KCQA PATIENT REPORTED OUTCOMES INITIATIVE: INTERVIEWS AND SURVEY ANALYSIS

SUMMARY

In Cycles 1 and 2, the Kidney Care Quality Alliance (KCQA) focused on measure development, leading to NQF-endorsed measures in Fluid Management and Medication Management. For Cycle 3, KCQA has pursued an initiative to develop a framework identifying principles, domains and subdomains, and priorities related to patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome performance measures (PRO-PMs) for patients with ESRD. To date, KCQA has pursued this initiative through an environmental scan, development of a draft framework outline, semi-structured interviews, commissioning of expert papers, and an on-line prioritization survey. This document summarizes the interview and online survey results.

Interviewees responded well to the draft framework outline, with no major deletions or additions suggested. Results on prioritizing the categories and domains of the framework outline from the semi-structured interviews of 52 KCQA members, patient, and other experts and an online survey (n=50 respondents) differed with respect to the highest ranked priority. 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 two populations did not overlap entirely, shifting 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, however, of the means and relative rankings by KCQA member and patient groups do provide insights into differences in emphasis by the two groups, even though the overall rankings appear similar.

Examining the subcategory domains within both *Health-Related Quality of Life* and *Patient Experience with Care* also identified small differences in priorities between KCQA members and patients. From the survey, patients place a greater priority on *Mental Health* and *Communication* for these two categories, respectively, than did KCQA members.

Based on the interviews and survey results, we recommend some modest changes to the draft framework outline, although overall it was viewed as comprehensive and appropriate for describing PRO measurement for patients with ESRD.

METHODOLOGY

From late October 2016 through early January 2017, we conducted 52 semi-structured interviews to receive KCQA member, patient, and other expert feedback on a draft outline framework and to identify preliminary priorities for PROs (Appendix A), which had been informed by an environmental scan that identified 139 PROMs and PRO-PMs and six PROM-related registries/platforms; the vast majority were not ESRD-specific.

In January 2017, KCQA members, patients, and the Steering Committee also were surveyed via surveymonkey for a formal ranking and prioritization of the categories and domains of the draft PRO framework outline. We received 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 Steering Committee members,[1] and 16 were patients.
- The American Kidney Fund, Dialysis Patient Citizens, the 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.

THEMES FROM INTERVIEWS AND SURVEY

The interviews and survey responses were excellent and point to refinements in the draft framework outline, which are discussed in the final section of this document. In addition to these proposed refinements, several themes emerged from the interviews and surveys:

1. Appropriateness of the high-level PRO Categories (*Health-related Quality of Life [HRQOL]*, *Symptoms*,[2] *Patient Experience with Care*, and *Health Behaviors*);
2. Priorities for PRO measurement;
3. Barriers to collecting meaningful PRO information;
4. Experience with ICH CAHPS and KDQOL;
5. Aspect of care that could be most improved through PROs; and
6. 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.

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

[2] The initial draft outline framework derived from the National Quality Forum's (NQF) categorization of PROs: *HRQOL*, *Symptoms and Symptom Burden*, *Patient Experience with Care*, and *Health Behaviors*. Although the draft framework outline recognized and acknowledged the overlap between *HRQOL* and *Symptoms and Symptom Burden*, during the course of the interviews and through the survey comments, it became clear that a disconnect persisted on the differentiation between these two categories, even though the subcategory domains had significant distinction. To bring greater clarity to the draft framework outline, we propose renaming "*Symptoms and Symptom Burden*" to "*Symptoms*." This emphasizes that PRO measurement in this category should focus on symptoms per se, whereas the impact of symptoms on *HRQOL* may manifest in multitudes of ways (and differently in different people). Throughout this document, we have adopted the proposed terminology of "*Symptoms*."

1. Appropriateness of Identified PRO Categories (*Patient Experience with Care, HRQOL, Symptoms*, and *Health Behaviors*), Domains, and Subdomains.

Overall input on the draft outline framework was obtained through the interviews:

- The identified PRO categories, domains, and subdomains were viewed as comprehensive and generally appropriate by all interviewees.
- 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.
- A number of interviewees and survey respondents noted there is some overlap between the categories and suggested the outline could be streamlined by eliminating such repetitions. (Small changes in the draft outline framework were made as a result of the interviews and carried into the survey. Additionally, as noted elsewhere, we propose to recast *Symptoms and Symptom Burden* to *Symptoms* based on the interviews and surveymonkey comments.)

2. Priorities for ESRD PRO Measurement

Information from the interviews and surveys was analyzed in three groups: All interviewees/respondents, KCQA members only, and patients only.[3] Interviewees were asked for their preliminary input[4] 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).[5]

Highest Priority, Interviews vs. Survey

Notably, 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.

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[3] 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.

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

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

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

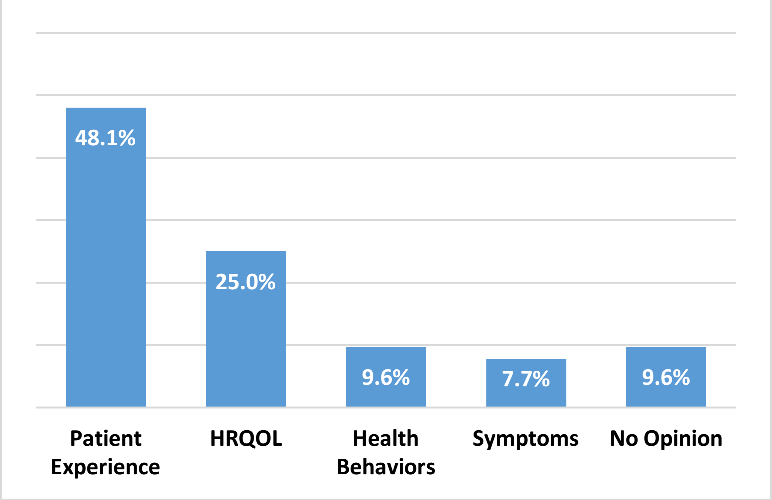
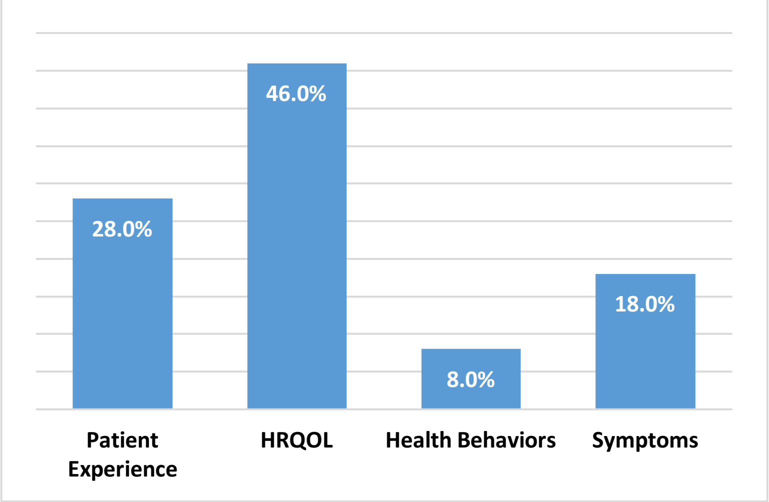


FIGURE 2: Percentage of All Survey Respondents (n=50) Ranking Each PRO Category #1



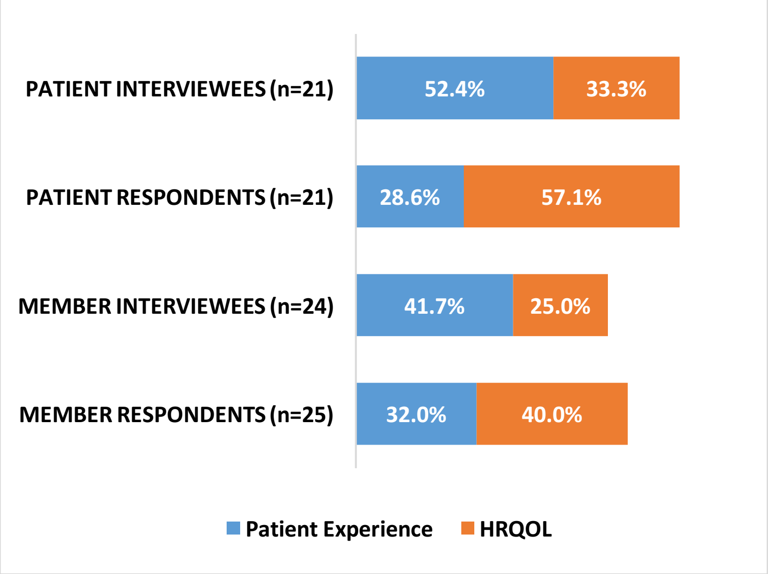
Analysis of Interview/Survey Incongruence

A detailed comparison of the interview and survey responses revealed how the shift towards *HRQOL* occurred. Specifically, 15 interviewees changed their highest priority when subsequently completing the survey, as follows:

- 6 (3 members, 3 patients) changed their top priority from *Patient Experience* to *HRQOL;*
- 1 member changed from *HRQOL* to *Patient Experience;*
- 1 member swapped *HRQOL* for *Symptoms;*
- 4 (2 members, 2 patients) changed from *Patient Experience* to *Symptoms;*
- 1 member changed from *Health Behaviors* to *HRQOL;*
- 3 (2 members and 1 patient) with no opinion in the interview ranked *HRQOL* #1 in the survey; and
- 1 member changed from *Health Behaviors* to *Symptoms* and another (member) did the opposite.

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

FIGURE 3: Patients and Members Ranking *Patient Experience* and *HRQOL* #1 in the Interviews and Survey[6,7]



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.

<u>Understanding the Incongruence</u>

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 potentially provides some information.[8]

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

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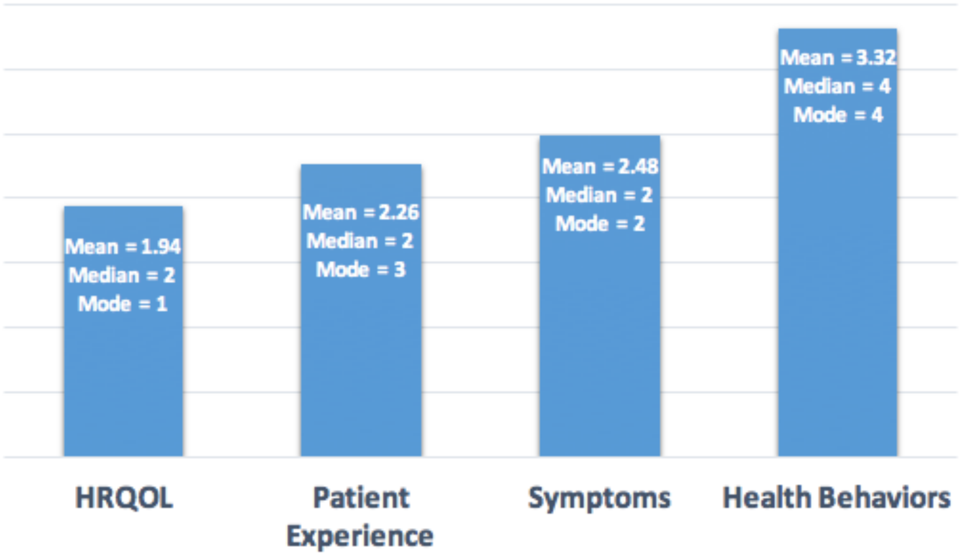
[6] All patient analyses displayed in this document include only patient interviewees/survey respondents; individuals from patient organizations who were not, themselves, patients, are not included in this cohort for these analyses. NOTE: The patient subgroup also was analyzed with the addition of responses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

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

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

the survey to prioritize one above the other; during the interview, respondents were asked only for their top category. As shown in Figure 4, the mean survey ranking for *HRQOL* and *Patient Experience* across all respondents was 1.94 and 2.26, respectively (where lower values [i.e., closer to 1] are more highly prioritized).

FIGURE 4: Mean Ranking of High-Level Categories, All Survey Respondents (n=50)



*Friedman Chi-Square = 31.46 with df = 3; p<0.0001.[9]

A similarly narrow margin exists between the means for *Patient Experience* and *Symptoms*. As can be seen from the modes in Figure 4, more respondents ranked *Symptoms* as their second highest priority than *Patient Experience*; however, the higher percentage ranking *Patient Experience* #1 placed it ahead of *Symptoms* overall. This is also demonstrated in Figures 7-9.

An analysis of the survey respondent subgroups (Figure 5) indicates that patients placed a somewhat higher priority on *HRQOL* (mean ranking = 1.71) than KCQA members (mean ranking = 2.08), while the *Patient Experience* mean ranking for both subgroups was nearly identical at 2.19 and 2.20, respectively. But again, the modes provide additional insight into how the groups voted. Notably, as many KCQA member respondents ranked *HRQOL* #3 as #1 (40% each, also displayed in Figure 8), 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.

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[9] Statistical significance was assessed using the Friedman Test, a non-parametric alternative to the one-way ANOVA with repeated measures used to test for differences between groups when the dependent variable (rank order) is ordinal (here, 1 through 4). The p value of <0.0001 indicates there is evidence to reject H_0 and conclude that there is a statistically significant difference between the mean ranks of the high-level PRO categories.

FIGURE 5: Mean Ranking of High-Level PRO Categories by Survey Respondent Subgroup (lower value=higher priority)

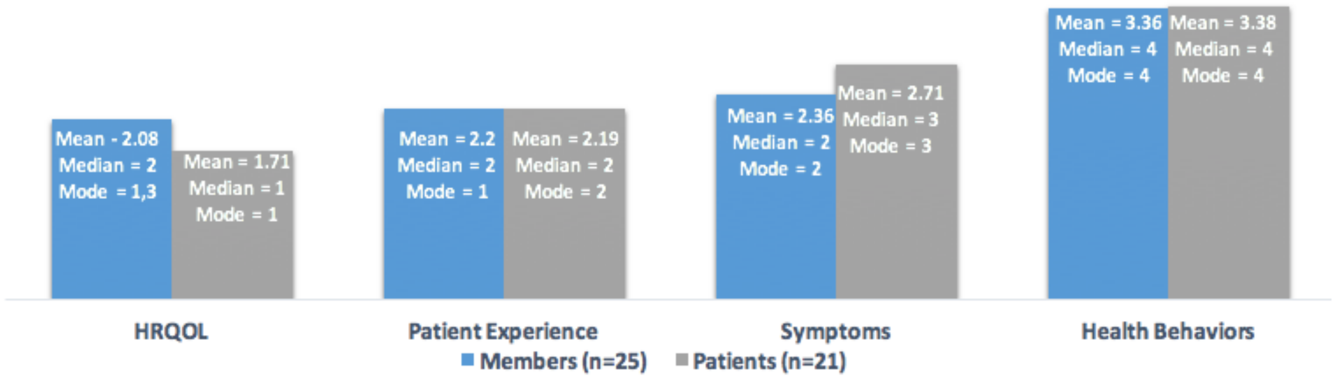
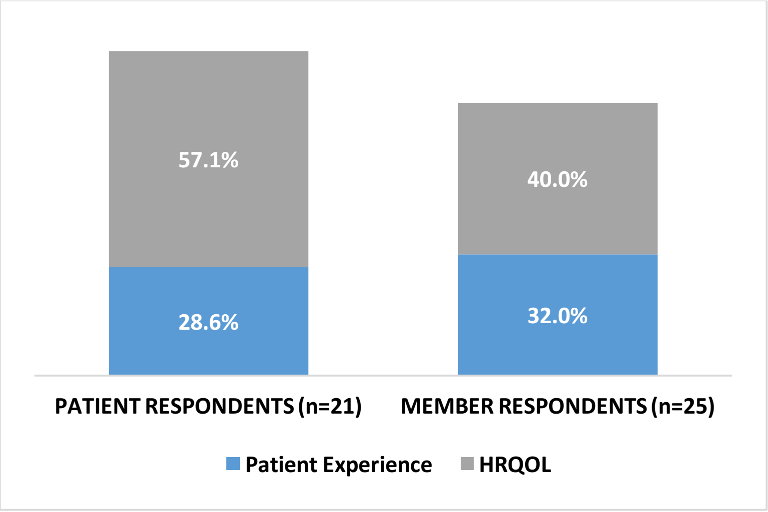


Figure 6 further elucidates the differences between the respondent subgroups. While *HRQOL* was the clear priority for patient respondents (57.1% ranked it as #1), the spread between *HRQOL* and *Patient Experience* was much narrower for members, with 40% prioritizing the former and 32% the latter.

FIGURE 6: Percentage Ranking *Patient Experience* and *HRQOL* #1 by Survey Subgroup



This finding is also reflected in an analysis of the percentage of survey respondents ranking each of the four high-level category numbers 1 through 4 (1 = highest priority, 4 = lowest). Figure 7, which demonstrates the rankings for all survey respondents, again clearly illustrates that 46% of respondents ranked *HRQOL* as #1 while only 28% did so for *Patient Experience* (also see Figure 2, page 2). However, it also reveals that *Patient Experience* was ranked #2 by substantially more individuals (30%) than was *HRQOL* (18%). Additionally, the *Symptoms* category was ranked #2 by more respondents (38%) than either *Patient Experience* or *HRQOL*, shedding light on the narrow margin between the three means illustrated in Figure 4.

FIGURE 7: Percentages of High-Level PRO Categories Rankings, All Respondents (n=50)

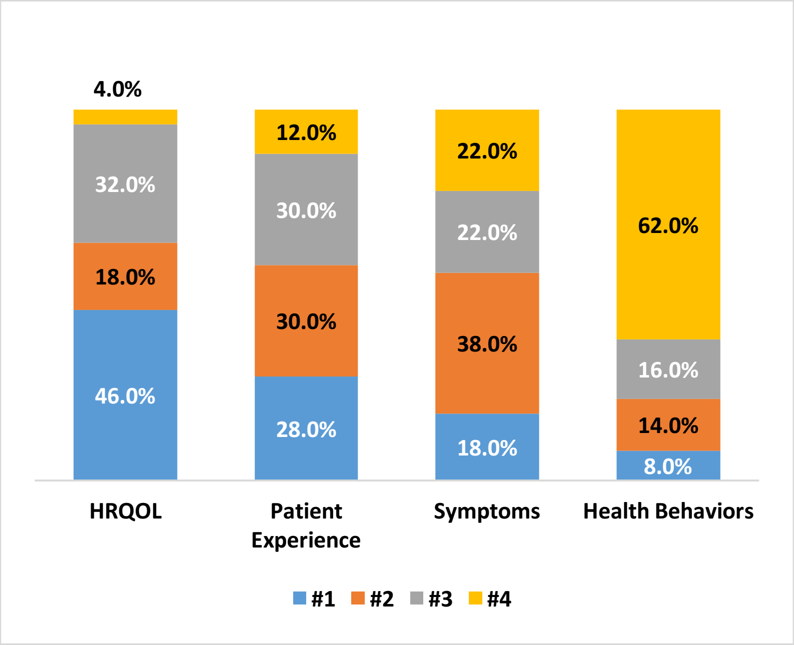
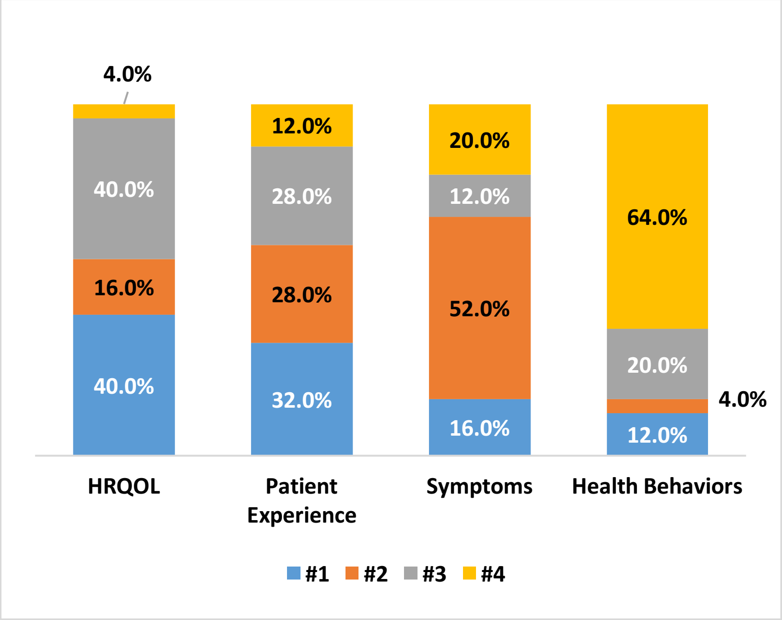


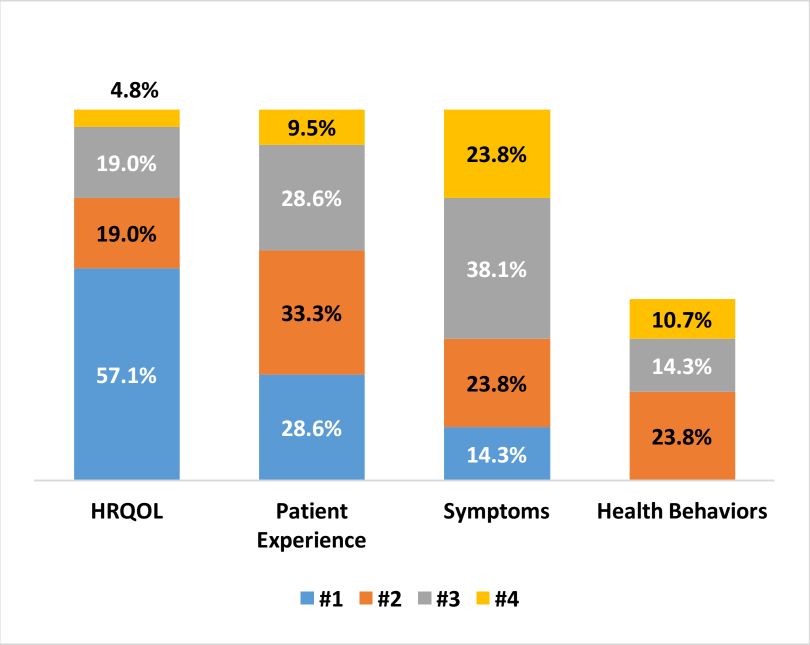
Figure 8 demonstrates the high-level categories rankings for the member respondent subgroup. Here we see an even greater portion that ranked *Symptoms* #2 (52%), again providing an explanation for the similar means between the three groups (Figure 4), despite the wide variation in the percentages identifying each as their top priority (Figure 2).

FIGURE 8: Percentages of High-Level Categories Rankings, Member Respondents (n=25)



Finally, Figure 9 presents the patient subgroup's rankings for the high-level categories, which suggest that patients place less focus on *Symptoms* as a priority for PRO measurement than do KCQA members.

FIGURE 9: Percentages of High-Level Categories Rankings, Patient Respondents (n=21)



Rationales for Prioritization

Interviewees were asked for their rationale for identifying X as their highest priority. Similarly, the survey provided space for respondents to provide commentary on their rankings. This section summarizes the overall rationales offered.

- ***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' QOL 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., QOL 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 QOL 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.

HRQOL and *Patient Experience* Subcategory Rankings

For this summary, we review the highest domain (i.e., primary subcategory) rankings for the top two high-level categories, *HRQOL* and *Patient Experience with Care*. Appendix B provides full data for all 13 domains under *HRQOL*, as well as the domain rankings for *Symptoms* and *Health Behaviors. Patient Experience with Care* only has four domains, so all are discussed in a following section.

- ***HRQOL:*** Survey respondents were asked to rank the 13 identified *HRQOL* subcategories according to what they feel is 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 10 illustrates the mean rankings for respondents' 4 highest HRQOL priorities.

FIGURE 10: Mean Ranking, Top 4 *HRQOL* Subcategories, All Respondents (n=49[10])

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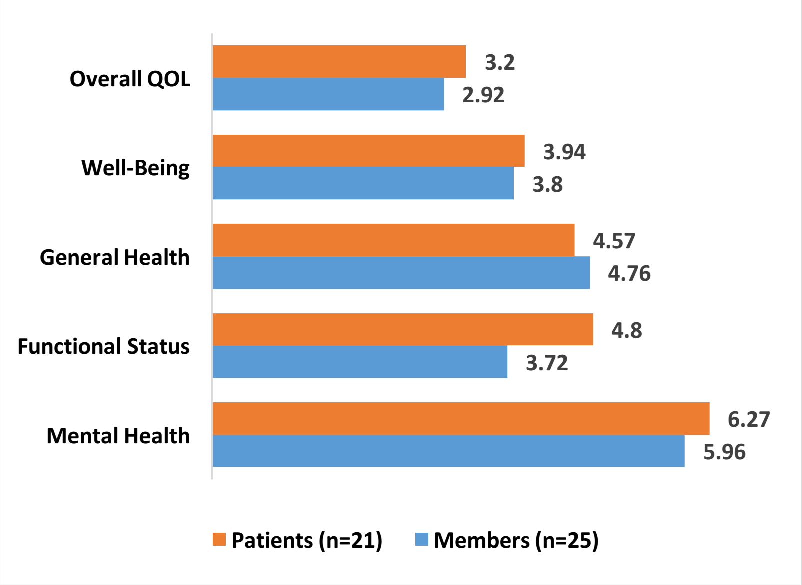
[10] One patient respondent only completed the high-level categories and the *Patient Experience* subcategories rankings, such that n=49 for the *HRQOL* "All Respondents" analysis and n=20 for the patient subgroup *HRQOL* analysis.

Table 1, demonstrates that these *HRQOL* 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. We note, however, that patients ranked *Mental Health* over *Functional Status*, such that the former replaced the latter in their Top 4 priorities.

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

RANKING	All Respondents	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 11: 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. Rankings again were consistent overall (Figure 12) and across the two respondent subgroups (Table 2 and Figure 13), except patients place a higher priority on *Communication* and KCQA members on *Care Received*.

FIGURE 12: Mean Ranking, *Patient Experience* Subcategories, All Respondents (n=50)

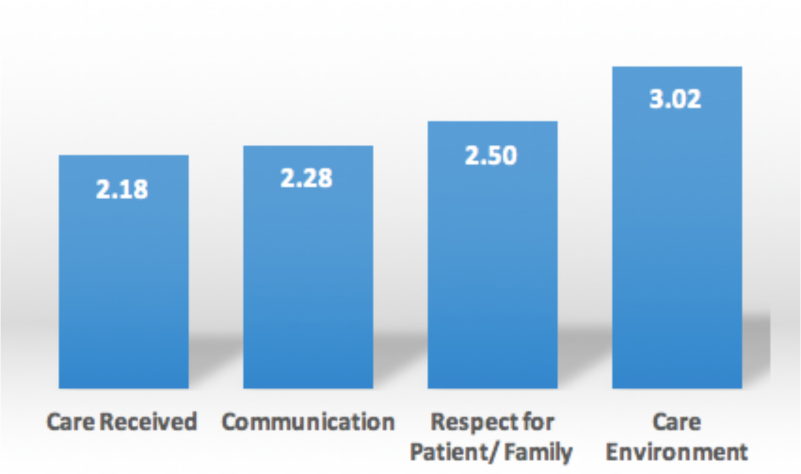
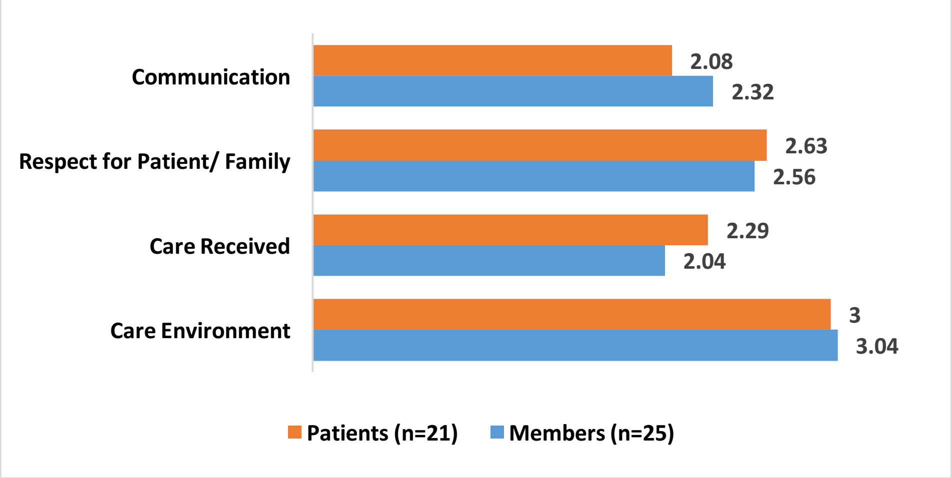


Table 2: Ranking of *Patient Experience* Subcategories by Survey Group

RANKING	All Respondents	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 13: Mean Ranking of *Patient Experience* Subcategories by Respondent Subgroup (lower values are more highly prioritized)



3. Barriers to Collecting Meaningful Patient-Reported Outcome Information

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

- Patients nearly universally identified patient survey fatigue as the 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%) 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 healthcare 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, 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.

4. Experience with ICH CAHPS and KDQOL

Input on the two widely used PRO instruments was obtained through the interviews:

- 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. 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 requirement, and that responses are not actually reviewed and 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. Some Steering Committee and KCQA members noted, however, that the survey was developed more than 20 years ago and was tested in a small group of patients in California; the survey could not be similarly validated in a larger, modern dialysis population. Moreover, it

was noted that the KDQOL has not been specifically tested or validated for use as a performance measure, and several interviewees noted that more effective instruments (e.g., PROMIS measures) exist. 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 survey to a performance metric.

5. Aspect of Care That Could Be Most Improved Through PRO Information

Information on the aspect of care that could be most improved through PROs was obtained through the interviews:

- The most common aspect of care that interviewees felt could be improved by PROs was the potential for improved patient experience with care—from addressing relatively simple issues, such as uncomfortable dialysis chairs and too-cold dialysis centers, to improving patient-provider communications by working to make the patient feel safe, respected, and heard.
- Interviewees also offered a wide variety of additional responses on which aspect of care could be most improved by PROs—e.g., timely identification and reduction of symptoms; recognition of individuals who need more intensive education to improve health behaviors and maximize patient activation; effective detection of patients with depression, cognitive dysfunction, or low functional status; and recognition of the need to return to providing dialysis as a personalized, professional service—rather than as a "utility"—to truly meet patients' needs.

6. Other Issues and Suggestions from Interviewees and Survey Respondents

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 methods, the following additional issues are noted:

- Nurses and technicians have very different roles and should be considered and evaluated separately in PRO measures; nurse practitioners should be specifically included in any description of "providers."
- Since it is a completely different experience for patients, home dialysis should be specifically addressed in any ESRD PRO-related work; there are few questions applicable to home dialysis in existing instruments and ICH CAHPS does not encompass them at all.
- 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?"
- Focusing on how a patient feels immediately after a treatment will improve quality-of-life.
- *Symptom Burden* should be eliminated as a distinct PRO category and instead be incorporated as a domain under *HRQOL*.
- Knowledge of prior QOL and health behaviors is required before measures in these areas can be validated.
- Fluid management and adequacy should somehow be addressed through PROs—either through the assessment of symptom burden or patient activation.

- Emphasis should be placed on questions addressing social and work functionality and interactions.
- PRO survey questions should be open-ended whenever feasible.
- While attendance to literacy level is important, questions should be asked in a manner that is not insulting to patients; "smiley-face" questions, in particular, were judged demeaning by one interviewee.
- 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.
- The potential for unintended consequences must be considered with PROs. For example, an issue for which a patient does not desire or expect any intervention might be identified through a survey (e.g., sexual dysfunction in an elderly patient). 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.
- Over the past several years, despite the substantial focus on patient empowerment, patient-centered care, and now patient-reported outcomes, the vast majority of patients interviewed expressed their perception is they are simply not heard, not respected, and not routinely included in decisions on their own care.

RECOMMENDED CHANGES TO DRAFT OUTLINE

As previously noted, the interviews and survey comments suggest a few refinements to the draft framework outline. We recommend the following revisions, which are reflected in the attached redlined PROM*s Domains Analysis Document* (Appendix C):

- Add advanced practice registered nurses to the list of relevant providers throughout the document.
- Include *Employment/Financial Functioning* as a distinct domain under *HRQOL*.
- Add *Other Mental Health Diagnoses* as a subdomain under the *Psychological/Emotional Functioning* domain in *HRQOL* and under the *Psychological/Emotional/Social Symptoms* domain in *Symptoms*.
- Include "fluid management goals" as an example for the *Patient Knowledge on Condition and Treatment* subdomain in *Health Behaviors*.
- Clarify that *Vitality/Energy* under *HRQOL* includes fatigue, weakness, tiredness, and time to recovery after a dialysis session.
- Rename the *Congruence Between Desired and Achieved Goals* subdomain in *HRQOL* "*Ability to Achieve Desired Goals*".

Finally, as noted earlier, we recommend renaming the high-level category *Symptom Burden* to "*Symptoms*" to more clearly indicate that the intent is to focus on the presence, intensity, and change-over-time of condition-specific symptoms rather than the impact and burden of symptoms on various aspects of *HRQOL*.

KCQA PATIENT-REPORTED OUTCOMES FRAMEWORK INITIATIVE

KCQA recently launched a new initiative to develop a framework identifying principles, domains and subdomains, and priorities related to patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome performance measures (PRO-PMs) for patients with ESRD, defined as follows:[1]

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

The framework will be used to facilitate KCQA's ability to engage with policymakers on how to thoughtfully and effectively utilize these important tools in dialysis performance measurement, public reporting, and accountability initiatives. The focus of this work is limited to patients actively on dialysis; both in-center and home (i.e., peritoneal and home hemodialysis) are included.

PRO CATEGORIES

NQF's *Patient-Reported Outcomes in Performance Measurement* report identifies, though not definitively, four PRO categories: *Patient Experience with Care*; *Health-Related Quality of Life* (including *Functional Status*); *Health Behaviors; Symptom/Symptom Burden*. While we believe it likely that KCQA will ultimately want and need to be more granular, the KCQA Steering Committee recommends beginning with these four categories as an initial approach.

ENVIRONMENTAL SCAN

A preliminary environmental scan of existing PROMs and PRO-PMs focused on a review of the NQF's Quality Positioning System (QPS) and Patient- and Family-Centered Care (PFCC) projects (which will include measures not endorsed and so not in the QPS), Avalere's database (to which we have access because we grant permission for them to publish KCQA specifications in full), AHRQ's National Quality Measures Clearinghouse, peer-reviewed literature, grey literature, material provided from KCQA members as they became aware of the initiation, and an increasing proliferation of proprietary entities (e.g., PROMIS, NQF's partnership with PatientsLikeMe, FasterCures' Framework for Patient Preferences into R&D Platforms, etc.). The scan identified an overwhelming number of both patient- and provider-administered instruments that have been developed and used over that past two decades. Identified PROMs and PRO-PMs vary in format from single-item questions to complex multi-component surveys and generally employ one of two different approaches to measurement—outcome assessment (e.g., the proportion of patients with a particular symptom) and process assessment (e.g., the proportion of patients who completed a given survey). Only one NQF-endorsed PROM was identified that is specifically germane to the CKD or ESRD populations (the *CAHPS In-Center*

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[1] National Quality Forum. *Patient-Reported Outcomes in Performance Measurement.* Washington, DC, National Quality Forum, January 10, 2013. Available at: http://www.qualityforum.org/Projects/n-r/Patient-Reported_Outcomes/Patient-Reported_Outcomes.aspx. Last accessed June 2016.

Hemodialysis Survey [NQF 0258]); 24 additional (unendorsed) measures and two PROM registries/platforms were identified that either directly pertain or can be applied to the ESRD or renal transplant populations. The ***PROM/PRO-PM Environmental Scan Table*** (n=128 as of October 15, 2016) details these as well as a sample of 103 non-renal-related but commonly used PROMs and PRO-PMs and four additional PRO registries. The table is not intended to be comprehensive, but rather to illustrate the current breadth and scope of measure types and constructs being used in the PRO realm so as to provide insight into constructing the framework.

PRO CATEGORY DOMAINS AND SUBDOMAINS

The environmental scan categorizes PROMs and PRO-PMs according to NQF's four suggested categories (*Patient Experience with Care*, *Health-Related Quality of Life*, *Health Behaviors*, *Symptom/Symptom Burden*). All measures included in the scan were then analyzed to identify the domains and subdomains most commonly addressed in each of those four categories. There was significant—oftentimes complete—agreement in the domains and subdomains across the PROMs included in each PRO category.

In the following pages, we detail the most common domains and subdomains identified in the four PRO categories and provide a number of illustrative examples of items/questions used in existing PROMs. (Some, ***but not all***, of the illustrative examples are from instruments used in the ESRD population.) We are using this analysis as the starting point to identify an initial draft framework for elucidating additional domains and/or parsing subdomains that are more relevant to ESRD, as well as for identifying gaps and priorities.

The current draft framework outline follows. **We are transmitting an accompanying document that indicates the type of information we will be seeking for the semi-structured interview.**

Patient Experience with Care Category

Addresses satisfaction with healthcare delivery and therapies and reflects actual experiences with healthcare services.[2] Identified domains and subdomains are detailed below:

- **Respect for Patient/Family**
    - Caring from doctor/nurses/staff
        - Example PROM Item: *In the last 3 months, how often did you feel your kidney doctors really cared about you as a person? ("Never" to "Always".)*[3]
    - Respect for autonomy/preferences
    - Respect for privacy
    - Patient/family included in care planning and decision-making
- **Communication**
    - Between doctors/nurses/dialysis technicians/other staff and patient/family on medical condition/ treatment options
        - Example PROM Item: *In the last 3 months, how often did your kidney doctors explain things in a way that was easy for you to understand? ("Never" to "Always".)*[3]
    - Between providers within and across care sites (i.e., care coordination)
- **Care Environment**
    - Cleanliness, quietness, safety, or comfort of care site
        - Example PROM Item: *In the last 3 months, how often was the dialysis center*

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[2] Cella D, Hahn EA, Jensen SE, et al. *Patient-Reported Outcomes in Performance Measurement.* RTI *Press Publication No. BK-0014-1509.* Research Triangle Park, NC: RTI Press. 2015.

[3] CMS. *ICH CAHPS Standard Survey.* December 2014. Available at: https://ichcahps.org. Last accessed October 12, 2016.

as clean as it could be? ("Never" to "Always".)[3]

- **Care Received**
  - Basic needs met
    - Example PROM Item: *In the last three months, how often did the dialysis center staff make you as comfortable as possible during dialysis? ("Never" to "Always".)*[3]
  - Responsiveness from doctors/nurses/dialysis technicians/other staff
  - Pain management

Health-Related Quality of Life Category
Multi-dimensional generic or condition-specific concept encompassing physical, social, and emotional well-being associated with illness and its treatment.[2] Domains and subdomains follow:

- **Overall Quality of Life**
  - Example PROM Item: *Thinking about your feelings, memory, and everyday life, how would you rate your overall quality of life? (" Very Good" to "Poor")*[4]
- **Well-Being**
  - Positive emotions/optimism, life satisfaction, pleasure in daily activities, finding life meaningful, resolution and fortitude, or positive self image
    - Example PROM Item: *The activities I do give me pleasure. ("Rarely" to "Always")*[5]
- **General Health**
  - Example PROM Item: *In general, how would you rate your health? ("Excellent" to "Poor".)*[6]
- **Functional Status**
  - Basic mobility, falls/fall risk/fear of falling, or ADLs
    - Example PROM Item: *Does your health now limit you in the moderate activities (e.g., vacuuming, golfing)? ("Yes, a Lot" to "No, Not at All")*[6]
- **Social Functioning**
  - Spiritual, familial, recreational, work, or financial functioning
    - Example PROM Item: *I feel like a burden on my family. ("Definitely True" to "Definitely False")*[6]
- **Mental Functioning**
  - Cognition or concentration/distraction/forgetfulness
    - Example PROM Item: *In the last week, how worried have you been about poor concentration? ("A Lot" to "Not at All")*[4]
- **Psychological/Emotional Functioning**
  - Mental status, depression, or anxiety/worry
    - Example PROM Item: *During the past 4 weeks, have you accomplished less than you would like as a result of any emotional problems (i.e., feeling depressed or anxious)? ("Yes/No")*[6]
- **Sexual Functioning**
  - Example PROM Item: *How much does kidney disease interfere with your sex life?*

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[4] Institute of Psychiatry. *Dementia Quality of Life Questionnaire.* 2015. Available at: https://www.bsms.ac.uk/research/cds/research/demqol.aspx. Accessed October 12, 2016.

[5] Eakman A. *Engagement in Meaningful Activities Survey.* Colorado State University. 2015. Available at: http://webcache.googleusercontent.com/search?q=cache:hQ2VMdOq_N8J:dolivewell.ca/wp-content/uploads/2015/05/Engagement-in-Meaningful-Activities-Survey_May-2015.pdf+&cd=1&hl=en&ct=clnk&gl=us. Accessed October 12, 2016.

[6] Hays, RD. *KDQOL: The Medical Outcomes Study (MOS) Measures of Patient Adherence.* Available at: http://www.rand.org/health/surveys/MOS.adherence.measures.pdf. Accessed October 12, 2016.

    - *(“Not at All” to “Extremely”)*[6]
- **Vitality and Energy**
    - Example PROM Item: *How much of the time during the past 4 weeks did you have a lot of energy? (“All of the Time” to “None of the Time”)*[6]
- **Self Image**
    - Example PROM Item: *Over the past two days, I felt good about myself as a person. (“Completely Disagree” to “Completely Agree”)*[7]
- **Sleep Health**
    - Example PROM Item: *During the past 30 days, for about how many days have you felt you did not get enough rest or sleep? (Number of days entered)*[8]
- **Congruence Between Desired and Achieved Goals**
    - Example PROM Item: *During the past 4 weeks, have you accomplished less than you would like with your work or other regular daily activities as a result of your physical health? (“Yes” or “No”)*[6]

Symptom Burden Category
A multi-dimensional concept that focuses on the presence and burden of specific condition-related symptoms and their impact on a patient’s functioning.[2] Identified domains and subdomains are as follows:

- **Physical Symptoms**
    - Presence of specific symptom (e.g., pain, itching, dry skin, numbness/tingling, fatigue)
        - Example PROM Item: *During the past week did you experience itching? (“Not at All” to “Very Much”.)*[9]
    - Symptom improvement/worsening/remission (over time with multiple PROM administration)
    - Symptom interference with physical functioning (e.g., basic mobility, ADLs)
- **Psychological/Emotional/Social Symptoms**
    - Familial, social, sexual, work, depression, anxiety, or sleep disturbances
        - Example PROM Item: *During the past month, about how often did you get together with friends or relatives, such as going out together, visiting in each other's home, or talking on the telephone? (“Every Day” to “Not at All”)*[6]
- **Mental Symptoms**
    - Cognition or concentration/distraction/forgetfulness
        - Example PROM Item: *During the past week did you have difficulty concentrating? (“Not at All” to “Very Much”.)*[6]
- **Medication/Treatment Side Effects**
    - Example PROM Item: *How troubling is X side effect to X medication to you? (“Not at All” to “Extremely”)*[10]

Health Behaviors Category
A concept that is specific to the given type of behavior and that typically measures the

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[7] Cohen R et al. The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advance disease. A preliminary study of validity and acceptability. *Palliative Med.* 1995;9(3):207-219.
[8] Centers for Disease Control and Prevention. *Health-Related Quality of Life-14.* Available at: http://www.cdc.gov/hrqol/hrqol14_measure.htm. Accessed October 12, 2016.
[9] University of Pittsburgh Medical Center, VA Healthcare System. *Dialysis Symptom Index.* Available at: http://webcache.googleusercontent.com/search?q=cache:ZnNnDS8eCiIJ:www.kidneysupportivecare.org/Files/DialysisSymptomIndex.aspx+&cd=1&hl=en&ct=clnk&gl=us. Accessed October 10, 2016.
[10] Winsett RP et al. Evaluation of an immunosuppressant side effect instrument: The Memphis Survey. *Prog Transplant.* 2004;14(3):210-216.

occurrence and frequency of that behavior.[2] Identified domains and subdomains follow:

- **Self-Management/Patient-Activation**
    - Patient knowledge on condition and treatment (e.g., modality options)
    - Patient problem-solving skills
    - Self-care behaviors
    - Self-monitoring behaviors
        - Example PROM Item: *I record my laboratory data and continually check it with my doctor. ("Never" to "Always".)*[11]
    - Treatment adherence (e.g., to prescribed medications, treatment plan, dietary restrictions)
        - Example PROM Item: *How often in the past three months have you forgotten to take your X medication? ("Never" to "Always")*[12]
- **Perceived Self-Efficacy**
    - Patient confidence and perception of ability to self-manage care
        - Example PROM Item: *How much confidence you have in taking your medication when nobody helps you get it ready? ("A lot" to "None")*[13]
- **Other High-Risk Behaviors**
    - Non-condition-specific high-risk behaviors such as smoking, alcohol abuse, drug use.

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[11] Weng LC et al. Effects of self-efficacy, self-care behaviors on depressive symptoms of Taiwanese kidney transplant recipients. *J Clin Nurs.* 2008;17(13):1786-1794.

[12] Chisholm MA, Lance CE, Williamson GM, Mulloy LL. Development and validation of the Immunosuppressant Therapy Adherence Instrument (ITAS). *Patient Education and Counseling.* 2005;59:13-20.

[13] Denhaerynck K et al. Validity testing of the Long-Term Medication Behavior Self-Efficacy Scale. *Journal of Nursing Measurement.* 2003;11(3):267-282.

APPENDIX B: TABLES AND GRAPHS

The tables and graphs in this appendix detail the data collected from the 52 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 B-1.

TABLE B-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

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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.

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 B-2 and Figures B-1 through B-3.

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

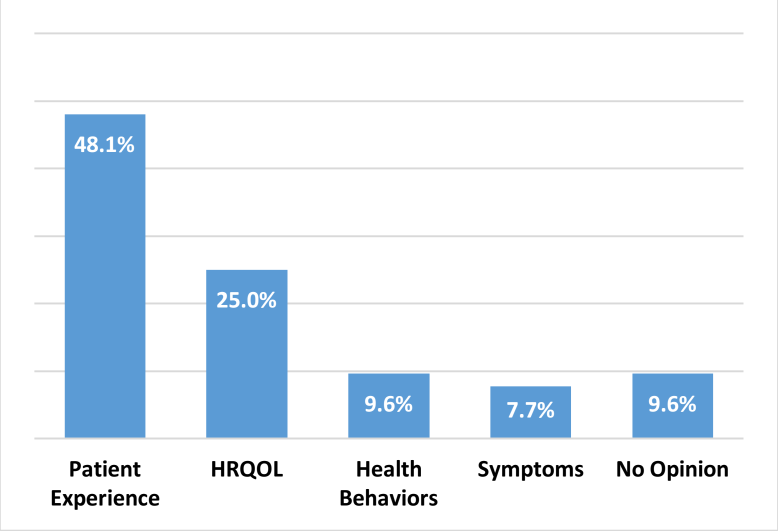
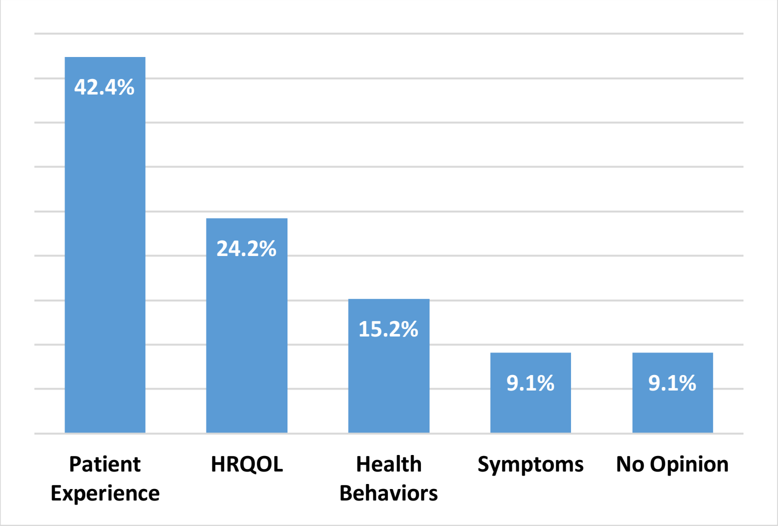


FIGURE B-2: Percentage of Member/Steering Committee Interviewees (n=33) Ranking Each PRO Category #1



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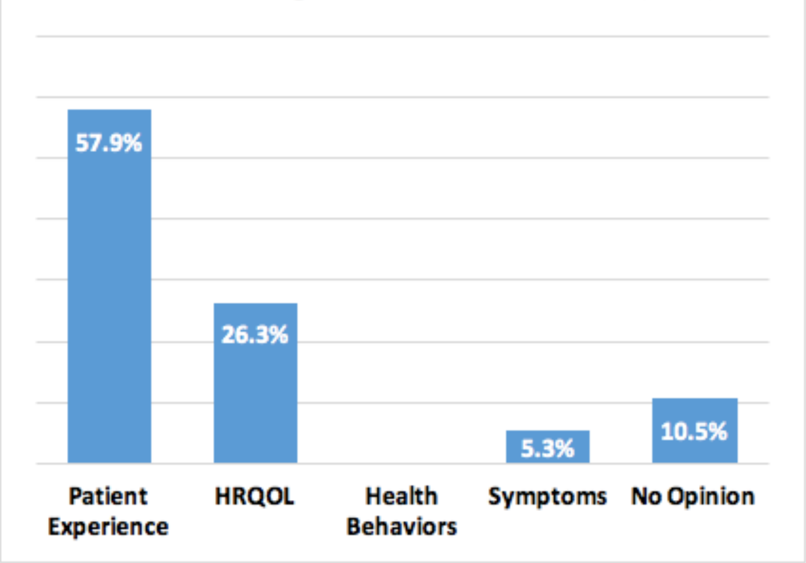
[3] Interviewees were advised that their response could be revised, if desired, when later completing the survey.

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



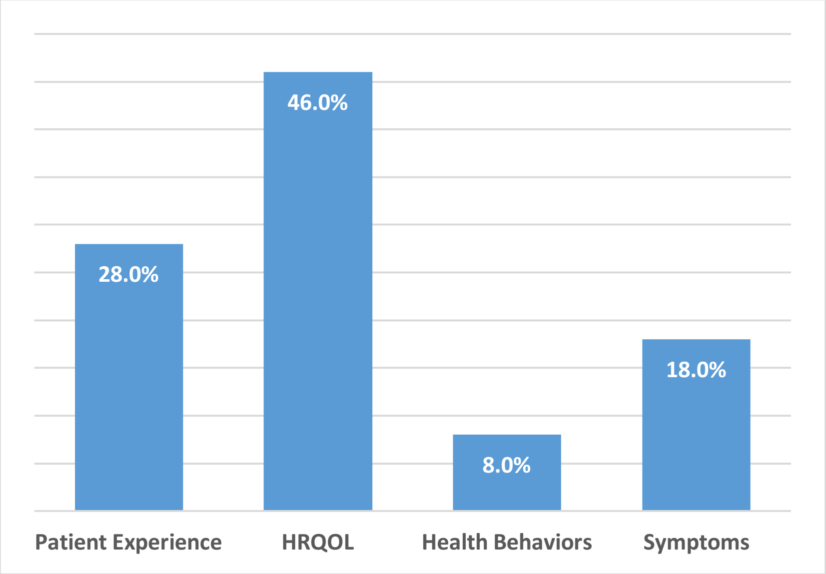
SURVEY RESPONSES

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 B-3 and Figures B-4 through B-6.

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

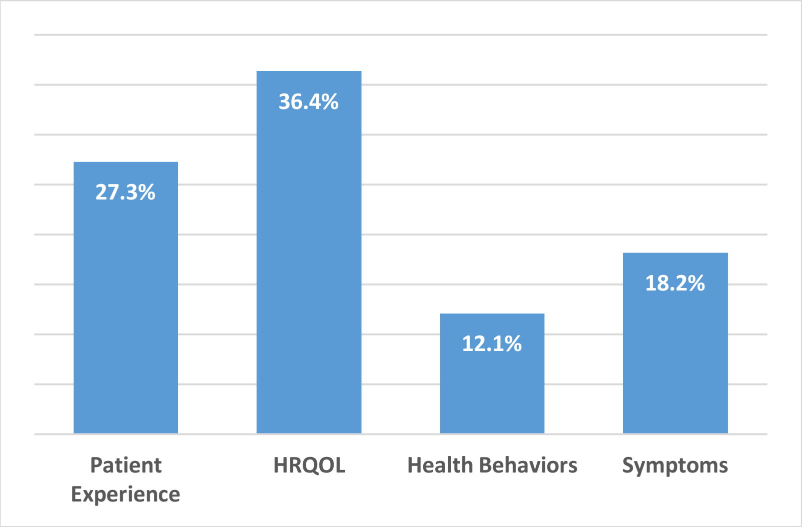
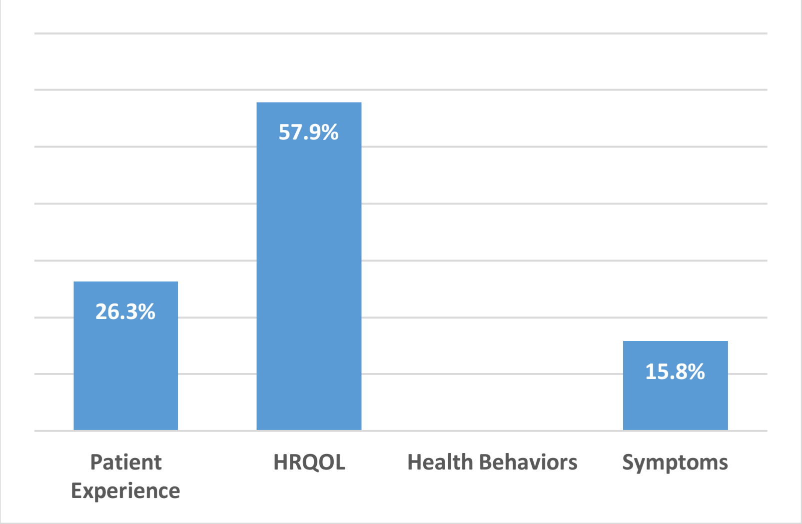


FIGURE B-6: Percentage of Patient Survey Respondents (n=19) Ranking Each PRO Category #1



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 B-4 presents the numbers of members and patients who revised their top priority in the survey.

TABLE B-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

	All	Members + Steering Committee	Patients
HRQOL→Symptoms	1	1	0
Health Behaviors→HRQOL	1	1	0
Health Behaviors→Symptoms	1	1	0
Symptoms→Health Behaviors	1	1	0

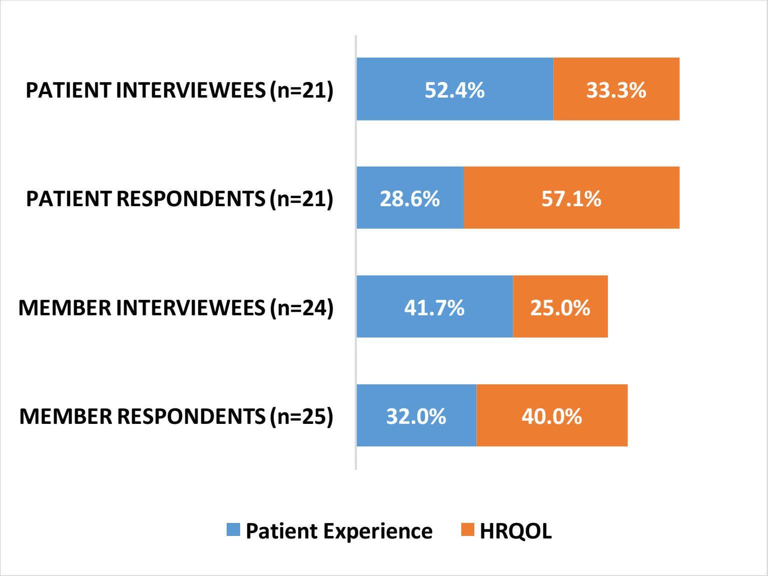
Additionally: 3 interviewees (2 members, 1 patient) who had no opinion on a top priority later prioritized *HRQOL* in the survey; 3 survey respondents (2 members, 1 patient) who were not interviewed but who completed the survey ranked *HRQOL* as their highest priority, and another 3 (2 members, 1 patient) 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 B5 and Figures B-7 and B-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 B-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 B-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 B-8: Percentage Ranking *Patient Experience* and *HRQOL* #1 by Survey Subgroup

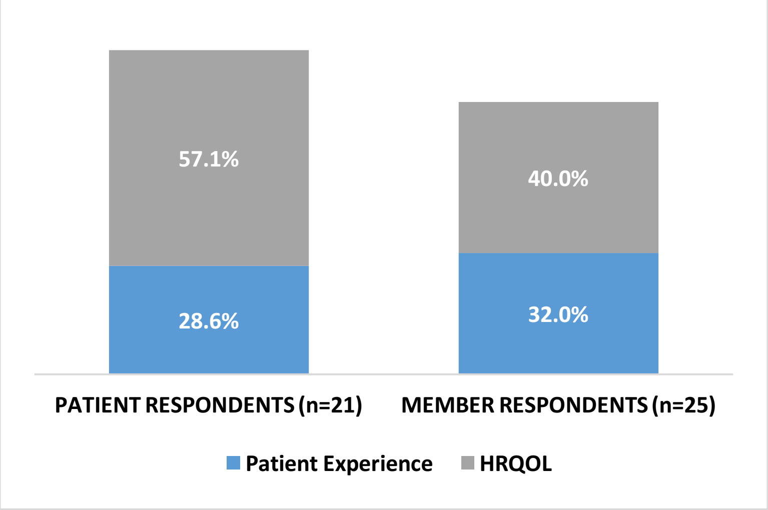


Table B-6 summarizes the number of all survey respondents (n=50) ranking each high-level PRO category as #1, 2, 3, and 4, and Figure B-9 shows the resulting mean rankings, medians, and modes for each category (where lower values [closer to 1] = higher priority).

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

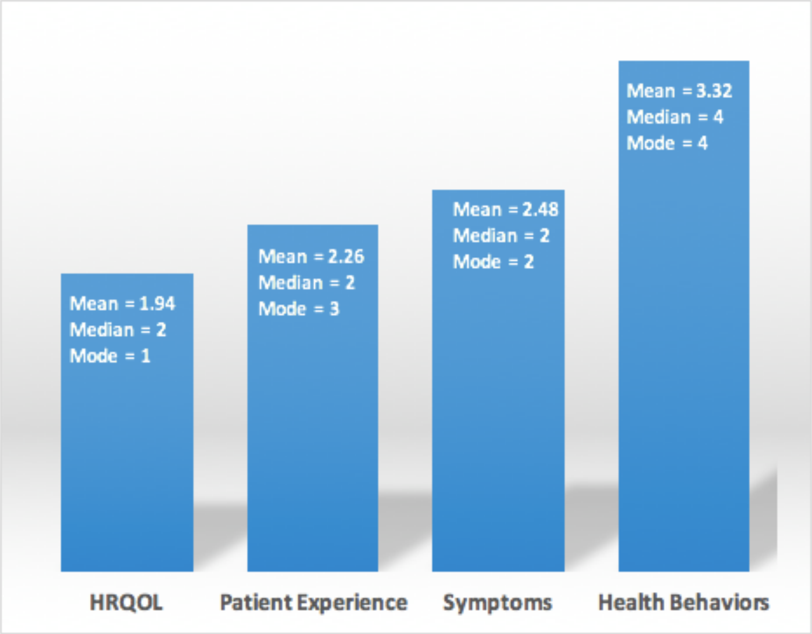
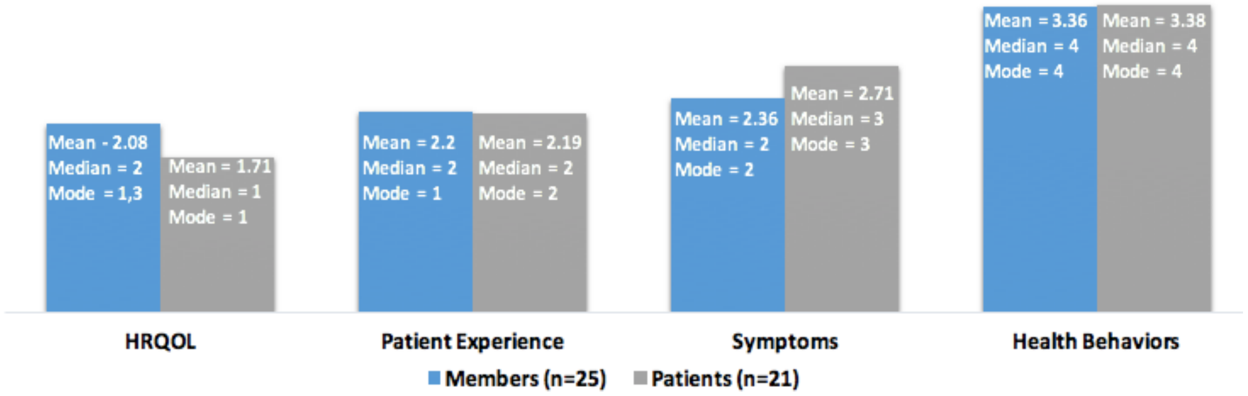


Table B-7 summarizes the number ranking each PRO category #s 1-4 by respondent subgroup, and Figure B-10 shows the resulting mean rankings, medians, and modes for each category.

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



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

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

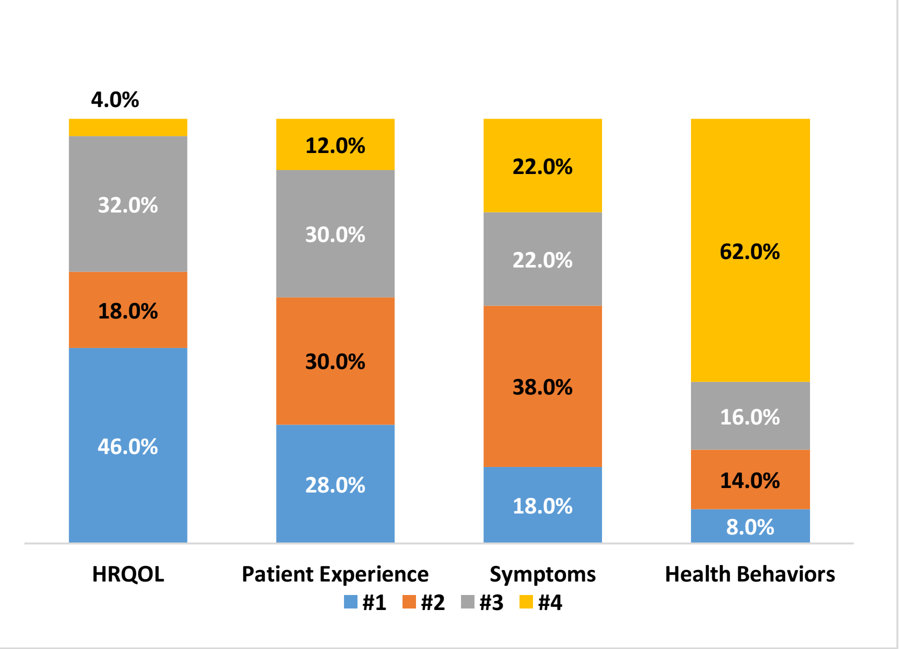


FIGURE B-12: Percentages of High-Level Categories Rankings, Member Respondents (n=25)

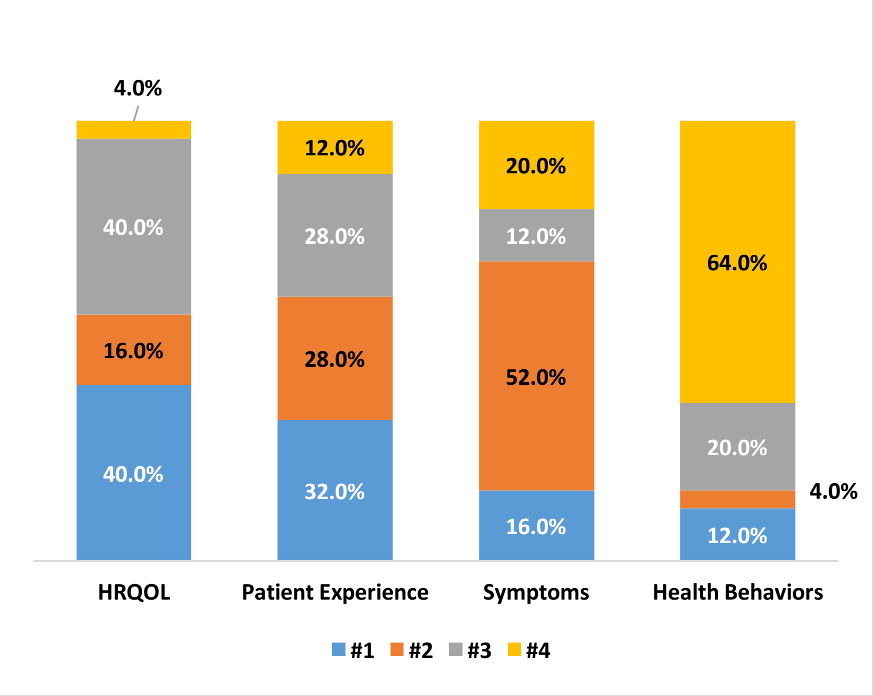
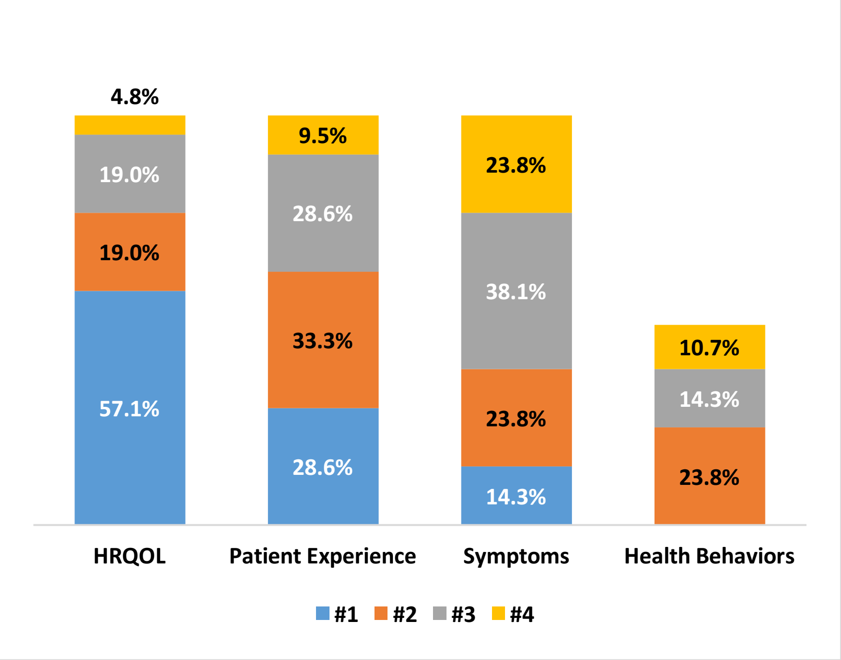


FIGURE B-13: Percentages of High-Level Categories Rankings, Patient Respondents (n=21)



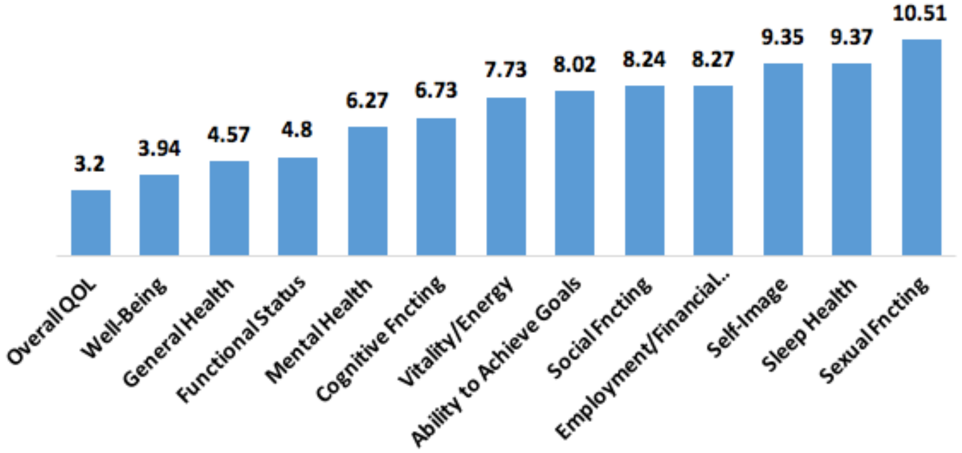
SUBCATEGORIES RANKINGS

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 B-14.

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



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 B-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

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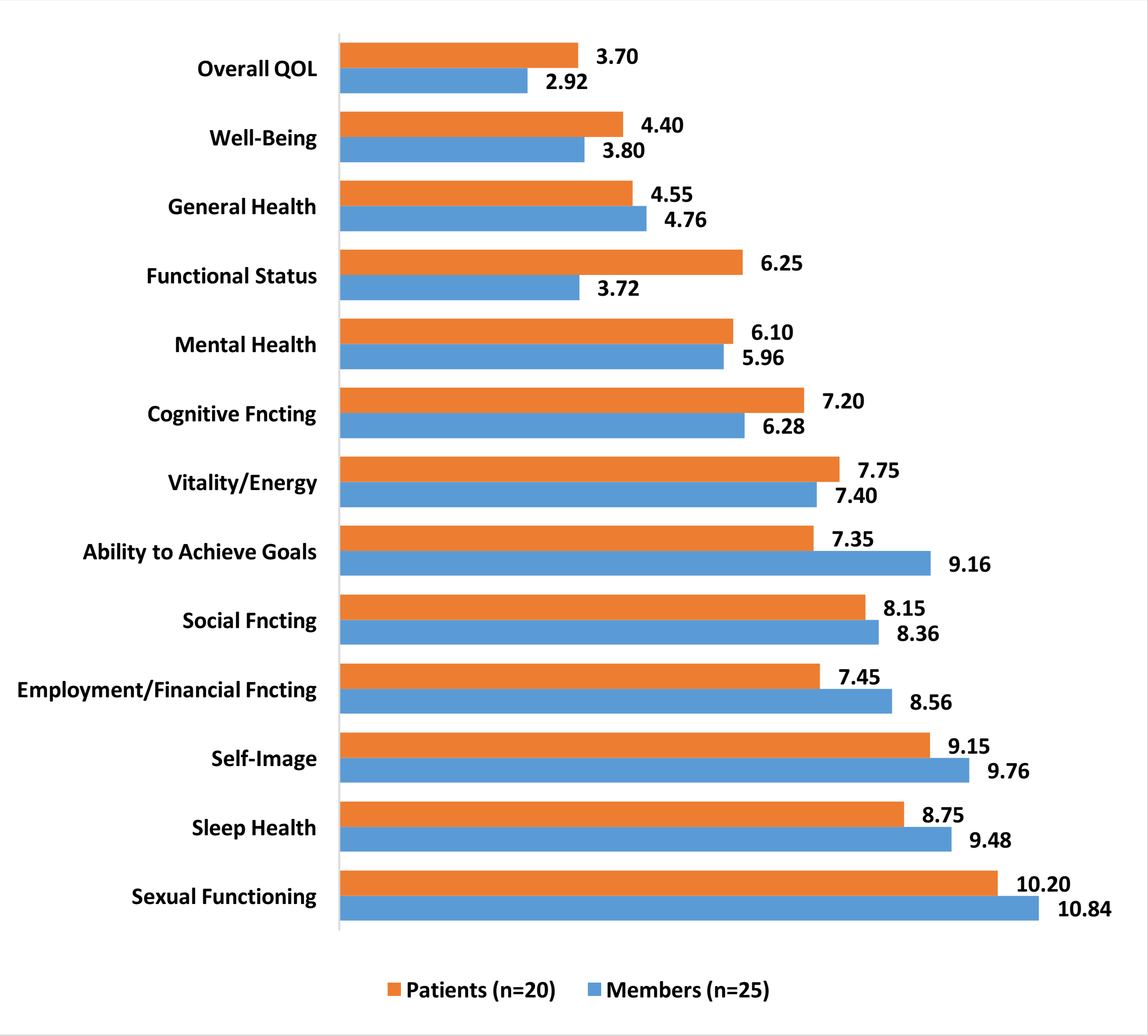
[9] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *HRQOL* "All Respondents" subcategories analysis and n=20 for the patient subgroup *HRQOL* analysis.

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



Patient Experience with Care Subcategories

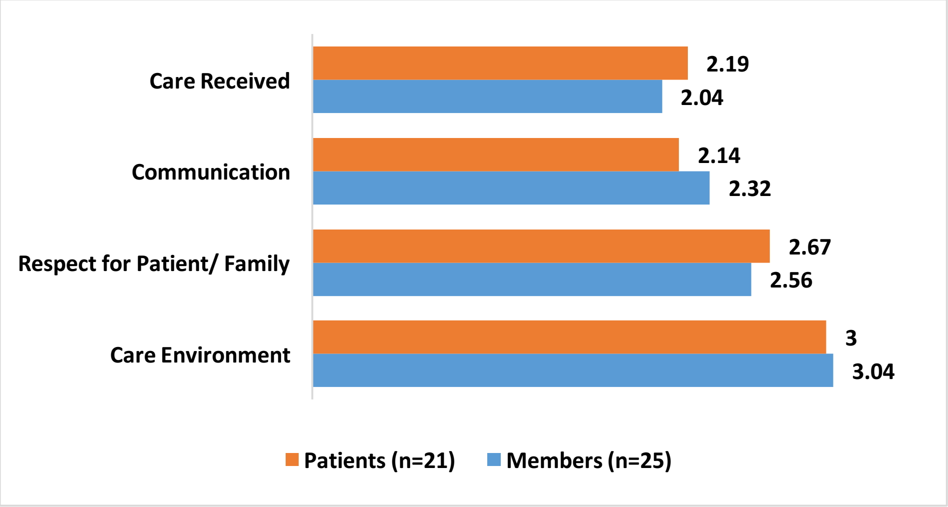
Respondents were asked to rank the 4 *Patient Experience* subcategories, with 1 being the highest and 4 the lowest priority. As illustrated in Figures B-16 and B-17 and Table B-9, the rankings were largely consistent across the two groups with the notable exception of a reversal of the top priority.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

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

TABLE B-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

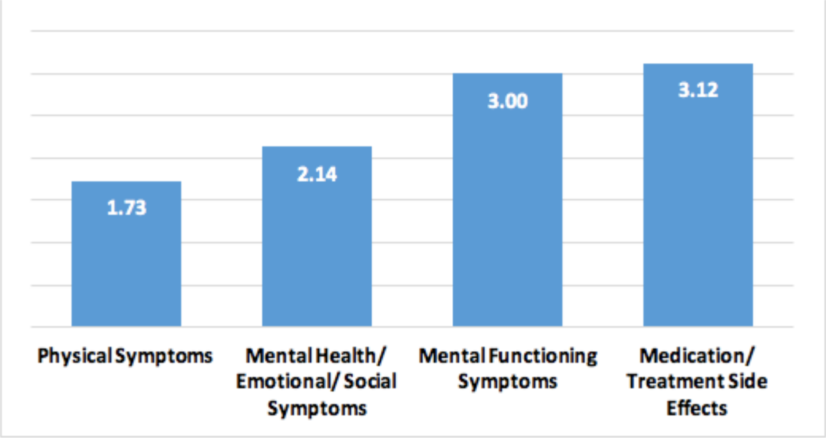
FIGURE B-17: Mean Ranking of *Patient Experience* Subcategories by Respondent Subgroup (lower values = higher priority)



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 B-18 and B-19 and Table B-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 B-18: Mean Ranking of *Symptoms* Subcategories, All Respondents (n=49)[10] (lower value=higher priority)



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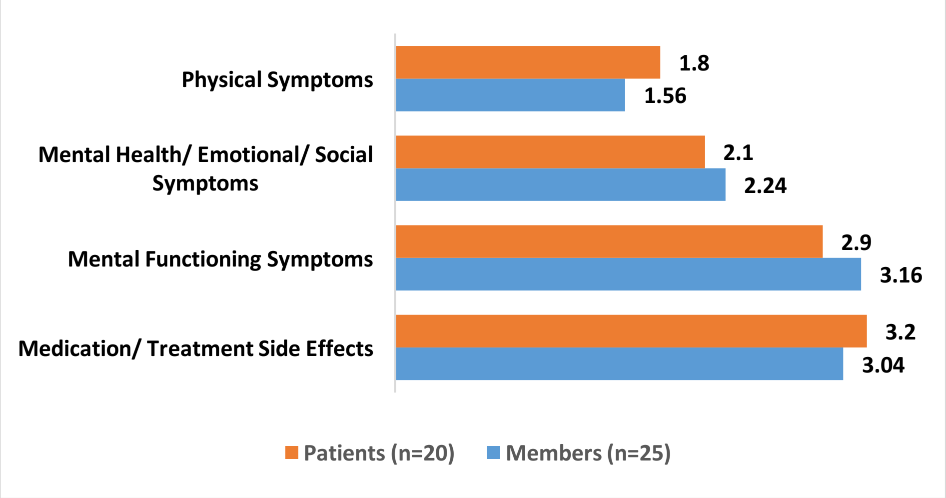
[10] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *Symptoms* "All Respondents" subcategories analysis and n=20 for the patient subgroup *Symptoms* analysis.

TABLE B-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

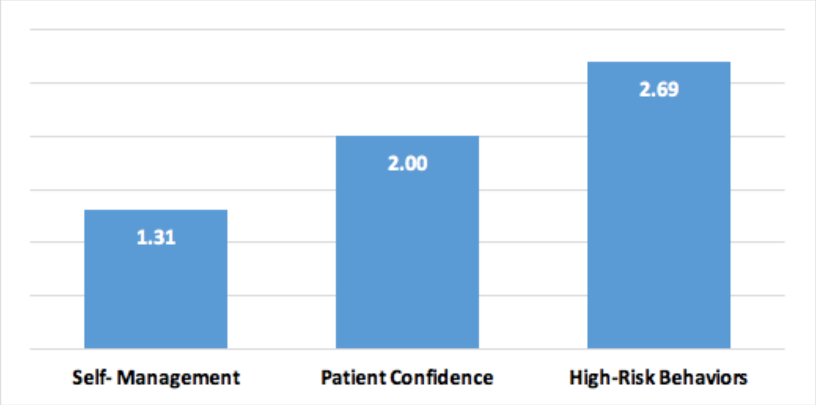
FIGURE B-19: Mean Ranking of *Symptoms* Subcategories by Respondent Subgroup (lower values = higher priority)



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 B-20 and B-21 and Table B-11, rankings were consistent across the two survey groups.

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



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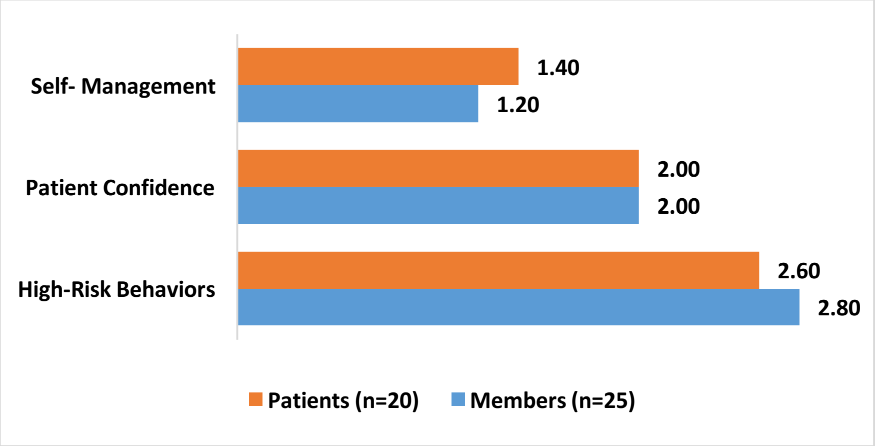
[11] One patient respondent only completed the high-level categories and *Patient Experience* subcategories rankings, such that n=49 for the *Health Behaviors* "All Respondents" subcategories analysis and n=20 for the patient subgroup *Health Behaviors* analysis.

TABLE B-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 B-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 B-12 through B-16.

TABLE B-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?
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.
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.
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.
Member	I have answered generally; however, my answers may vary depending on the perspective and purpose of measurement.

RESPONDENT CATEGORY	COMMENT
	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.
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.
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.
Patient/ Member	Focusing on how a patient feels after a treatment will improve quality-of-life.
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 B-13: ***HRQOL*** **Subcategories Comments**

RESPONDENT CATEGORY	COMMENT
Patient	My choices for #1-7 are all pretty close in importance.
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.
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.
Patient	Subcategory 1, Overall Quality of Life, is too broad.
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.
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.
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.
Patient/ Member	I find this very difficult to rank.
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 B-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.
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.
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.
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.
Patient/ Member	Care has to be top priority. I don't understand how respect for family can be measured?
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 B-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 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.
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.
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	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 B-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

RESPONDENT CATEGORY	COMMENT
	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.
Member	I don't view these as being reflective of a dialysis clinic's quality.
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	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.

FRAMEWORK OUTLINE: PROMS DOMAINS ANALYSIS

NQF's *Patient-Reported Outcomes in Performance Measurement* report identifies, though not definitively, four categories of PRO measurement: ***Patient Experience with Care; Health-Related Quality of Life*** (including *Functional Status*); ***Health Behaviors***; and ***Symptom/ Symptom Burden***. As previously noted, we believe it likely that KCQA will want/need to be more granular, but as an initial approach we sorted the measures identified in the environmental scan into these four broad categories.

This document provides a detailed analysis of how the PROMs and PRO-PMs included in the environmental scan (n=139, plus six PROM-related registries/platforms~~28~~) falling within each of those four categories approach measurement. All available PROMs/PRO-PMs in the environmental scan were reviewed. The domains and subdomains in each were then identified and compared to other measures falling within the same PRO category. There was significant (oftentimes complete) agreement between measures in terms of domains and subdomains within a given measure category. The remainder of this document provides a synthesis of the most common domains/subdomains identified in measures in each of the four NQF measure categories.

To provide context for the domain/subdomain, we have identified illustrative "case examples," so that it becomes a bit more concrete as to the types of questions/scales that are used for a given domain.

PATIENT EXPERIENCE WITH CARE DOMAINS/SUBDOMAINS

Patient Experience with Care measures address satisfaction with healthcare delivery and therapies, reflects actual experiences with healthcare services, and fosters patient activation.[1]

- **Respect for Patient/Family**
    - Caring from doctors/advanced practice registered nurses/nurses/staff
    - Respect for autonomy and preferences
    - Respect for privacy
    - Patient/family included in care planning and decision-making
- **Communication**
    - Between doctors/advanced practice registered nurses/nurses/staff and patient/family on medical condition/treatment options (e.g., modality education)
    - Between providers within and across care site (i.e., coordination of care)
- **Care Environment**
    - Safety
    - Cleanliness
    - Quietness

CASE EXAMPLES

The *Patient Experience with Care* domains from the ICH CAHPS measure and Hospital Compare are provided here for reference:

ICH CAHPS Patient Experience Domains

- Nephrologists' Communication and Caring
- Quality of Dialysis Center Care and Operations
- Providing Information to Patients
- Global Rating of the Nephrologist
- Global Rating of Dialysis Center Staff
- Global Rating of the Dialysis Facility

Hospital Compare Patient Experience Domains

- Communication with Nurses
- Communication with Doctors
- Responsiveness of Hospital Staff
- Pain Management
- Cleanliness and Quietness of Hospital Environment
- Communication about Medicines
- Discharge Information
- Overall Rating of Hospital

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[1] Cella D, Hahn EA, Jensen SE, et al. *Patient-Reported Outcomes in Performance Measurement.* RTI *Press Publication No. BK-0014-1509.* Research Triangle Park, NC: RTI Press. 2015.

    - Comfort
- **Care Received**
    - Basic needs met
    - Responsiveness from doctors/advanced practice registered nurses/nurses/ staff
    - Pain management
- **Global Staff Rating** (usually 1-10 scale)
- **Global Doctor Rating** (usually 1-10 scale)
- **Global Care Rating** (usually 1-10 scale)
- **Global Facility Recommendation** (usually yes/no)

HEALTH-RELATED QUALITY OF LIFE DOMAINS/SUBDOMAINS

Health-Related Quality of Life (HRQOL) is a multi-dimensional generic or condition-specific concept encompassing physical, social, and emotional well-being associated with illness and its treatment.[1]

- **Overall Quality of Life**
- **Well-Being**
    - Positive emotions/optimism
    - Life satisfaction
    - Pleasure in daily activities
    - Finding life meaningful
    - Resolution and fortitude
    - Positive self image
- **General Health**
- **Functional Status**
    - Basic mobility
    - Falls/fall risk/fear of falling
    - ADLs
- **Employment/Financial Functioning**
- **Social Functioning**
    - Familial functioning
    - Recreational functioning
    - Spiritual functioning
    - ~~Work functioning~~
    - ~~Financial functioning~~
- **~~Mental~~Cognitive Functioning**
    - Cognition
    - Concentration/distraction/forgetfulness
- **~~Psychological/Emotional Functioning~~Mental Health**
    - Mental status
    - Depression
    - Anxiety/worry
    - Other mental health diagnoses
- **Sexual Functioning**
- **Vitality/Energy**
    - Fatigue/weakness/tiredness
    - Time to recovery (TTR) after hemodialysis sessions
- **Self Image**

CASE EXAMPLE

For reference, the KDQOL (access the survey questions here) is a 36-item HRQOL survey with four subscales:

- **The SF-12 Measure of Physical (PCS) and Mental (MCS) Functioning (Questions 1-12)** contains items about general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities.
- **Burden of Kidney Disease Subscale (Questions 13-16)** contains 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 (Questions 17-28b)** contains 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 (Questions 29-36)** contains 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.

- **Sleep Health**
- **~~Congruence Between Desired and~~Ability to Achieve~~d~~ Desired Goals**

HEALTH BEHAVIORS DOMAINS/SUBDOMAINS

A concept that is specific to the given type of behavior and that typically measures the occurrence and frequency of that behavior.[1]

- **Self-Management/Patient Activation**
  - 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)
- **Perceived Self-Efficacy**
  - Patient confidence and perception of ability to self-manage care
- **Other High-Risk Behaviors**
  - Non-condition-specific high-risk behaviors such as smoking, alcohol abuse, drug use

SYMPTOMS ~~BURDEN~~ DOMAINS/SUBDOMAINS

A multi-dimensional concept that focuses on the presence, intensity, and change-over-time ~~and burden~~ of condition-specific symptoms ~~and their impact on a patient's functioning~~.

- **Physical Symptoms**
  - Presence of specific symptom (e.g., pain, itching, dry skin, numbness/tingling, fatigue, frailty)
  - Symptom improvement/worsening/remission (over time with multiple PROM administration)
  - ~~Symptom interference with physical functioning (e.g., basic mobility, ADLs)~~
- **~~Psychological/Emotional/Social~~Mental Health Symptoms**
  - ~~Work~~
  - ~~Familial~~
  - ~~Social~~
  - ~~Sexual~~
  - Depression/anxiety/other mental health diagnoses
  - Sleep disturbances
- **~~Mental~~ Cognitive Symptoms**
  - Cognition
  - Concentration/distraction/forgetfulness
- **Medication/Treatment Side Effects**

CASE EXAMPLE

The *COPD Assessment Test* (***CAT***) is a well-validated PROM used in two COPD PRO-PMs in the Environmental Scan. Questions address symptom burden and are scored on a 0 to 5 scale (0 = always true/mild symptom, 5 = never true/severe symptom). Scores are then summed; a total score of <10 corresponds to low symptom burden, 10-20 medium, 20-30 high, >30 very high. Questions include the following:

1. I never cough. 0/1/2/3/4/5
2. I have no phlegm in my chest at all.
3. My chest does not feel tight at all.
4. When I walk up a hill or one flight of stairs I am not breathless.
5. I am not limited doing any activities at home.
6. I am confident leaving my home despite my lung condition.
7. I sleep soundly.
8. I have lots of energy.

CASE EXAMPLE

For reference, the Dialysis Symptom Index (DSI) (access the survey questions here) is a 30-item survey addressing symptom-burden across three domains:

- Psychological symptoms/dysfunction
- Physical symptoms
- Mental symptoms