opportunities throughout the semi-structured interview process to opine on PRO-related issues of importance to them that did not center on the advance questions. Additionally, survey respondents were afforded the opportunity to provide comments. Based on these collection

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[+] The original version of this report stated testing was conducted *only* in California, when in fact it was conducted at six sites in Southern California, two sites in the Northwest, and one site in the Midwest.

methods, the following additional issues are noted as being particularly significant to future PROM and PRO-PM development for the facility level:

- Questions asked in PRO surveys should be structured to extend beyond simple characterizations to provide more transactional information—e.g., "what did your doctor/nurse/staff do to address your problem?" In a related vein, many patient interviewees felt PRO survey questions should be open-ended whenever feasible to provide them the opportunities to focus on their particular concerns.
- The potential for unintended consequences must be considered with PROMs and PRO-PMs. For example, an issue for which a patient does not desire or expect any intervention might be identified (e.g., sexual dysfunction). While time and resources could clearly be better spent elsewhere, the facility might feel the need to address all issues identified through the survey—even those not of concern to the patient—to improve performance.
- Focusing on how a patient feels immediately after a treatment will improve quality-of-life.
- Despite the substantial focus for the past several years on patient engagement, patient-centered care, and now patient-reported outcomes, the vast majority of patients interviewed expressed their perception that they are simply not heard, not respected, and not routinely included in decisions on their own care.
- Family and caregiver outcomes also should be assessed; there would be great value in understanding how the dialysis experience is impacting them and acting on potential opportunities to improve that experience, which in turn could improve patients' outcomes.

INPUT FROM THE EXPERT COMMISSIONED PAPERS

For its PRO Initiative, KCQA commissioned two papers from experts in patient-reported outcome measurement methodology and in their use for patients with ESRD and other clinical areas. The papers were integral to shaping the discussion at the in-person meeting on May 16, 2017, in Washington, DC, and are provided as Appendix G. This section briefly summarizes each commissioned paper. A robust discussion of papers and the prioritization results occurred at the meeting, and is reflected in the final section of this report.

Methodological Issues: Peipert Hays Commissioned Paper

John D. Peipert, PhD and Ron D. Hays, PhD, "Methodological Considerations in Using PROs, PROMs, and PRO-PMs in ESRD", reviewed the methodological considerations of PROs, PROMs, and PRO-PMs, generally; identified methodological considerations that are unique or require special consideration in the dialysis setting (e.g., modality considerations), if any; and recommended how the renal community might best approach any methodological challenges.

Drs. Peipert and Hays also reviewed the current KDQOL and ICH CAHPS instruments, and reported on the potential application of PROMIS, a state-of-the-art system that uses computer-adapted technology (CAT), for use with patients with ESRD. Drs. Hays and Peipert noted the importance of modernizing PROM administration through web-based electronic means, which allows for efficient data capture, flexible timing, and increased convenience. At the same time, however, they noted that such an approach would require additional testing to ensure equivalency with paper surveys and bring additional costs for new systems and ongoing maintenance; depending on where the survey was administered, privacy concerns also might be of concern. Finally, Drs. Peipert and Hays suggested transplantation-related PROs might be an additional area that should be explored.

Drs. Peipert and Hays made six recommendations to advance the use of PROMs to improve quality of care for patients with ESRD:

- Continue the use of KDQOL-36 for dialysis center internal quality improvement, but improve current iteration by replacing SF-12 PCS & MCS with PROMIS items.
- Continue use of ICH CAHPS for CMS's dialysis center performance monitoring, but improve parsimony by reducing the number of items in the scales.
- Develop a PROM focused on whether patients have been informed about their options for transplant.
- Evaluate equivalence between electronic and paper versions prior to widespread use of electronic administration.
- Explore mechanisms for CMS to reimburse costs of administration/data entry and material costs.
- Develop effective, low-cost training programs to help providers administer PROMs, including e-learning programs.

Clinical Issues: Finkelstein Commissioned Paper

Fredric O. Finkelstein, MD, "PROMs and the ESRD Patient: A Time to Rethink Our Approach", reviewed the evolution of patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome performance measures (PRO-PMs), generally. It examined how they are being implemented in other clinical fields, and made recommendations how the renal community might best approach the use of PROM and PRO-PMs in the dialysis setting.

In particular, Dr. Finkelstein noted that studies in the renal patient population demonstrate an association between PROs and "hard" outcomes, such as mortality and hospitalization.[20,21,22,23,24,25] He also pointed out PROs could be particularly valuable to renal health care professionals and patients with ESRD, given the evidence that substantial discordance exists between a provider's and patient's perceptions of her/his health status, symptoms, quality of life (QOL), general health, and depression.[26,27,28] Drawing upon the published literature, Dr. Finkelstein noted that experiences with PROMs in neurology, gyn-oncology, psychiatry, and oncology all provide examples of successful PROM and PRO-PM deployment for future PROM/PRO-PM development for patients with ESRD.[29]

Dr. Finkelstein also reviewed the existing instruments (ICH CAHPS and KDQOL) and concluded they had significant limitations and challenges related to burden, actionability, lag time between scores and opportunity to intervene and improve, focus on areas (e.g., some aspects of HRQOL) not viewed as important to many patients, the diversity of comorbidities among patients with ESRD, and were outdated in their approach to measuring PROs. He posited that the current 5-Star system and QIP use of PROMs is detrimental to patient care in that they shift provider focus to performing for measures at the expense of individualized patient care.

Dr. Finkelstein recommended:

- Mandate PROMs be incorporated into routine patient care, addressing some or all issues discussed.
- Leave mode, frequency of administration, and choice of instrument to discretion of facility.
- Encourage innovative approaches, given a lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences.
- Require documentation of patient concerns and a plan to address those concerns (e.g., address problem using facility resources or referral to other providers/community resources).

SUMMARY, FINDINGS, AND RECOMMENDATIONS

Data from "conventional" structural (reporting), process, and outcome clinical measures demonstrate that outcomes and quality of care for patients with kidney disease have improved,[30,31,] but few would argue that additional improvements are not within reach. In addition to focusing on clinical measures that matter, appropriately developing and implementing PRO-PMs for patients with ESRD could increase patient-centered care and therefore advance kidney care quality.

Based on the environmental scan, prioritization of framework categories and domains, and review and discussion of the expert commissioned papers, KCQA makes findings and recommendations in three specific areas—Patient Experience with Care and ICH CAHPS, KDQOL as a PROM/PRO-PM, and Health-Related Quality of Life and PROM/PRO-PM Development—as well as overarching findings and recommendations.

Patient Experience with Care and ICH CAHPS

CMS has adopted ICH CAHPS as the PROM to assess facility-level *Patient Experience with Care* for both payment (QIP) and public reporting (e.g., Dialysis Five-Star) purposes. Abandoning this metric in favor of a new, shorter survey is unlikely, so KCQA makes the following findings and recommendations specific to ICH CAHPS:

- ICH CAHPS is viewed more favorably than KDQOL and aspects can be actionable at the facility level.
- **Administration of the ICH CAHPS survey and survey burden—both the length and frequency of administration—are highly problematic and need significant improvement. A shorter, but valid, instrument should be a high priority.** The validity of ICH CAHPS results is increasingly threatened with decreasing response rates due to the high frequency of administration and survey length. Dialysis patients, in particular, experience a high degree of survey burden and fatigue—e.g., in addition to twice yearly ICH CAHPS, they may well receive Hospital CAHPS from hospitalization(s), and Clinician and Group CAHPS.
    - Consideration should be given to an approach that requires patients to respond to a randomly assigned, single ICH CAHPS composite (nephrologists communication and caring, quality of dialysis center care and operations, and providing information to patients) or the global rating questions for a given measurement period, thereby shortening any one person's burden.
    - If CMS continues to require the whole survey, the number of items should be significantly reduced.
    - The twice yearly frequency is becoming untenable and should be reduced while maintaining validity of the score.
    - CMS, in particular, as well as providers and patient organizations, should enhance general outreach that emphasizes to patients the importance of completing the survey.
- **ICH CAHPS is deficient in representing patient experience for home dialysis patients. Development of a valid patient experience PROM for home dialysis should be a priority.**
    - KCQA should support ongoing private-sector efforts to develop a home dialysis patient experience with care measure.
    - CMS and the Agency for Healthcare Quality Research should provide additional funding to accelerate the ongoing private-sector effort to address the lack of a home dialysis PROM/PRO-PM.

KDQOL as a PROM/PRO-PM

The Conditions for Coverage encourage use of KDQOL for purposes of patient-specific, individual quality of life assessment; though other instruments may be deployed, as a practical matter they are not.

KCQA makes the following findings specific to KDQOL:

- KDQOL is an individual patient assessment tool for which scores should not be aggregated to measure facility quality.
- **KCQA recognizes the importance and priority of HRQOL PROMs/PRO-PMs, but KDQOL is not an appropriate starting point for a facility-level, HRQOL-related PROM/PRO-PM.**

Health-Related Quality of Life and PROM/PRO-PM Development

KCQA's interviewees and survey respondents view HRQOL as a priority for PROM development. At the same time, HRQOL for patients with ESRD is multi-factorial and varies significantly over time, even for an individual patient. Accordingly, the overall HRQOL of a facility's patient population is not a valid endpoint to represent the quality of care at a facility. KCQA makes the following findings and recommendations for HRQOL-related PROM/PRO-PM measure development:

- **Broadly measuring global HRQOL of a facility's patient population for the purpose of facility-level accountability is problematic because of limits to facility control of many aspects, complexity of individual assessments being attributed as group characteristics, and case mix.** A global index also has the potential to divert resources that would be best served by targeted, specific HRQOL-related PROMs/PRO-PMs and a potential to lead to cherry-picking of patients.
- **Specific subdomains of HRQOL appear amenable for near-term PROM/PRO-PM measure development. Specifically, KCQA supports initial HRQOL-related measure development that focuses on an aspect of HRQOL that occurs during, or in the immediate aftermath, of treatment.** For example, a scientifically valid PROM/PRO-PM to assess "recovery time after dialysis," a subdomain of the HRQOL Energy and Vitality domain, could address a common patient concern about post-dialysis fatigue. Similarly, intradialytic symptoms or experiences with treatment that have a significant impact on HRQOL (e.g., cramping, nausea, lightheaded-ness or modality education, respectively) could similarly be priority areas for PROM/PRO-PM measure development.
- Regardless of the specific aspect of HRQOL that is being measured, any measure should be constructed to acknowledge that patients can be satisfied without complete resolution of a given issue, and that there are issues they do not want addressed, which will vary by patient. Patients should be asked about x and whether the matter is even of concern to them. Only if it is, should they be queried as to whether the concern has been addressed.
- Even as it is not appropriate as a facility-level HRQOL PROM/PRO-PM, KDQOL also is not state-of-the art for assessing the HRQOL of individual patients, whereas PROMIS is. PROMIS should be considered as an updated mechanism for individual assessment, as well as how it might be leveraged for any new, targeted HRQOL-related PROM/PRO-PM development.
- **Any new HRQOL-related measure development by CMS should be a multi-stakeholder process that relies on the state-of-the art science and technology and reduces redundancy and burden at both the individual assessment and facility accountability levels, be meaningful for patients, and be actionable by providers.**
- **Given the significant hurdles for patients new to dialysis and the overall trajectory of the disease, it is important that HRQOL-related measures account for these factors (e.g., through risk adjustment or stratifying incident vs. prevalent populations).**

Overarching Findings and Recommendations

Over the course of this Initiative, several observations were made during the interviews, through survey comments, and at the in-person meeting about PROMs and PRO-PMs that were not specific to a category, but were overarching to patient-reported outcomes. KCQA makes the following findings and recommendations on these themes:

- **Survey fatigue and survey burden impact both patients and providers and is in urgent need of improvement.** CMS should work with KCQA and others to significantly reduce the burden of existing PROMs/PRO-PMs, regardless of adding new PROMs/PRO-PMs to this area.

- **Approximately 70 percent of patients interviewed indicated a reluctance to be honest about complaints because of mistrust and fear of retribution.** In contrast, many providers indicated providing flexibility in choosing survey mode and place of administration, specifically at the facility, could improve opportunities to act specifically and immediately about concerns. **Ultimately, the use of PROMs/PRO-PMs should address patients' concerns for privacy: Patients must be comfortable answering honestly if the measures are to drive improved quality. Increased attention by facility personnel and physicians needs to regularly ensure that patients understand why they are surveyed, and patients need to know about the specific actions that have been taken to enhance care because of survey responses.**

- **New PRO instruments must be shorter and simpler, and must be validated before deployment. Patients must resonate with any new PRO survey; they must be asked about matters important and meaningful to them. At the same time, dialysis facilities and health care professionals must be able to deploy evidence-based interventions that impact scores from any new PROMs/PRO-PMs and improve quality in as real-time as possible.**
    - Any new instrument must balance other quality priorities against the burden of time on patients to participate and the resources (cost and time) on facilities to administer and intervene to improve outcomes.
    - Implementation of any new instrument must ensure receipt of a sufficient number of timely responses, from which meaningful statistical analyses can be conducted and improved outcomes can be achieved.

- **New PROMs/PRO-PMs should be reviewed and endorsed by NQF prior to implementation.**

CONCLUSION

All KCQA stakeholders view PROMs and PRO-PMs as valuable tools that provide different and important information as compared to traditional clinical and structural reporting measures. Not surprisingly, however, KCQA found a few differences between what subdomains patients would like to see addressed by new PROMs/PRO-PMs compared to the priorities of non-patient KCQA members.

Developing and implementing new PROMs/PRO-PMs must acknowledge and balance the sometimes competing and conflicting stakeholder interests of patients and health care providers on the relative importance of a topic, privacy, and actionability. The potential of any new ESRD PROMs/PRO-PMs to improve quality of dialysis care depends on having patients view them as meaningful and providers being assured they are reliable and valid.

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APPENDIX A: KCQA MEMBERS

The Kidney Care Quality Alliance (KCQA) was initially convened in 2005 to develop performance measures; its members represent the full range of stakeholders working together to improve the quality of care for patients with ESRD. Since its founding, KCQA has successfully developed, and had endorsed by the National Quality Forum, measures in vascular access, influenza immunization, patient education, fluid management, and medication reconciliation. Additional information on the current NQF-endorsed measures and their specifications is available at http://kidneycarepartners.com/kidney-care-quality-alliance-kcqa/.

AbbVie
Akebia Therapeutics, Inc.
American Kidney Fund
American Nephrology Nurses’ Association
American Renal Associates, Inc.
American Society of Nephrology
American Society of Pediatric Nephrology
Amgen
Baxter Healthcare Corporation
Board of Nephrology Examiners and Technology
Centers for Dialysis Care
Centers for Medicare and Medicaid Services
DaVita Healthcare Partners, Inc.
Dialysis Clinic, Inc.
Dialysis Patient Citizens
Fresenius Medical Care North America
Fresenius Medical Care Renal Therapies Group
Greenfield Health Systems
Keryx Biopharmaceuticals, Inc.
Kidney Care Council
Kidney Care Partners
National Forum of ESRD Networks, The
National Kidney Foundation
National Renal Administrators Association
Nephrology Nursing Certification Commission
Northwest Kidney Centers
NxStage Medical
Renal Physicians Association
Renal Support Network
Rogosin Institute
Sanofi
Satellite Healthcare
U.S. Renal Care

APPENDIX B: KCQA STEERING COMMITTEE

Patient-Reported Outcomes for End-Stage Renal Disease: A Framework & Priorities for Measurement represents the many contributions of KCQA members, patients, and other experts through interviews, the on-line prioritization survey, and an in-person meeting. This work was overseen through the significant time and efforts of the KCQA Steering Committee.

Allen R. Nissenson, MD, Co-Chair – DaVita HealthCare Partners

Paul Palevsky, MD, Co-Chair – Renal Physicians Association

Jason Spangler, MD – Amgen

Gail Wick, MHSA, RN – American Kidney Fund

Donna Bednarski, RN, MSN – American Nephrology Nurses Association

Raymond Hakim, MD, PhD – American Society of Nephrology

Sarah J. Swartz, MD – American Society of Pediatric Nephrology

Chris Lovell, RN, MSN – Dialysis Clinics, Inc.

Mike Guffey – Dialysis Patient Citizens

Lorien Dalrymple, MD, MPH – Fresenius Medical Care North America

Thomas Manley, RN, BSN – National Kidney Foundation

Jesse Roach, MD – Center for Medicare and Medicaid Services (CMS Liaison Member)

APPENDIX C: KCQA MEMBER, PATIENT, AND ADDITIONAL EXPERT INTERVIEWEES AND SURVEY PARTICIPANTS

In preparation for the prioritization survey and in-person meeting convened on May 16, 2017 in Washington, DC, KCQA conducted semi-structured interviews and an online prioritization survey to gather perspectives on the draft framework and help prioritize the focus for discussions at the meeting. KCQA is grateful to the following individuals for providing critical input to the project.

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American Society of Pediatric Nephrology
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Amgen
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Board of Nephrology Examiners and Technology
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Jeffrey Hymes, MD

Fresenius Medical Renal Therapies Group
Robert Kossman, MD

Greenfield Health Systems
Jennifer Holcomb, RD

Keryx Biopharmaceuticals, Inc.
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Kidney Care Council
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U.S. Renal Care
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Jason Early, referred by AKF
Andrew Conkling, referred by Dialysis Patient Citizens (DPC)
Julie Crandall, referred by DPC
Thomas Jones, referred by DPC
Robert Lee, referred by DPC
Flossie Lewis, referred by DPC
Della Major, referred by DPC
Jack Reynolds, referred by DPC
Nancy Scott, referred by DPC
Erik Austin, referred by Forum of ESRD Networks

Robin Blomberg, referred by Forum of ESRD Networks
Stephanie Dixon, referred by Forum of ESRD Networks
Katrina Lang-Lindsey, referred by Forum of ESRD Networks
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Bob Friedman, referred by NKF
Amanda Grandinetti, referred by NKF
Jamie Jones, referred by NKF
Melanie Lift, referred by NKF
Bobbie Reed, referred by NKF
John Schmidt, referred by Kidney Care Partners
Joe Karan, referred by Forum of ESRD Networks

Additional Experts

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Klemens Meyer, MD, Tufts Medical Center
Michelle Richardson, PharmD, Tufts Medical Center

APPENDIX D: PARTICIPANTS, KCQA PATIENT-REPORTED OUTCOME INITIATIVE MEETING

Following semi-structured interviews of KCQA members, patients, and additional experts and a formal survey-monkey prioritization, KCQA convened an in-person meeting on May 16, 2017, in Washington, DC, to review the interview and prioritization results, as well as to discuss the two commissioned papers. The thoughtful discussions at the Summit provided critical input for this report, and KCQA is grateful for the participation of the following individuals.

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Rogosin

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Centers for Medicare and Medicaid Services

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Renal Physicians Association

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Centers for Dialysis Care

APPENDIX E: KCQA GUIDING PRINCIPLES

Since its inception in 2005, KCQA's work has been guided by a set of common principles, regardless of the measure topic focus, including this Patient-Reported Outcome Initiative.

KCQA has adopted the following principles to guide its work:

- KCQA processes and actions and decisions of the Steering Committee, Workgroups, and full KCQA will be transparent.
- The KCQA Steering Committee, Workgroups, and full KCQA will maintain clear minutes of their meetings and make them available on the KCQA section of KCP's web site.
- Quality measures will address independent dialysis facility and hospital-based provider (provider)-level accountability. Quality measures may include both process- and outcome-based measures.
- Quality measures shall:
    - be patient-centered.
    - reflect the values and needs of patient/families/caregivers.
    - allow for appropriate variations in individual patient care regimens.
    - be equitable and ensure that all patients continue to receive high quality care, regardless of severity of illness or socio-demographic status.
    - appropriately address patient literacy and health literacy.
    - be consistent with the patient-physician relationship, as well as the relationship between patients/families/caregivers, providers, facilities, and other healthcare professionals.
    - reflect an array of aspects of care.
    - encourage improved quality and effective practices.
    - focus on improving the safety, effectiveness, and efficiency of care.be public to ensure integrity and allow for understanding of reported data by patients and their families.
    - produce consistent and credible results.
    - be reliable, valid (including psychometrically sound, when applicable), precise, based on sound scientific evidence, and predictive of overall quality performance.
    - be standardized, transparent, explicit, and measurable.
    - be based on standardized definitions, technical specifications, and methodologies.
    - allow for mastering benchmarks and demonstrating improvement.
    - facilitate meaningful comparisons at the facility-level and be risk adjusted or risk stratified when appropriate.
    - appropriately address the potential for unintended consequences related to measure implementation.
    - be based on KCQA's prioritization of the Blueprint's domains/subdomains.
    - build upon existing dialysis-related reporting requirements and use measures that are available and accessible without imposing undue burden on providers and caregivers.
    - be based on a strong consensus.

APPENDIX F: ENVIRONMENTAL SCAN

As part of this initiative, KCQA undertook an environmental scan of the literature (peer-reviewed and gray) and performance measure databases (e.g., the AHRQ National Quality Measures Clearinghouse) to identify Patient-Reported Outcome Measures (PROMs). This appendix provides information on 150 PROMs and six PROM-related registries/platforms identified through the environmental scan. The vast majority of PROMs are not specific to kidney disease; examination of PROMs from all areas was undertaken to identify what aspects of ESRD care could be appropriate to include in KCQA's framework for measurement.

The environmental scan was comprehensive, but was not intended to be all-encompassing. Rather, it illustrates the current breadth and scope of PROMs. The table is organized, as follows:

- Measures/instruments are listed alphabetically by title.
- The domains refer to the schema adopted by KCQA (based on NQF's categories)—*Health-Related Quality of Life* (including *Functional Status*); *Symptoms*; *Patient Experience with Care*; and *Health Behaviors* (Q, S, E, B, respectively).
- Gray cells indicate current NQF-endorsement.
- Measures/instruments pertinent to ESRD patients (including transplant recipients) are highlighted yellow.

	MEASURE	DESCRIPTION	DOMAIN
1.	**3-Item Care Transition Measure (CTM; NQF 0228)** • 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.	Q/S[1]

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

	MEASURE	DESCRIPTION	DOMAIN
5.	**ACORN Adult Outcome Questionnaire** • Steward: Center for Clinical Informatics • Level: Not stated	Not available.	Q/S[2]
6.	**Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Healthcare (NQF 2789)** • 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.	**Average Change in Functional Status Following Total Knee Replacement Surgery (NQF 2653)** • 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.	**CAHPS Clinician & Group Survey (CG-CAHPS)—Adult, Child (NQF 0005)** • 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	E

	MEASURE	DESCRIPTION	DOMAIN
		the age of 18. Patients who have had at least one visit during the past 12-months are eligible to be surveyed. 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.	**CAHPS Health Plan Survey v3.0 Children with Chronic Conditions Supplement (NQF 0009)** • 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.	**CAHPS Health Plan Survey, v5.0 (Medicaid and Commercial; NQF 0006)** • 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) • 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)	E

	MEASURE	DESCRIPTION	DOMAIN
		- Measure 7: How People Rated Their Health Care (1 item) - Measure 8: How People Rated Their Health Plan (1 item)	
15.	**CAHPS Home- and Community-Based Services Measures (NQF 2967)** - Steward: CMS - Level: Facility	CAHPS Home- and Community-Based Services measures derive from a cross disability survey to elicit feedback from adult Medicaid beneficiaries receiving home and community based services (HCBS) about the quality of the long-term services and supports they receive in the community and delivered to them under the auspices of a state Medicaid HCBS program. The unit of analysis is the Medicaid HCBS program, and the accountable entity is the operating entity responsible for managing and overseeing a specific HCBS program within a given state. The measures consist of seven scale measures, 6 global rating and recommendation measures, and 6 individual measures: Scale Measures 1. Staff are reliable and helpful –top-box score composed of 6 survey items 2. Staff listen and communicate well –top-box score composed of 11 survey items 3. Case manager is helpful - top-box score composed of 3 survey items 4. Choosing the services that matter to you - top-box score composed of 2 survey items 5. Transportation to medical appointments - top-box score composed of 3 survey items 6. Personal safety and respect - top-box score composed of 3 survey items 7. Planning your time and activities top-box score composed of 6 survey items Global Ratings Measures 8. Global rating of personal assistance and behavioral health staff- top-box score on a 0-10 scale 9. Global rating of homemaker- top-box score on a 0-10 scale 10. Global rating of case manager- top-box score on a 0-10 scale Recommendations Measures 11. Would recommend personal assistance/behavioral health staff to family and friends – top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes) 12. Would recommend homemaker to family and friends — top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes) 13. Would recommend case manager to family and friends– top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes) Unmet Needs Measures 14. Unmet need in dressing/bathing due to lack of help–top-box score on a Yes, No scale 15. Unmet need in meal preparation/eating due to lack of help– top-box score on a Yes, No scale 16. Unmet need in medication administration due to lack of help– top-box	E

	MEASURE	DESCRIPTION	DOMAIN
		score on a Yes, No scale 17. Unmet need in toileting due to lack of help– top-box score on a Yes, No scale 18. Unmet need with household tasks due to lack of help– top-box score on a Yes, No scale Physical Safety Measure 19. Hit or hurt by staff – top-box score on a Yes, No scale	
20.	**CAHPS Home Health Care Survey (NQF 0517)** - 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
21.	**CAHPS In-Center Hemodialysis Survey (NQF 0258)** - 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
22.	**CAHPS Nursing Home Survey—Discharged Resident Survey (NQF 0691)** - 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

	MEASURE	DESCRIPTION	DOMAIN
23.	**CAHPS Nursing Home Survey—Family Member Instrument (NQF 0693)** • 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
24.	**CAHPS Nursing Home Survey—Long-Stay Resident Survey (NQF 0692)** • 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
25.	**Center for Disease Control and Prevention HRQOL-14** • Steward: Public domain • Level: Not indicated	The standard 4-item set of Healthy Days core questions (CDC HRQOL– 4) has been in the State-based Behavioral Risk Factor Surveillance System (BRFSS) since 1993. From 2000 to 2012, the CDC HRQOL– 4 has been in the National Health and Nutrition Examination Survey (NHANES) for persons aged 12 and older. Since 2003, the CDC HRQOL– 4 has been in the Medicare Health Outcome Survey (HOS)—a measure in the National Commission for Quality Assurance's (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS). Standard Activity Limitation and Healthy Days Symptoms modules have also been available since January 1995. When used together, these measures comprise the full CDC HRQOL–14 Measure.	Q
26.	**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
27.	**Change in Basic Mobility as Measured by the AM-PAC (NQF 0429)** • 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
28.	**Change in Daily Activity Function as Measured by the AM-PAC (NQF 0430)** • 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
29.	**Child Hospital CAHPS (NQF 2548)** • Steward: Center for Quality	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	E

	MEASURE	DESCRIPTION	DOMAIN
	Improvement and Patient Safety, AHRQ • Level: Facility	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.	
30.	**Chinese Dialysis Quality of Life Scale (CDQOL)** • Developer: WL Suet-Ching • Level: Not indicated	A 29-item measure designed to measure the QOL of Chinese dialysis patients. Scored on a 5-point Likert scale. Higher scores indicate better quality of life as perceived by the patient.	Q
31.	**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

	MEASURE	DESCRIPTION	DOMAIN
32.	**CKD Symptom Burden Index (CKD-SBI)** • Steward: University of Pittsburgh • Level: Not indicated	A 32-item measure of symptom burden, derived from the DSI. The CKD-SBI was developed for use in patients with CKD stages IV and V. The measure has 4 dimensions: • Prevalence • Distress • Severity • Frequency Total score ranges from 0 to 100 and higher scores indicate higher symptom burden.	S
33.	**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
34.	**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
35.	**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
36.	**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
37.	**COPD Clinical Questionnaire (CCQ)** • Steward: University Medical	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	Q/S

	MEASURE	DESCRIPTION	DOMAIN
	Center Groningen - Level: Not indicated	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.	
38.	**CoreQ Long-Stay Family Measure (NQF 2616)** - Steward: American Health Care Association - Level: Not indicated	The measure calculates the percentage of family or designated responsible party for long stay residents (i.e., residents living in the facility for 100 days or more), who are satisfied. This consumer reported outcome measure is based on the CoreQ: Long-Stay Family questionnaire that has three items.	E
39.	**CoreQ Long-Stay Resident Measure (NQF 2615)** - Steward: American Health Care Association - Level: Not indicated	The measure calculates the percentage of long-stay residents, those living in the facility for 100 days or more, who are satisfied. This patient reported outcome measure is based on the CoreQ: Long-Stay Resident questionnaire that is a three item questionnaire.	E
40.	**CoreQ Short-Stay Measure (NQF 2614)** - Steward: American Health Care Association - Level: Not indicated	The measure calculates the percentage of individuals discharged in a six-month time period from a SNF, within 100 days of admission, who are satisfied. This patient reported outcome measure is based on the CoreQ: Short Stay Discharge questionnaire that utilizes four items.	E
41.	**Dementia Quality of Life Questionnaire (DEMQOL)** - Steward: Institute of Psychiatry - Level: Not indicated	DEMQOL is a patient reported outcome measure designed to enable the assessment health-related quality of life of people with dementia. It was developed according to best quality psychometric principles by a multidisciplinary team including BSMS, KCL, the London School of Hygiene and Tropical Medicine, the London School of Economics and Nottingham and Sheffield Universities. DEMQOL is designed to work across dementia subtypes and care arrangements and can be used at all stages of dementia. The measure consists of two questionnaires. 1. DEMQOL is a 28 item interviewer-administered questionnaire answered by the person with dementia. 2. DEMQOL-Proxy is a 31 item interviewer-administered questionnaire answered by a caregiver. In the majority of studies, DEMQOL and DEMQOL-Proxy are used together.	Q
42.	**Depression Remission at Six Months (NQF 0711)** - 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
43.	**Depression Remission at Twelve Months (NQF 0710)** - 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
44.	**Depression Response at Six Months—Progress Towards Remission (NQF 1884)** - 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	S

	MEASURE	DESCRIPTION	DOMAIN
		not have a follow-up PHQ-9 score at six months (+/- 30 days) are also included in the denominator.	
45.	**Depression Response at Twelve Months—Progress Towards Remission (NQF 1885)** - 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 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 denominator.	S
46.	**Depression Utilization of the PHQ-9 Tool (NQF 0712)** - 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.	[2]
47.	**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
48.	**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
49.	**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 patient education, vascular access, transplant referral, mineral metabolism, adequacy, anemia, infections, and mortality and hospitalization).	E
50.	**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
51.	**Edmonton Symptom Assessment Tool, Modified (ESAS)** - Developer: E. Bruera et al. - Level: Not indicated	Measure of symptom burden for use in dialysis patients. There are 10 symptom-specific items and 10 visual analogue scales with superimposed 0–10 scale. The scale for each symptom is anchored by the words 'No' and 'Severe' at 0 and 10, respectively, and the sum of scores range from 0 to 100 with higher scores indicating greater symptom distress and burden.	S
52.	**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	S

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

	MEASURE	DESCRIPTION	DOMAIN
		an open category).	
53.	**End-Stage Renal Disease Symptom Checklist–Transplantation Module (ESRD_SCLTM)** • Steward: University of Essen, Germany • Level: Not indicated	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: 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.	Q/S
54.	**Engagement in Meaningful Activity Survey** • Steward: Public domain • Level: Not indicated	12-item survey that assesses patients' day to day activities. Scoring is conducted by summing the responses (ranging from 1=Rarely to 4=Always) of the 12 items for a possible score range of 12-48. Persons may be classified as perceiving the meaningfulness of their activities as being either low (< 29), moderate (29 – 41), or high (> 41). 1. The activities I do help me take care of myself. 2. The activities I do reflect the kind of person I am. 3. The activities I do express my creativity. 4. The activities I do help me achieve something which gives me a sense of accomplishment. 5. The activities I do contribute to my feeling competent. 6. The activities I do are valued by other people. 7. The activities I do help other people. 8. The activities I do give me pleasure. 9. The activities I do give me a feeling of control. 10. The activities I do help me express my personal values. 11. The activities I do give me a sense of satisfaction. 12. The activities I do have just the right amount of challenge.	Q
55.	**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
56.	**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
57.	**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

	MEASURE	DESCRIPTION	DOMAIN
58.	**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
59.	**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
60.	**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
61.	**Family Evaluation of Hospice Care (NQF 0208)** - 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
62.	**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
63.	**Fluid Management Survey** - Steward: Not identified - Level: Not indicated	Developed to assess hemodialysis patient–stated preferences regarding fluid management.	S
64.	**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-,	Q

	MEASURE	DESCRIPTION	DOMAIN
		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.	
65.	**Functional Change in Self-Care Score for Nursing Home Facilities (NQF 2769)** • Steward: Uniform Data System for Medical Rehabilitation • Level: Facility	Change in Rasch-derived values of self-care function from admission to discharge among adult patients treated as short term rehabilitation patients in a skilled nursing facility who were discharged alive. The time frame for the measure is 12 months. The measure includes the following 8 items: Eating, Grooming, Dressing Upper Body, Dressing Lower Body, Toileting, Bowel, Expression, and Memory.	Q
66.	**Functional Outcome Assessment (NQF 2243)** • 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
67.	**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
68.	**Functional Status Assessment for Complex Chronic Conditions (PQRS 377)** • 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
69.	**Functional Status Assessment for Dementia (PQRS 282)** • 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
70.	**Functional Status Assessment for Knee Replacement (PQRS 375)** • 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
71.	**Functional Status Change for Patients with Hip Impairments (NQF 0423)** • Steward: Focus on Therapeutic Outcomes	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	Q

	MEASURE	DESCRIPTION	DOMAIN
	(FOTO) • Level: Clinician (group/practice, individual, facility), Health Plan, Integrated Delivery	quality.	
72.	**Functional Status Assessment for Rheumatoid Arthritis (PQRS 178)** • 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
73.	**Gains in Patient Activation (PAM) Scores at 12 Months (NQF 2483)** • 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.	B[3]
74.	**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
75.	**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),	S

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[3] Although often categorized under patient experience, engagement/activation is not precisely captured by that domain’s overall focus and seems more appropriate under *Health Behaviors*.

	MEASURE	DESCRIPTION	DOMAIN
		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.	
76.	**Geriatric Depression Scale** • Steward: Public domain • Level: Not indicated	15-item geriatric-specific depression screening tool.	S
77.	**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
78.	**Hemodialysis Quality of Life Questionnaire (HQL)** • Steward: Not identified • Level: Not indicated	Developed to assess hemodialysis patient QOL and physical and emotional symptoms.	Q
79.	**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
80.	**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
81.	**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.	Q/S
82.	**HowRwe** • Steward: R-Outcomes Ltd. • Level: Not indicated	4-item generic patient questionnaire on patient satisfaction.	E
83.	**HowRu** • Steward: R-Outcomes Ltd. • Level: Not indicated	4-item generic patient questionnaire on quality of life.	Q
84.	**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
85.	**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

	MEASURE	DESCRIPTION	DOMAIN
86.	**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
87.	**Informed, Patient-Centered (IPC) Hip and Knee Replacement Surgery (NQF 2958)** - Steward: Mass General Hospital - Level: Clinician	The measure is derived from patient responses to the Hip or Knee Decision Quality Instruments. Participants who have a passing knowledge score (60% or higher) and a clear preference for surgery are considered to have met the criteria for an informed, patient-centered decision. The target population is adult patients who had a primary hip or knee replacement surgery for treatment of hip or knee osteoarthritis.	B
88.	**Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure—Change in Mobility Score for Medical Rehabilitation Patients (NQF 2634)** - 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
89.	**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
90.	**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
91.	**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)	A 134-item QOL measure designed for use in kidney disease patients undergoing dialysis. It consists of SF-36 dimensions (see below), 11 kidney disease targeted scales and an item that assesses change in health over a year (overall health rating). All scale scores are transformed linearly into 0–100 point scales with higher scores indicating better HRQOL.	Q
92.	**KDQOL (Modified)** - Developer: RAND/public domain	A 55-item QOL measure derived from the KDQOL. Using affinity mapping, 11 subscales were identified: - Pain	Q

	MEASURE	DESCRIPTION	DOMAIN
	- Level: Not a performance measure (i.e., is a PROM, not PRO-PM)	- Psychological dependency - Cognitive functioning - Social functioning - Dialysis-related symptoms - Cardiopulmonary symptoms - Sleep (viii) energy - Cramps - Diet - Appetite The measure is scored on a 0 to 100 scale with higher scores indicating better HRQOL.	
93.	**KDQOL-36** - Developer: RAND/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, 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.	Q
94.	**KDQOL-SF** - Developer: RAND/public domain - Level: Not a performance measure (i.e., is a PROM, not PRO-PM)	An 80-item HRQOL measure designed for use in kidney disease patients undergoing dialysis. There are 8 generic dimensions from the SF-36 and 8 disease-specific dimensions: - Symptoms/problems - Effects of kidney disease on daily life - Burden of kidney disease - Work status - Cognitive function - Quality of social interaction - Sexual function - Sleep There are 3 additional dimensions: - Social support - Dialysis staff encouragement - Patient satisfactio. Scores range from 0 to 100 for each dimension and higher scores indicate better HRQOL.	Q
95.	**Kidney Disease Questionnaire (KDQ)** - Steward: University of	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

	MEASURE	DESCRIPTION	DOMAIN
	Calgary - Level: Not indicated		
96.	**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
97.	**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
98.	**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) 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.	Q
99.	**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	Q

	MEASURE	DESCRIPTION	DOMAIN
		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.	
100	**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
101	**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
102	**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	Q/S
103	**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
104	**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
105	**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
106	**Mental Health/Substance Abuse: Mean of Patients' Overall Change Scores on**	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	Q/S

	MEASURE	DESCRIPTION	DOMAIN
	the Basis-24 Survey - Developer: Susan V. Eisen, PhD - Level: Individual Clinician	assess change during or following treatment. Six subscales are also calculated for the BASIS-24.	
107	**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
108	**Modified Transplant Symptom Occurrence and Symptom Distress Scale-59 Items Revised (MTSOSD-59R)** - Steward: Universiteit Leuven - Level: Not indicated	Updated 59-item version of the 45-item Modified Transplant Symptom Occurrence and Symptom Distress 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).	S
109	**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
110	**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
111	**NCQA Supplemental Items for CAHPS 4.0 Adult Questionnaire (NQF 0007)** - 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
112	**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
113	**OsteoARthritis Treatment Satisfaction (ARTS)**	18-item questionnaire to assess patient satisfaction with osteoarthritis treatment.	E

	MEASURE	DESCRIPTION	DOMAIN
	Questionnaire • Developer: Pouchet et al. • Level: Not indicated		
114	**Osteoporosis Patient Treatment Satisfaction Questionnaire (OPSAT-Q)** • Developer: Roche Laboratories, Inc. • Level: Not indicated	Measure to assess satisfaction with bisphosphonate treatment in postmenopausal women. Contains 16 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.	E
115	**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
116	**Pain Assessment and Follow-Up (NQF 0420)** • Developer: CMS • Level: Clinician	Percentage of visits for patients aged 18 years and older with documentation of a pain assessment using a standardized tool(s) on each visit AND documentation of a follow-up plan when pain is present.	S
117	**Palfrey's Specific Health Questionnaire for ESRD Patients** • Steward: Not identified • Level: Not indicated	Description not identified.	?
118	**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.	B[4]
119	**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	S

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[4] Although often categorized under patient experience, engagement/activation is not precisely captured by that domain's overall focus and seems more appropriate under *Health Behaviors*.

	MEASURE	DESCRIPTION	DOMAIN
		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.	
120	**Patient Experience of Psychiatric Care as Measure by the Inpatient Consumer Survey (ICS; NQF 0726)** • 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	E

	MEASURE	DESCRIPTION	DOMAIN
		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 strongly disagree to strongly agree.	
121	**Patient Experience with Surgical Care Based on the CAHPS Surgical Care Survey (NQF 1741)** • 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
122	**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
123	**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
124	**Patient-Reported Outcomes Measures Information System (PROMIS) Measures** • 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. The following areas are of particular relevance to patients with renal disease: • Overall symptom burden • CKD uncertainty • Fatigue • Depression • Anxiety • Mobility • ADLs • Symptoms: Pain, itching, skin changes, loss of appetite, GI symptoms (nausea, vomiting), shortness of breath, sleep disorders, restless legs, and sexual dysfunction .	Q/S
125	**Patient Satisfaction**	50-item survey that taps global satisfaction with medical care as well as	E

	MEASURE	DESCRIPTION	DOMAIN
	Questionnaire: PSQ-III • Steward: RAND • Level: Not indicated	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.	
126	**Pediatric Comfort Assessment** • Developer: Ambuel et al. • Level: Not indicated	Comfort care assessment of physical, psychospiritual, environmental, environmental, sociocultural aspects of care.	S
127	**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
128	**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
129	**Physical Symptom Distress Scale** • Developer: CP Chiu • Level: Not indicated	Developed to estimate the degree of symptom distress experienced by ESRD patients.	S
130	**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
131	**ReTransQOL(RTQ) Version 1** • Developer: S. Gentile et al. • Level: Not indicated	A 45-item measure designed to assess QOL in renal transplant patients. There are 5 dimensions: • Physical health • Mental health • Medical care • Fear of losing graft • Treatment All dimensions are linearly transformed to a 0 to 100 scale and higher scores indicate better HRQOL.	Q
132	**ReTransQOL(RTQ) Version 2** • Developer: S. Gentile et al. • Level: Not indicated	A 32-item measure designed to assess QOL in renal transplant patients. There are 5 dimensions: • Physical health • Social functioning • Medical care • Fear of losing graft • Treatment	Q

	MEASURE	DESCRIPTION	DOMAIN
		All dimensions are linearly transformed to a 0 to 100 scale and higher scores indicate better HRQOL.	
133	**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
134	**Shared Decision-Making Process (NQF 2962)** • Steward: Informed Medical Decisions Foundation • Level: Clinician	This measure assesses the extent to which health care providers actually involve patients in a decision-making process when there is more than one reasonable option. This proposal is to focus on patients who have undergone any one of 7 common, important surgical procedures: total replacement of the knee or hip, lower back surgery for spinal stenosis of herniated disc, radical prostatectomy for prostate cancer, mastectomy for early stage breast cancer or percutaneous coronary intervention (PCI) for stable angina. Patients answer four questions (scored 0 to 4) about their interactions with providers about the decision to have the procedure, and the measure of the extent to which a provider or provider group is practicing shared decision making for a particular procedure is the average score from their responding patients who had the procedure.	B
135	**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
136	**Sickness Impact Profile (SIP)** • Steward: Johns Hopkins University • Level: Not indicated	136-item generic questionnaire.	Q/S
137	**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
138	**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
139	**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
140	**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
141	**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
142	**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
143	**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
144	**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
145	**Validated Family-Centered Questionnaire for Parents' and Patients' Experiences During Inpatient Pediatric Hospital Stay (NQF 0725)** • 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
146	**Varicose Veins Treatment with Saphenous Ablation—Outcomes Survey (PQRS 420)** • 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
147	**Vulnerable Elders Scale-13 (VES-13)**	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	Q

	MEASURE	DESCRIPTION	DOMAIN
	• Steward: RAND • Level: Not indicated	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.	
148	**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
149	**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
150	**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 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.	NA
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	NA

	MEASURE	DESCRIPTION	DOMAIN
		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.	
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

APPENDIX G: COMMISSIONED PAPERS

As part of this initiative, KCQA commissioned two papers from experts in patient-reported outcome measurement methodology and in their use for patients with ESRD and other clinical areas. KCQA gratefully acknowledges the thoughtful analyses presented; the papers were integral to shaping the discussion at the in-person meeting on May 16, 2017, in Washington, DC.

Links to each paper are provided here, and the PowerPoint presentations based on them are at http://kidneycarepartners.com/kidney-care-quality-alliance-kcqa/measure-development-process/

- Fredric O. Finkelstein, MD, "PROMs and the ESRD Patient: A Time to Rethink Our Approach" reviews the evolution of patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome performance measures (PRO-PMs), generally; examines how they are being implemented in other clinical fields; and recommends how the renal community might best approach the use of PROMs and PRO-PMs in the dialysis setting.

- John D. Peipert, PhD and Ron D. Hays, PhD, "Methodological Considerations in Using PROs, PROMs, and PRO-PMs in ESRD" reviews the methodological considerations of PROs, PROMs, and PRO-PMs, generally; identifies methodological considerations that are unique or require special consideration in the dialysis setting (e.g., modality considerations), if any; and recommends how the renal community might best approach any methodological challenges.

APPENDIX H: ADDITIONAL SURVEY ANALYSES

As part of this initiative, KCQA interviewed Members and patients, as well as conducted an on-line survey to prioritize the categories and domains for potential measure development. The tables and graphs in this appendix were provided as part of the meeting materials for attendees at the in-person meeting and detail the data collected from the 52 semi-structured interviews and 50 surveys completed by representatives of KCQA organizations, KCQA Steering Committee members, and patients with ESRD.

PARTICIPANTS AND SUBGROUPS

The numbers of interviewees and survey respondents are displayed by group in Table 1.

TABLE 1: Numbers of Interviewees and Survey Respondents by Group

	Total	Number Interviewed + Competed Survey	Number Interviewed	Number Completed Survey	Only Interviewed	Only Completed Survey
All	**60**	42	52	50	10	8
Members	32[1]	21	27	26	6	5
Steering Committee[2]	6	5	6	5	1	0
Patients	22	16	19	19	3	3

As illustrated above:

- In all, 60 individuals participated in the project.
- 42 of these (70%) completed both the interview and survey, including 21 representatives from KCQA member organizations, 5 Steering Committee members, and 16 ESRD patients. Of the remaining 18, 10 individuals were interviewed, but did not complete the survey; 8 did not respond to the request for an interview, but completed the survey.
- 21 of 32 KCQA members (65.6%) were both interviewed and surveyed; 5 who did not participate in the interview completed the survey, and 6 were interviewed but did not complete the survey.
- 4 of the 12 KCQA Steering Committee members also act as the KCQA representative for their organizations; for the analyses displayed in this appendix, these individuals are counted in the "Members" group. Six of the remaining 8 Steering Committee members also participated in the project; 5 of these (83.3%) were both interviewed and surveyed, and 1 who was interviewed did not complete the survey.
- 16 of the 22 patients (72.7%) who participated were both interviewed and responded to the survey, 3 who did not respond to the request for an interview completed the survey, and 3 who were interviewed did not complete the survey.

Additionally, two member representatives—one of whom is also a Steering Committee member—also are ESRD patients. Because of the unique dual perspective these individuals bring to this project, their input is included in the calculations and analyses for both the "Members" and the "Patients" groups. Finally, the "All Respondents/Interviewees" analyses incorporate input from all patients, Steering Committee Members, and KCQA member organizations, regardless of the interviewee's/respondent's affiliation; conversely, the "Members Only" analyses limit input to that from one individual per KCQA member organization. The net result is four more individuals in the "All Respondents" analyses than the sum of the "Members" and "Patients" analyses; these individuals are other experts or Steering Committee members who are not also the representative for their organization.

INTERVIEWEES' TOP PRIORITY

Interviewees (n=52) were asked for their preliminary input[3] on which of the four high-level PRO categories they believe should be the highest priority in ESRD PRO measurement. Responses are displayed in Table 2 and Figures 1 through 3.

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[1] Includes four Steering Committee members, as described in the fourth bullet.

[2] Steering Committee members who also served as the representative for their KCQA member organization are counted in the "Members" group.

TABLE 2: Numbers of All Interviewees (n=52) Ranking Each PRO Category #1

	Patient Experience	HRQOL	Health Behaviors	Symptoms	No Opinion
All Interviewees (n=52)	**25**	13	5	4	5
Members + Steering Committee (n=33)	14	8	5	3	3
Patients (n=19)	11	5	0	1	2

FIGURE 1: Percentage of All Interviewees (n=52) Ranking Each PRO Category #1

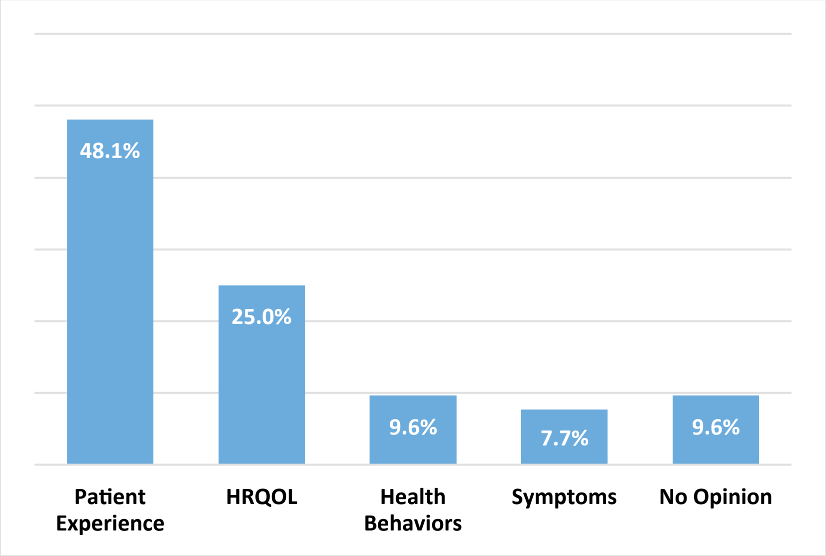
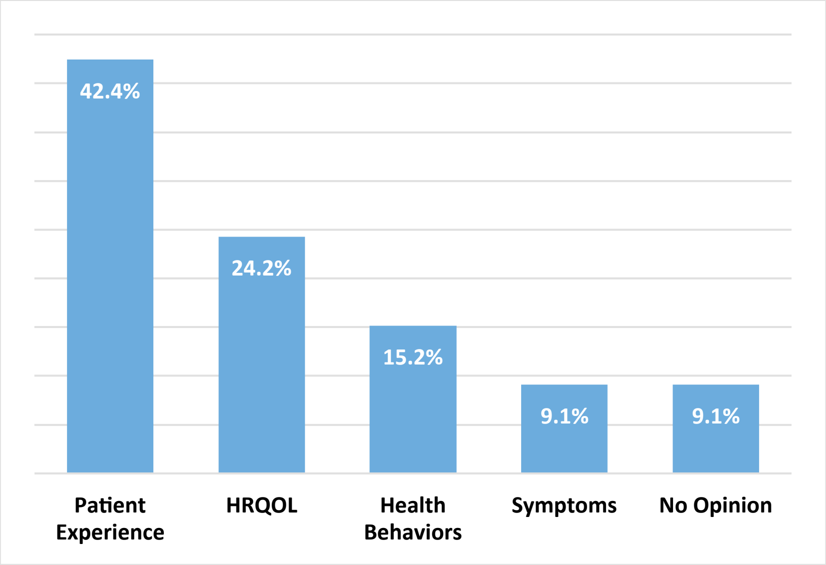


FIGURE 2: Percentage of Member/Steering Committee Interviewees (n=33) Ranking Each PRO Category #1



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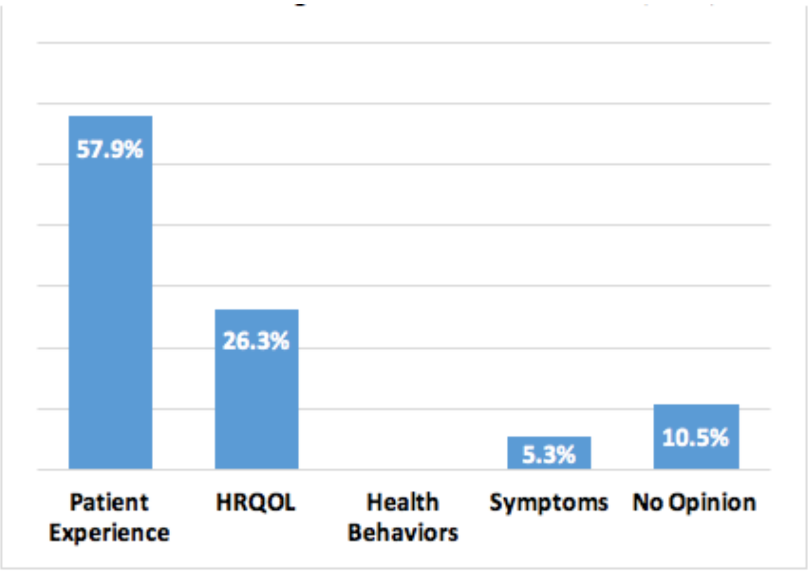
[3] Interviewees were advised that their response could be revised, if desired, when later completing the survey.

FIGURE 3: Percentage of Patient Interviewees (n=19) Ranking Each PRO Category #1



SURVEY RESPONSES

Survey respondents (n=50) were asked via surveymonkey to rank the high-level PRO categories according to what they feel is most important for patients with ESRD (1 = highest priority, 4 = lowest).[4] Results are illustrated in Table 3 and Figures 4 through 6.

TABLE 3: Numbers of All Survey Respondents (n=50) Ranking Each High-Level PRO Category #1

	Patient Experience	HRQOL	Health Behaviors	Symptoms
All Respondents (n=50)	14	**23**	4	9
Members + Steering Committee (n=31)	9	12	4	6
Patients (n=19)	5	11	0	3

FIGURE 4: Percentage of All Survey Respondents (n=50) Ranking Each PRO Category #1

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[4] Survey respondents who were also interviewed were not reminded of their previously-noted priority.

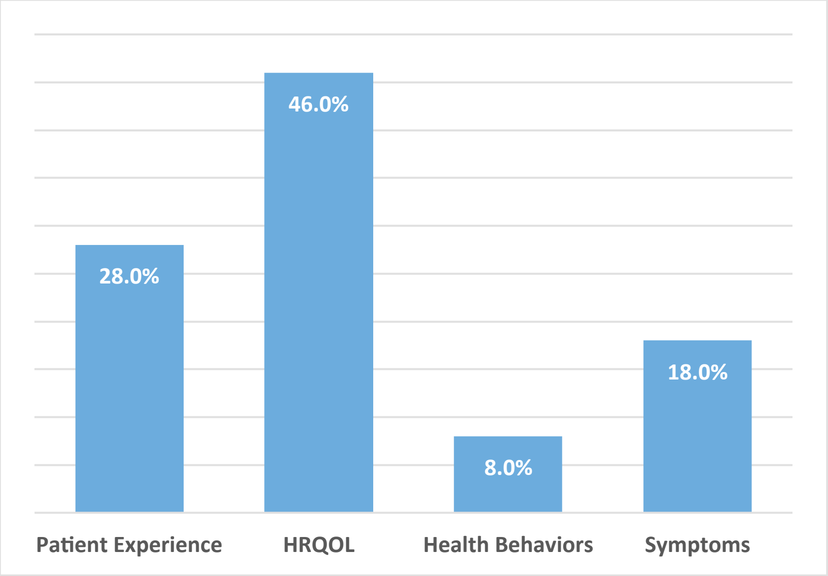


FIGURE 5: Percentage of Member/Steering Committee Survey Respondents (n=31) Ranking Each PRO Category #1

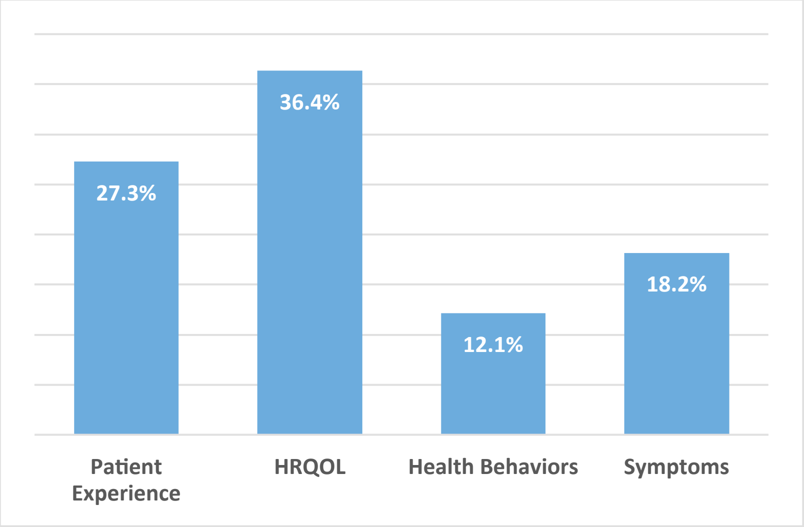
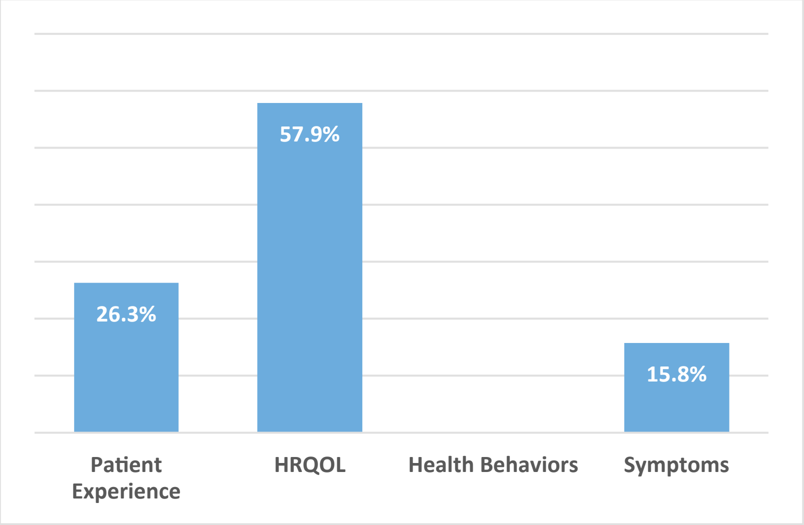


FIGURE 6: Percentage of Patient Survey Respondents (n=19) Ranking Each PRO Category #1



EXAMINATION OF DIFFERENCES BETWEEN INTERVIEW AND SURVEY RESPONSES

Forty-two individuals who participated in the interviews also completed the surveys (80.8% overlap). As displayed above, however, the prioritization rankings between the two modalities were not congruent: 15 of the 42 (35.7%) modified their #1 ranking from that which they named in the interview, with a net effect of a reversal of the two top priorities from *Patient Experience with Care* in the interviews to *HRQOL* in the survey. Table 4 presents the numbers of members and patients who revised their top priority in the survey.

TABLE 4: Interview/Survey Incongruence

	All	Members + Steering Committee	Patients
Total Interviewed + Surveyed	42	26	16
Total with Discrepancy	**15 (35.7%)**	**10 (38.5%)**	**5 (31.5%)**
Patient Experience→HRQOL	6	3	3
Patient Experience→Symptoms	4	2	2
HRQOL→Patient Experience	1	1	0
HRQOL→Symptoms	1	1	0
Health Behaviors→HRQOL	1	1	0
Health Behaviors→Symptoms	1	1	0
Symptoms→Health Behaviors	1	1	0

Additionally: 3 interviewees (2 members, 1 patient) who had no opinion on a top priority later prioritized *HRQOL* in the survey; 3 survey respondents (2 members, 1 patient) who were not interviewed but who completed the survey ranked *HRQOL* as their highest priority, and another 3 (2 members, 1 patient) who were surveyed but not interviewed ranked *Patient Experience* #1.

The net result was a loss of 6 individuals prioritizing *Patient Experience* and a gain of 11 for *HRQOL* in the survey, as compared to the interviews. Table 5 and Figures 7 and 8 illustrate how these shifts impacted the percentages of members and patients ranking *Patient Experience* and *HRQOL* as #1 in the interviews compared to the surveys.

TABLE 5: Numbers Ranking *Patient Experience* and *HRQOL* #1 in Interviews and Survey

	Patient Experience	HRQOL
Patient Interviewees (n=21)[5]	11 (52.4%)	7 (33.3%)
Patient Survey Respondents (n=21)	6 (28.6%)	12 (57.1%)
Member Interviewees (n=24)	10 (41.7%)	6 (25.0%)
Member Survey Respondents (n=25)[6]	8 (32.0%)	10 (40.0%)

FIGURE 7: Numbers Ranking *Patient Experience* and *HRQOL* #1 in Interviews and Survey[7,8]

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[5] For the remainder of the analyses, the patient subgroup includes responses from the two KCQA member organizations who also are patients, such that n=21 for both the interviews and survey.

[6] For the remainder of the analyses, the KCQA members subgroup excludes responses from the six Steering Committee members who are not also the member representative for their organization, such that n=25.

[7] All patient analyses displayed in this document include only patient interviewees/survey respondents; individuals from patient organizations who were not, themselves, patients, are not included in this cohort. NOTE: The patient subgroup also was analyzed with the addition of responses from KCQA's patient organization representatives who were not also patients, with no appreciable change in priorities/rankings.

[8] As previously noted, "Members" analyses limit input to that from one individual per KCQA member organization.

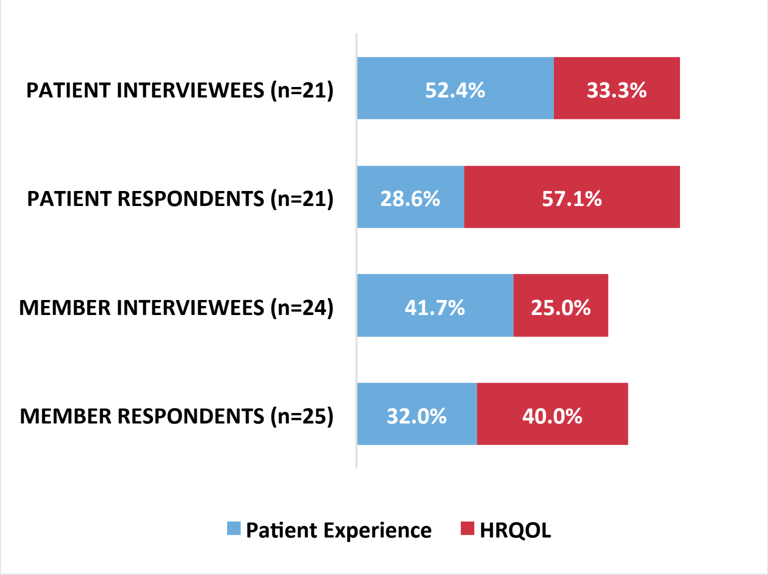


FIGURE 8: Percentage Ranking *Patient Experience* and *HRQOL* #1 by Survey Subgroup

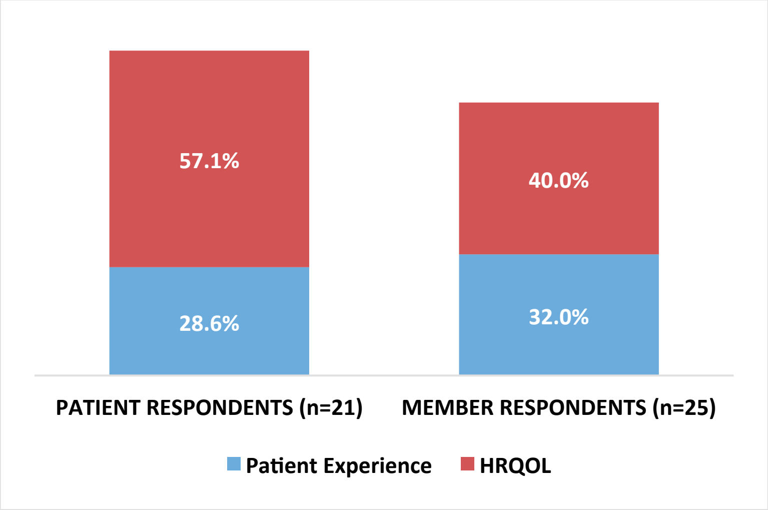


Table 6 summarizes the number of all survey respondents (n=50) ranking each high-level PRO category as #1, 2, 3, and 4, and Figure 9 shows the resulting mean rankings, medians, and modes for each category (where lower values [closer to 1] = higher priority).

TABLE 6: Numbers Ranking Each High-Level Category #1-4, All Survey Respondents (n=50)

Ranking	Patient Experience	HRQOL	Health Behaviors	Symptoms
#1	14 (28%)	23 (46%)	4 (8%)	9 (18%)
#2	15	9	7	19
#3	15	16	8	11
#4	6	2	31	11

FIGURE 9: Mean Ranking of High-Level Categories, All Survey Respondents (n=50)

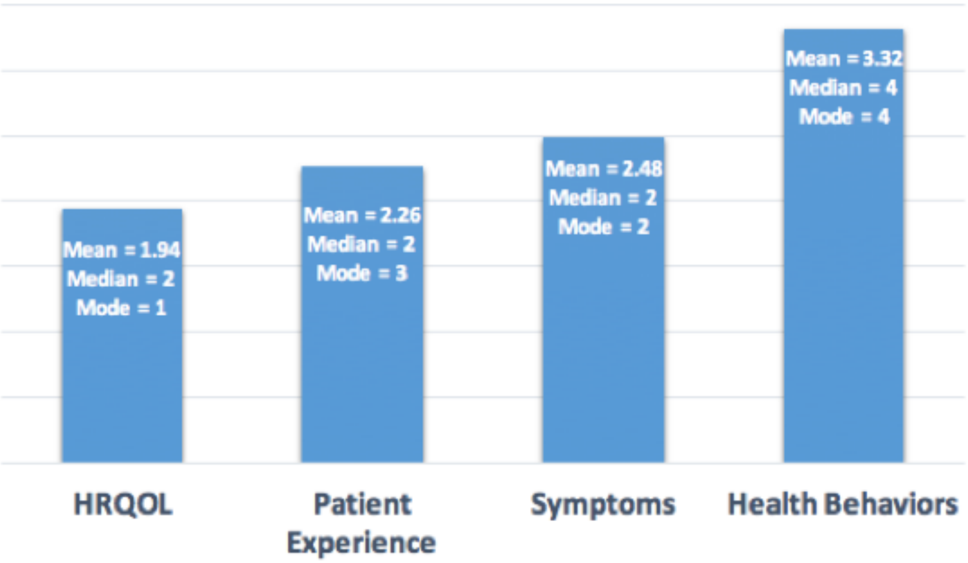
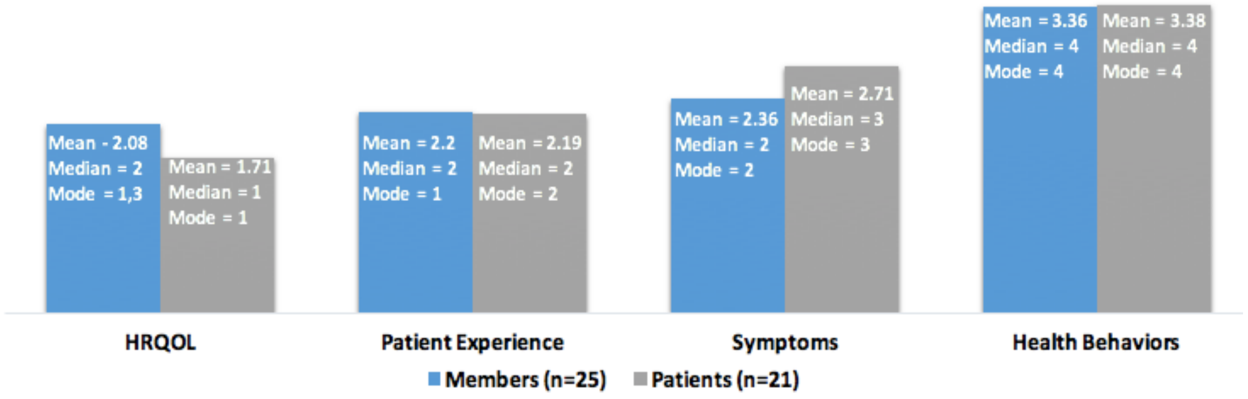


Table 7 summarizes the number ranking each PRO category #s 1-4 by respondent subgroup, and Figure 10 shows the resulting mean rankings, medians, and modes for each category.

TABLE 7: Numbers Ranking Each Category #1-4 by Survey Respondent Subgroup

Ranking	PATIENT EXPERIENCE		HRQOL		HEALTH BEHAVIORS		SYMPTOMS	
	Members (n=25)	Patients (n=21)	Members	Patients	Members	Patients	Members	Patients
#1	**8 (32%)**	**6 (28.6%)**	**10 (40%)**	**12 (57.1%)**	3	0	4	3
#2	7	7	4	4	1	5	13	5
#3	7	6	10	4	5	3	3	8
#4	3	2	1	1	16	13	5	5

FIGURE 10: Mean Ranking of PRO Categories by Survey Respondent Subgroup (lower value=higher priority)



Finally, Figures 11 through 13 demonstrate the percentages ranking each high-level category #1, 2, 3, and 4 for all survey respondents (Figure 11) and for each subgroup (Figures 12 and 13).

FIGURE 11: Percentages of High-Level PRO Categories Rankings, All Respondents (n=50)

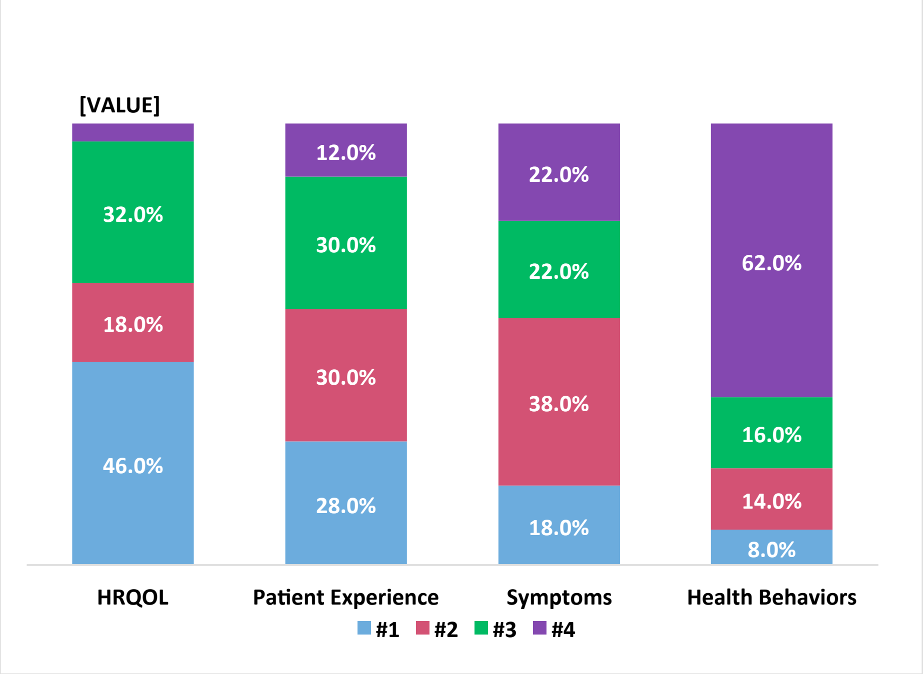


FIGURE 12: Percentages of High-Level Categories Rankings, Member Respondents (n=25)

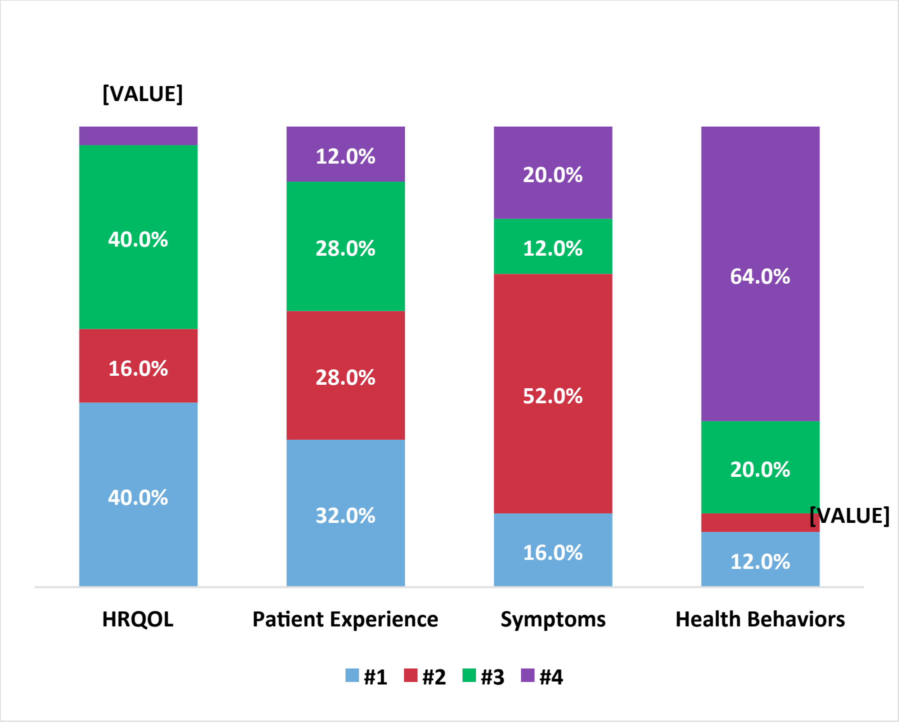
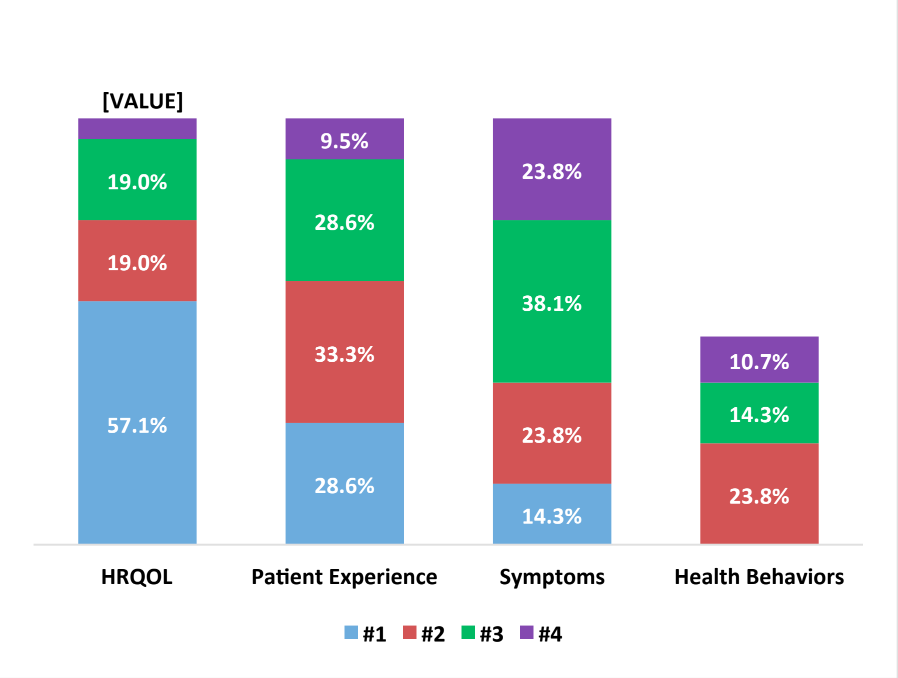


FIGURE 13: Percentages of High-Level Categories Rankings, Patient Respondents (n=21)



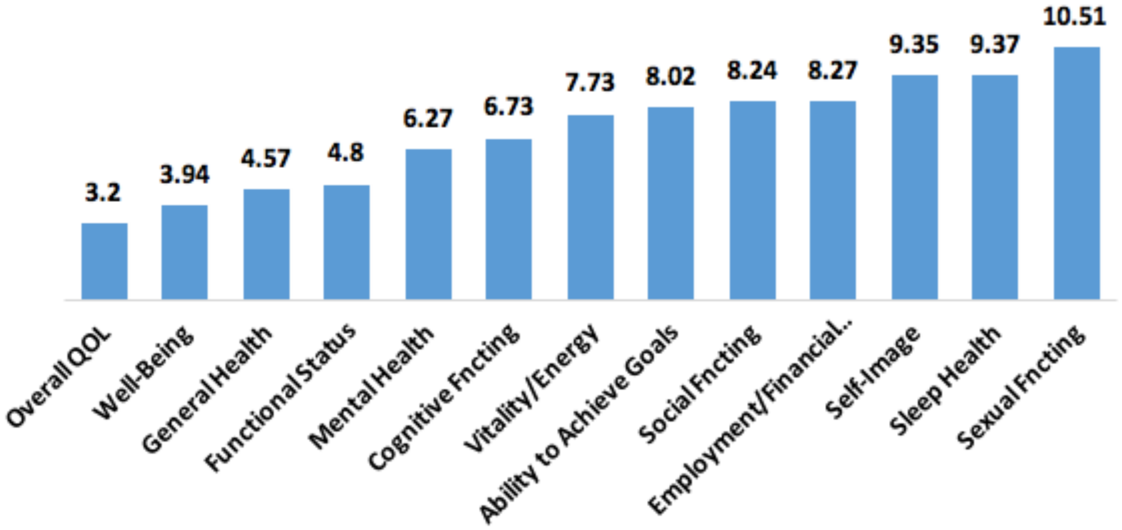
SUBCATEGORIES RANKINGS

Per the draft framework outline, each of the four major categories had additional domains/subcategories. For the surveymonkey prioritization, respondents were asked to rank order these subcategories.

HRQOL Subcategories

Survey respondents were asked to rank the 13 *HRQOL* subcategories, with 1 being the highest priority and 13 the lowest, according to what they feel is most important for patients with ESRD. Ranking of the subcategories across all respondents is illustrated in Figure 14.

FIGURE 14: Mean Ranking of *HRQOL* Subcategories, All Respondents (n=49)[9] (lower value=higher priority)



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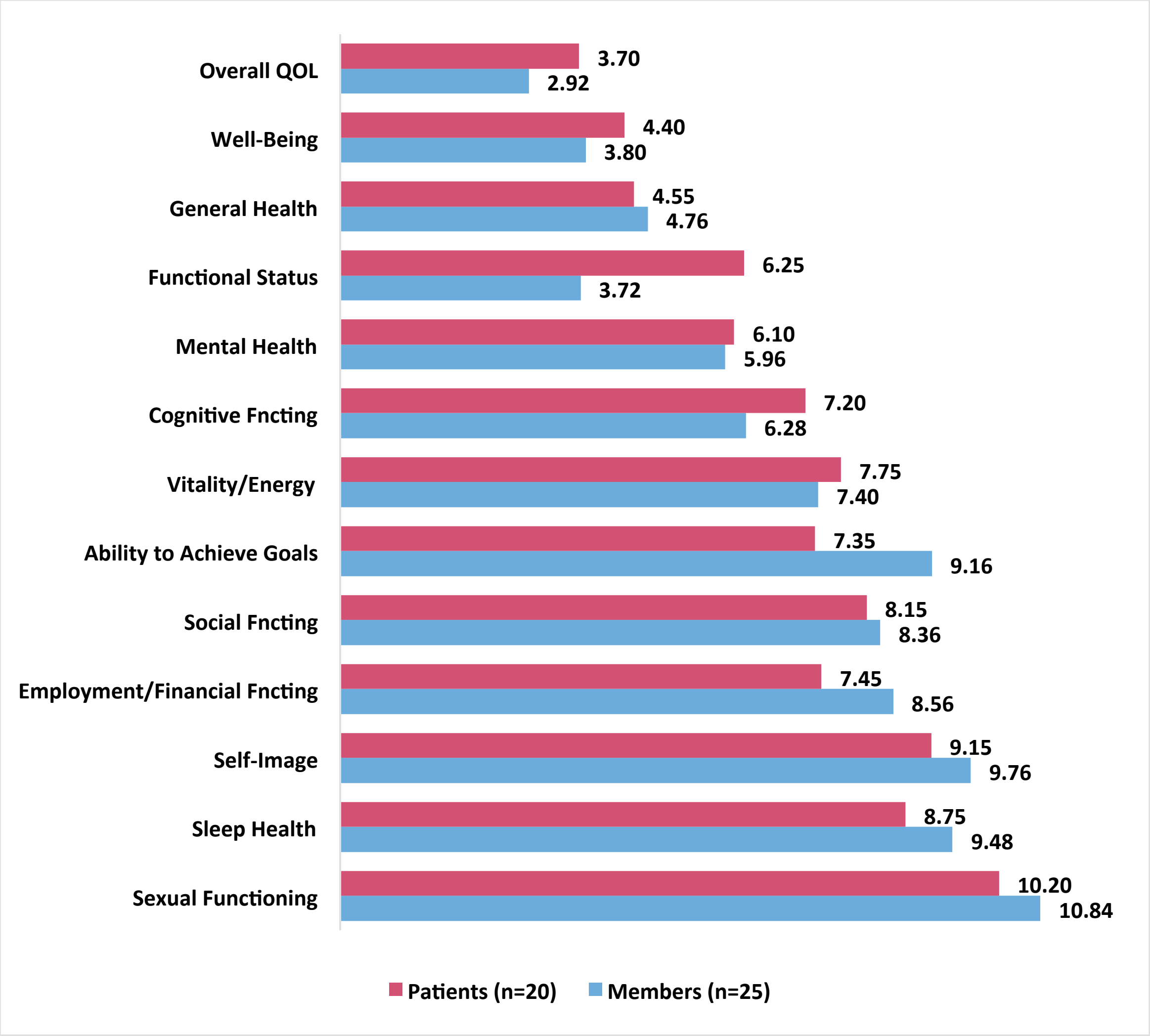
[9] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *HRQOL* "All Respondents" subcategories analysis and n=20 for the patient subgroup *HRQOL* analysis.

This ranking was generally consistent across both survey subgroups, with *Overall QOL* being the top priority. Differences did exist, however, with patients placing a higher priority on mental health and a lower priority on functional status as compared to KCQA members.

TABLE 8: Ranking of *HRQOL* Subcategories by Survey Group

RANKING	All Respondents (n=49)	Members (n=25)	Patients (n=20)
#1	Overall QOL	Overall QOL	Overall QOL
#2	Well-Being	Functional Status	Well-Being
#3	General Health	Well-Being	General Health
#4	Functional Status	General Health	Mental Health
#5	Mental Health	Mental Health	Functional Status
#6	Mental (Cognitive) Functioning	Mental (Cognitive) Functioning	Mental (Cognitive) Functioning
#7	Vitality/Energy	Vitality/Energy	Ability to Achieve Goals
#8	Ability to Achieve Goals	Social Functioning	Vitality/Energy
#9	Social Functioning	Employment/Financial Functioning	Employment/Financial Functioning
#10	Employment/Financial Functioning	Sleep Health	Social Functioning
#11	Sleep Health	Ability to Achieve Goals	Sleep Health
#12	Self-Image	Self-Image	Self-Image
#13	Sexual Functioning	Sexual Functioning	Sexual Functioning

FIGURE 15: Mean Ranking of *HRQOL* Subcategories by Respondent Subgroup (lower values [closer to 1] = higher priority)



Patient Experience with Care Subcategories

Respondents were asked to rank the 4 *Patient Experience* subcategories, with 1 being the highest and 4 the lowest priority. As illustrated in Figures 16 and 17 and Table 9, the rankings were largely consistent across the two groups with the notable exception of a reversal of the top priority. Patients place a higher priority on *Communication* and KCQA members on *Care Received*.

FIGURE 16: Mean Ranking, *Patient Experience* Subcategories, All Respondents (n=50)

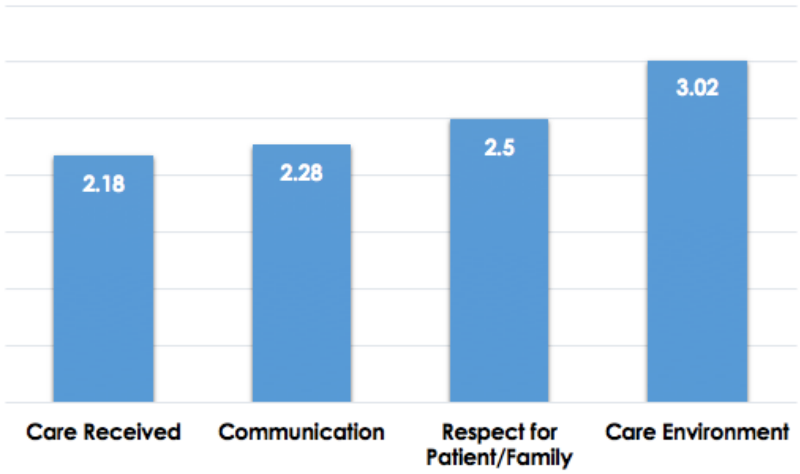
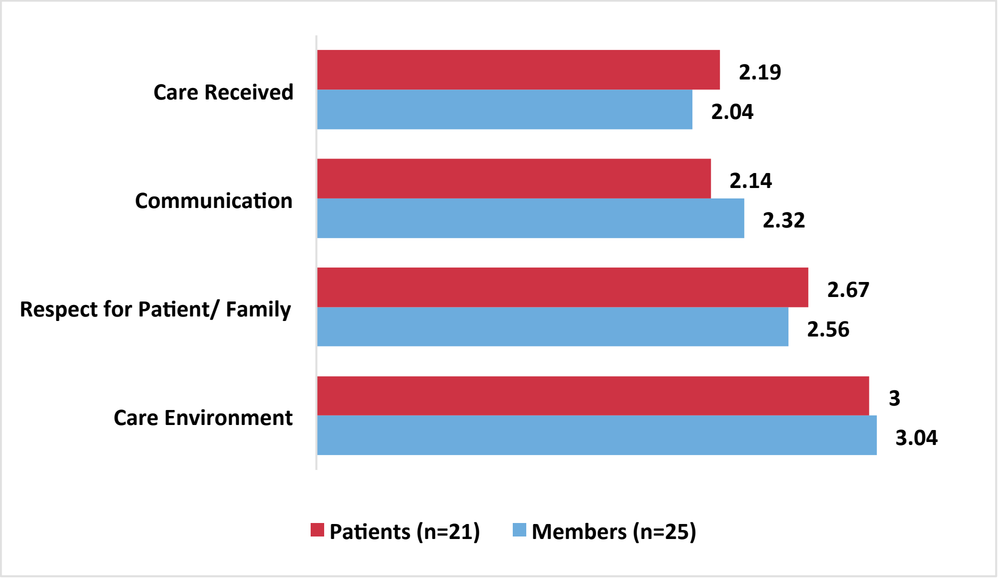


TABLE 9: Ranking of *Patient Experience* Subcategories by Survey Group

RANKING	All Respondents (n=50)	Members (n=25)	Patients (n=21)
#1	Care Received	Care Received	Communication
#2	Communication	Communication	Care Received
#3	Respect for Patient/Family	Respect for Patient/Family	Respect for Patient/Family
#4	Care Environment	Care Environment	Care Environment

FIGURE 17: Mean Ranking of *Patient Experience* Subcategories by Respondent Subgroup (lower values = higher priority)



Symptoms Subcategories

Respondents were asked to rank the 4 identified Symptoms subcategories, with 1 being the highest priority and 4 the lowest. Again, as illustrated in Figures 18 and 19 and Table 10, rankings were generally consistent across the two groups, except patients prioritize *Cognitive Symptoms* (#3) over *Medication and Treatment Side Effects* (#4) and KCQA members reverse this ranking.

FIGURE 18: Mean Ranking of *Symptoms* Subcategories, All Respondents (n=49)[10] (lower value=higher priority)

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[10] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *Symptoms* "All Respondents" subcategories analysis and n=20 for the patient subgroup *Symptoms* analysis.

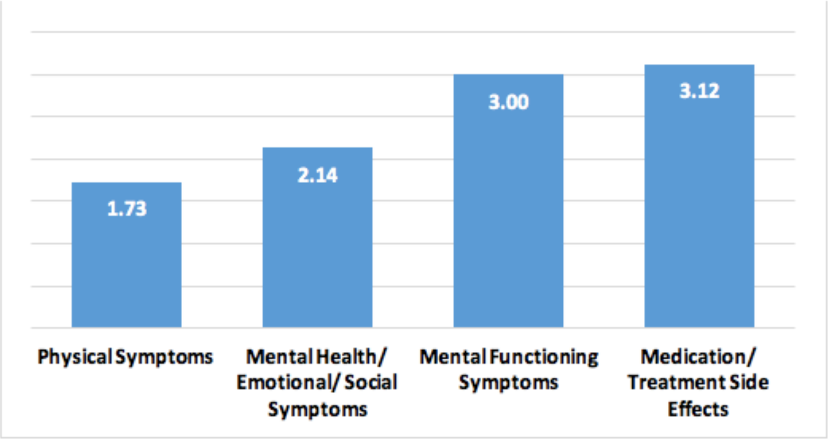
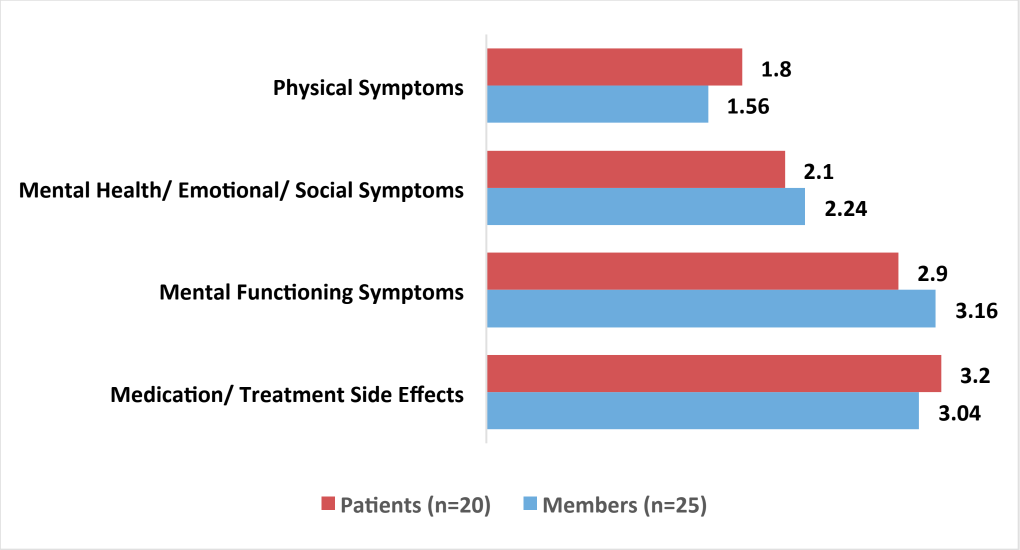


TABLE 10: Ranking of *Symptoms* Subcategories by Survey Group

RANKING	All Respondents (n=49)	Members (n=25)	Patients (n=20)
#1	Physical Symptoms	Physical Symptoms	Physical Symptoms
#2	Mental/Social/Emotion Symptoms	Mental/Social/Emotion Symptoms	Mental/Social/Emotion Symptoms
#3	Cognitive Symptoms	Medication/Treatment Side Effects	Cognitive Symptoms
#4	Medication/Treatment Side Effects	Cognitive Symptoms	Medication/Treatment Side Effects

FIGURE 19: Mean Ranking of *Symptoms* Subcategories by Respondent Subgroup (lower values = higher priority)



Health Behaviors Subcategories

Finally, survey respondents were asked to rank the 3 identified *Health Behaviors* subcategories, with 1 being the highest priority and 3 the lowest. As shown in Figures 20 and 21 and Table 11, rankings were consistent across the two survey groups.

FIGURE 20: Mean Ranking of *Health Behaviors* Subcategories, All Respondents (n=49)[11] (lower value=higher priority)

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[11] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *Health Behaviors* "All Respondents" subcategories analysis and n=20 for the patient subgroup *Health Behaviors* analysis.

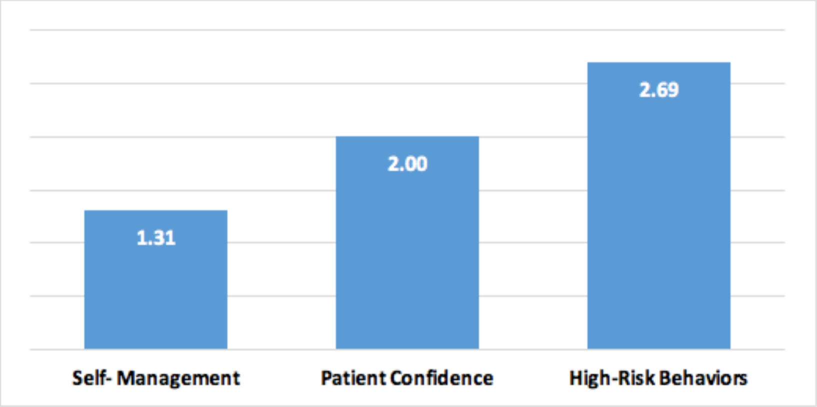
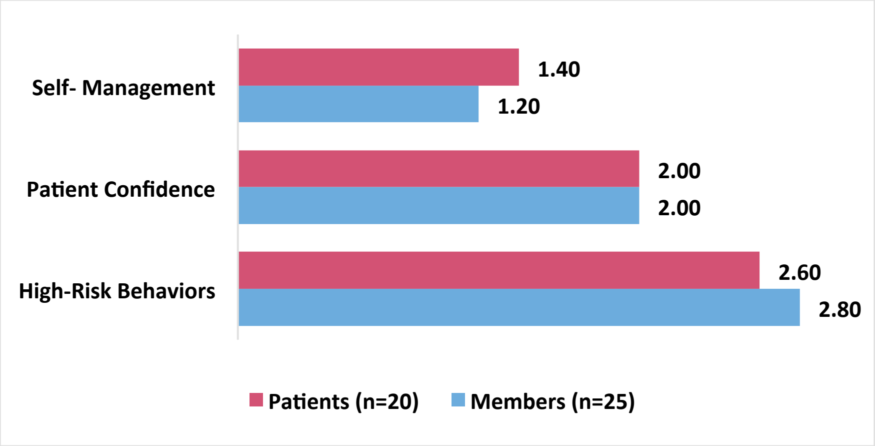


TABLE 11: Ranking of *Health Behaviors* Subcategories by Survey Group

RANKING	All Respondents (n=49)	Members (n=25)	Patients (n=20)
#1	Self Management	Self Management	Self Management
#2	Patient Confidence	Patient Confidence	Patient Confidence
#3	High-Risk Behaviors	High-Risk Behaviors	High-Risk Behaviors

FIGURE 21: Mean Ranking of *Health Behaviors* Subcategories by Respondent Subgroup (lower values = higher priority)



SURVEY RESPONDENT COMMENTS

Survey respondents were provided the opportunity to include comments for both the high-level categories and subcategories. All comments received are reported verbatim in Tables 12 through 16.

TABLE 12: High-Level Categories Comments

RESPONDENT CATEGORY	COMMENT
Patient	Quality of life is key to helping patients live with kidney disease.
Patient	As a dialysis patient, if I can't afford my medication, or am too tired to get out of bed, or stressed that I am becoming too big of a burden on my family, the rest doesn't matter one bit to me. Secondly, if I am not being treated with respect in a clean environment at the dialysis center then what makes a healthcare team think that I would have respect for myself and see the necessity for a clean environment at home?
Patient	First priority should always be the health of patients.
Patient	I believe the patient's experience with their care affects the other categories.
Patient	My treatments in center have been a positive experience when all parties are actively engaging in my care.
Patient	Patient trust in care-givers is very important, but in the end, I believe patients must feel as normal and productive as possible and that can only be accomplished if patient and providers are on the same page.

RESPONDENT CATEGORY	COMMENT
Patient	They are all extremely significant; however, it is necessary to focus equally on how to improve patient outcomes for each category.
Patient	I think these can be combined more. They tend to overlap. For example, symptom burden might affect my quality-of-life.
Patient	Staff at units need to be very well trained. It is more than just putting a patient on and taking a patient off. Staff need to be knowledgeable in all areas. Such as venous, arterial pressures, individual blood pressures and have the ability to detect problems with a patient's access. Staff need to be diligent in patient care. Often patients are not checked on during their run unless the alarms go off. Patients are individuals and need to treated as such.
Patient	I feel these are all equally important, but if improved in specific order, you will have a better outcome with the next high level PRO category. That is what I thought about when prioritizing this section.
Patient	Complications include blood pressure fluctuations, seizures, and hypoglycemia.
Patient	I believe when you have a high quality of life which is reinforced by the care given, symptoms and health related quality of life will improve.
Patient	I think one needs to know prior QOL and health behaviors before any current data can be validated.
Patient/ Member	Focusing on how a patient feels after a treatment will improve quality-of-life.
Member	I do not understand why Health Behaviors are categorized together with these other patient reported outcomes, apart from the fact that we collect information about them by asking about them. I don't think that they're particularly patient-centered. Health behaviors are clearly very important in kidney failure treatment: fluid intake, dietary phosphorus, use and timing of medications, smoking, exercise, alcohol and recreational drug use are examples. I would be very interested in doing research about these, but I don't know how I would use measurement of them now to improve care or to assess its quality.
Member	I have answered generally; however, my answers may vary depending on the perspective and purpose of measurement. Although I answered based on general priorities, I think there are also gaps in the tools available to measure the most important areas.
Member	The National Kidney Foundation believes that KCQA prioritization for Patient Reported Outcome domains should primarily rely on what is most meaningful to patients. Our prioritization was informed by our past surveys and discussions with patients on how they judge the quality of care they receive and the ideal outcomes they want to experience.
Member	In our experience, patient-reported experience with care is highly subjective and variable depending on staffing and season. I find this information the least helpful in managing the unit from day to day. We use Quality-of-Life measures and burden-of-care as better metrics to manage specific patient care.
Member	Health-related quality-of-life is of course important (and to me seems to be a linked measure to disease burden). I placed it fourth only because it seems quite likely that as ESRD vintage progresses, disease burden also progresses. This likely impacts QOL measures and, therefore, understanding the impact of disease burden may help us more directly improve QOL measures.
Member	I believe that Health-Related Quality-of-Life encompasses the other categories in that if one has a high symptom burden, their health-related quality-of-life is poor; if one has a poor experience with care, their health-related quality-of-life is poor. I don't know that I really understand health behaviors sufficiently.
Member	Improvement and relief of symptoms appears to be a foundational requirement for the other three categories.
Member	HRQOL really seems to embody the key issue here. And symptoms are what patients are most aware of.

TABLE 13: *HRQOL* Subcategories Comments

RESPONDENT CATEGORY	COMMENT
Patient	My choices for #1-7 are all pretty close in importance.
Patient	Overall health is important to everything else.
Patient	It was extremely difficult to rate these; so many of them are on the same level.
Patient	Overall well being and good health is more important to dialysis patients.
Patient	Very hard to rank this many items. Obviously it makes a tremendous difference in if the patient is eligible for a kidney and also what age a patient is. Also was the patient working when they entered ESRD.
Patient	Being able to have a good quality of life effects positive functioning in all areas. Helping patients have a quality life definitely includes assessment and FOLLOW THROUGH of mental health. Many times the above areas are surveyed but there is not follow through for help for the patient.

RESPONDENT CATEGORY	COMMENT
Patient	Subcategory 1, Overall Quality of Life, is too broad.
Patient	Life is a struggle…. Health and mental health declines with each year on dialysis.
Patient	All of the above I feel are of equal importance. It is very hard to assign most to least in these areas because they make up the total person. Making any of these appear to be of least importance takes away or diminishes the impacted person.
Patient/ Member	I find this very difficult to rank.
Member	I think that these are all really important, and for me, they are very closely ranked. The key is that we need DYNAMIC, INTERACTIVE tools which allow us to identify what is important for the individual, and hone in on that, and on the individual's level on that domain.
Member	I have difficulty supporting a metric that is more reflective of the patient's underlying illness than the performance of the dialysis clinic.
Member	In response to Congruence Between Desired and Achieved Goals. We are presuming this is a congruence between patients generated desired goals, not provider goals.
Member	My thoughts on these areas are probably quite different from patients' views, and, I believe would vary greatly from patient to patient.
Member	This one was difficult as there are several that overlap.
Member	For me I think this is a good example of why we need the pts to tell is what is important to them... I put general health last only because it seems to be embedded into many of the other areas .. or maybe I don't fully understand the specificity of the groupings.
Member	Many of these categories overlap and are highly individual.
Member	Curious to see how patients rank this. Wondering about the congruence with MD assessment.
Member	There is nothing here that is not important.

TABLE 14: *Patient Experience* Subcategories Comments

RESPONDENT CATEGORY	COMMENT
Patient	The level of care must be exemplary.
Patient	No one talks to anyone else anymore. I'm sick of having to relay every bit of information and waste 20 minutes every doctor's visit to every doctor explaining why or what another doctor did. Share your progress notes with one another! Cleanliness is important just as much as comfort. I see my nephrologist or her staff twice a month for an hour or longer each time, it should be comfortable.
Patient	Communication is my biggest priority.
Patient	Communication has always been my top priority. I believe that if you have good communication with your healthcare team, that shows respect, and it also improves the care received.
Patient	Its the day-in day-out care that the patient will remember. HIPAA rules are a down-side to dialysis care and clinic reality.
Patient	Care received should be outstanding. Care environment is important as is communication. Sitting in an uncomfortable dialysis chair for hours takes its toll and adds to patients' ailments.
Patient	Once again, if you have good communication, all other aspects can be readily addressed and improved upon.
Patient/ Member	Care has to be top priority. I don't understand how respect for family can be measured?
Member	We should be able to list more than one item as "most desired." The system above does not allow this.
Member	There's nothing wrong with being shabby, as long as you're clean.
Member	These are all equally important.
Member	Communication is always tops to me, care environment is a broad and mixed bucket (we can NEVER get the temperature of the facility right for everyone), but since SAFETY is included in this category it has to be high on the list.
Member	Again, I think care received encompasses the other factors; communication and respect for patient/family are intimately related so difficult for me to separate. If care environment encompasses the physical environment, it is less important to a point but if poor enough may become the most important factor. Depending on how its scope is defined, care environment could include treatment by the staff so it would then include the other factors listed.
Member	Difficult to categorize these items, as they seem to be ALL important. Care received seems to be a bare minimum.

TABLE 15: *Symptoms* Subcategories Comments

RESPONDENT CATEGORY	COMMENT
Patient	I really don't have issues with three of the items on this list, so it is difficult for me to rate them.
Patient	I think that the health/emotional/social symptoms have a great impact on a patient's functioning. Once

RESPONDENT CATEGORY	COMMENT
	these symptoms are under control, you can deal with other symptoms.
Patient	The ability to maintain an effective life style is highly important. Because of the stress and strain of kidney disease, it had become difficult to maintain employment and maintain a healthy life at the same time.
Patient	Physical will affect Mental and in turn the Emotional. Its a 3-legged stool that the individual must learn to balance.
Patient	Alleviating physical symptoms does wonders for patients' state-of-mind. Addressing mental health is a must, as it has a high potential to determine patients' well being and how they perceive their quality of life.
Patient	I feel very strongly that each of these symptoms are interconnected and impact one another. These are all important in terms of management of ones well-being and health.
Member	Some of the sub categories under the main categories don't appear to relate one another and had they been grouped differently our responses may have changed. For example, we did not believe that on average employment ranked as high as sleep disturbances or familial relationships for patients.
Member	I have difficulty supporting a metric that is more reflective of the patient's underlying illness than the performance of the dialysis clinic.
Member	Understanding the elements of mental and emotional help from the patient's perspective could be quite valuable and could help direct care. The obvious caveat is that every patient is an individual with separate needs and priorities and desires so learning how to collect AND USE aggregate data in a meaningful manner will be an important part of any robust PRO/PROM plan.
Member	Very individual.

TABLE 16: *Health Behaviors* Subcategories Comments

RESPONDENT CATEGORY	COMMENT
Patient	Education is key to improving overall health.
Patient	This was somewhat difficult for me. I do not smoke or drink or use drugs of any kind, except prescribed.
Patient	I think that the other high-risk behaviors should be prioritize first because it significantly relates to the other categories.
Patient	An educated patient has a much better chance of coping with their medical issues than a person uncaring and disengaged from the reality of their situation.
Patient	Patients should be provided the best resources and highly encouraged to become self managers. Patients who have high risk behaviors need to be consistently engaged in programs to help them. Patients who do not comply with treatments, etc. should be consistently engaged in conversations, programs to help them realize the damage they are doing to themselves. Patients who miss treatments are habitually late, etc. often have extra treatments due to missing scheduled treatments and take a chair that could be used for another patient should be made aware of their interference of treatments for others and realize there are consequences. Allowing this behavior creates a feeling of entitlement.
Patient	It he high-risk behaviors can be addressed through education and outlining each risk. Confidence and self management are related to how you learn, what you want to learn, and your ability to think critically about the illness. Being aware and making decisions that benefit you is important. Your confidence will grow with the more you know and act on your own behalf.
Patient	Self-management and confidence to manage illness are essential. Accomplishing these two aspects of care will definitely lower the high-risk behaviors portion.
Member	I don't view these as being reflective of a dialysis clinic's quality.
Member	Perceived self-efficacy is very interesting, and as it is developed, it may separate into several sub-categories. There are data that suggest that pts who BELIEVE they are knowledgeable and don't seek or accept help BUT in actually are not that well-schooled about their illness (despite their own independent assessments), actually have worse outcomes. I think this is an area where PROs and PROM s could be very helpful.
Member	High-risk behaviors are the most negative but may be most important to outcomes.
Member	Health literacy is critically important and may be something to consider here as it can influence patient activation and self management as well as perceive self-efficacy.