KCQA Patient-Reported Outcome Initiative In-Person Meeting

BREAKOUT DISCUSSION GUIDE

The morning plenary session of the in-person meeting will focus on a review and discussion of the two commissioned papers and the results of the KCQA interviews and surveymonkey prioritization. Following the plenary and lunch, KCQA members will be split into two parallel breakout sessions, each covering the same material. The breakouts are intended to provide the opportunity for a more granular and robust dialogue than would otherwise be possible in the larger group.

The goals for the breakouts are three-fold:

1. Review and discuss whether the current KCQA Principles that guide our measure development activities are salient and applicable to Patient-Reported Outcome Measures (PROMs).
2. Consider the recommendations in the Finkelstein and Peipert/Hays papers, along with the findings of the KCQA interviews and surveymonkey prioritization and discuss whether there is consensus on a single priority (*Patient Experience with Care* or *HRQOL*) or whether the group still feels both are of equal priority for PROM development for patients with ESRD.
3. For either or both categories, identify consensus on a (or a few) subcategories that merit particular exploration for measure development in the near-term. (NOTE: KCQA itself has not committed to developing PROMs/PRO-PMs, but the group should think broadly given CMS recently issued a call for a PRO TEP.)

The following sections summarize background and identify candidate questions for discussion. They are not intended, however, to limit discussion but are provided as starting points for the conversation.

KCQA Guiding Principles

At its founding in 2007, KCQA adopted guiding principles for its measure development work, which were modestly updated in the Phase 2 "reboot" in 2014. Although this initiative is not developing PROMs per se, it is important to examine whether KCQA's existing guiding principles (Attachment A) are appropriate for these types of measures. We recommend small changes to the principles to ensure that they fully address PROMs. Additionally, we provide for context information from the NQF and CMS related to principles and scope.

- *Does KCQA's Guiding Principles, initially approved for "traditional" measure development translate appropriately in the context of PROMs?*
- *Do you agree/disagree with the suggested redlines?*
- *Are there other additions or deletions to the KCQA Guiding Principles you believe should be considered?*

Commissioned Paper Recommendations & Interview/Survey Findings

Dr. Finkelstein's paper makes four recommendations:

1. Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues indicated in Table 1 (depression, anxiety, physical symptoms, family and marital discord, sexual dysfunction, caregiver burden, satisfaction with care and dialysis treatment regimen, cognitive impairment, impact of treatment regimen on pateints' life, physical functioning, fatigue).
2. Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
3. Encourage innovative approaches given the lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences
4. Require that there be documentation that domains of individual patient concerns have been acknowledged and that a plan to address these concerns has been noted. Plans could include addressing the problem using facility resources or making referrals to other health care providers or community resources.

The Peipert/Hays paper makes five recommendations:

1. Continue the use of KDQOL-36 for dialysis centers' internal quality improvement activities and the ICH-CAHPS for public dialysis center performance monitoring, but promote efforts to modify these instruments by incorporating PROMIS general health items (KDQOL-36) and reducing the length of the ICH-CAHPS.
2. Adopt a PRM of whether dialysis patients have been informed about their option for transplant.
3. Evaluate equivalence between electronic and paper versions of PRMs prior to widespread use of electronic administration.
4. Explore reimbursement of costs of PRM administration by the Centers for Medicare and Medicaid Services.
5. Continue development of provider trainings in PRM administration and interpretation.

The principle KCQA Interview/Survey Prioritization findings are:

1. For purposes of PROMs for patients with ESRD, *HRQOL* and *Patient Experience with Care* are clearly the highest ranked categories, although the interview and survey findings differ.
2. The subcategory emphases between KCQA members and patients are similar, but not identical—in particular for *HRQOL*.
3. Survey fatigue was widely cited as a significant barrier to PROMs by KCQA members and patients alike.
4. A range of solutions on the best way to approach data collection was offered, but they were often contradictory (e.g., anonymized vs. in-person/identifiable collection).
5. Enthusiasm for the existing ESRD-centered PROMs is modest. ICH CAHPS is not held in high favor for a range of reasons. KDQOL is viewed more favorably by a few

interviewees (n=13), however concern is expressed about its use for purposes of accountability (i.e.,g Five Star and/or QIP).

Given these recommendations and findings:

- *CMS has adopted ICH CAHPS as its PROM to assess Patient Experience with Care. What additional measure development might be valuable for purposes of accountability? Should we acknowledge ICH CAHPS is here to stay and work to improve it?*
- *The Conditions for Coverage encourage use of KDQOL for purposes of patient-specific, internal quality improvement, though other instruments may be deployed. Additionally, the Finkelstein and Peipert/Hays papers emphasize the importance of PROMs for ESRD patients in the area of HRQOL. Both, however, do not recommend the instrument for accountability purposes. Peipert/Hays explicitly calls for KDQOL's use only for internal quality improvement. Finkelstein recommends increased focus on HRQOL PROMs, but states mode and frequency of administration need to be flexible to facilities' needs (thereby excluding the potential for accountability). Given the priority KCQA members and patients place on HRQOL, can PROM measure development proceed in this area in the near-term?*
- *If meeting participants concur that HRQOL is a priority for PROM development, what categorie(s) – recognizing there is the competing need to be parsimonious and reduce survey fatigue, should be the near-term focus?*
- *What do participants think about the use of PROMIS to assess HRQOL for patients with ESRD (Peipert/Hays paper)?*
- *The recent KECC report to CMS on PROs recommended that the Agency focus on HRQOL and "recovery." (NOTE: KCQA's framework outline incorporates "time to recovery" (TTR) as a subcategory of HRQOL, not an end unto itself.) Do you believe TTR is a high priority for specific measure development – i.e., a strong evidentiary base for measurement and identifiable interventions to improve upon any potential measurement scores?*
- *Given the papers, interview summary, and survey findings, what is your single most important message to convey to CMS about development and deployment of PROMs for accountability purposes (no consensus expected)?*

KIDNEY CARE QUALITY ALLIANCE GUIDING PRINCIPLES—PHASE 2

KCQA has adopted the following principles to guide its work:

- KCQA processes—the Steering Committee, ~~Data/Feasibility~~ Workgroups, and full KCQA—will be transparent.
- The KCQA Steering Committee, Workgroups, and full KCQA will maintain clear minutes of their meetings and make them available on the KCQA section of KCP's web site.
- Quality measures will address independent dialysis facility (facility)- and hospital-based provider (provider)-level accountability.
- Quality measures may include both process- and outcome-based measures.
- Quality measures shall:
    - be patient-centered.
    - reflect ~~patient~~ the values and needs of patients/families/caregivers.
    - allow for appropriate variations in individual patient care regimens.
    - be equitable and ensure that sicker patients continue to receive high quality care.
    - appropriately address patient literacy and health literacy.
    - be consistent with the patient-physician relationship, as well as the relationship between patients/families/caregivers, providers, facilities, and other healthcare professionals.
    - reflect an array of aspects of care.
    - encourage improved quality and effective practices.
    - focus on improving the safety, effectiveness, and efficiency of care.
    - be public to ensure integrity and allow for understanding of reported data by patients and their families.
    - produce consistent and credible results.
    - be reliable, valid (including psychometrically sound, when applicable), precise, based on sound scientific evidence, and predictive of overall quality performance.
    - be standardized, transparent, explicit, and measurable.
    - be based on standardized definitions, technical specifications, and methodologies.
    - allow for mastering benchmarks and demonstrating improvement.
    - facilitate meaningful comparisons at the facility-level and be risk adjusted or risk stratified when appropriate.
    - appropriately address the potential for unintended consequences related to measure implementation.
    - be based on KCQA's prioritization of the Blueprint's domains/ subdomains.

- build upon existing dialysis-related reporting requirements and use measures that are available and accessible without imposing undue burden on providers and caregivers.
- be based on a strong consensus.

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To provide additional context for KCQA's Guiding Principles, we reviewed NQF and CMS documents, and report the following:

NQF GUIDING PRINCIPLES FOR PROMS AND PRO-PMS

The National Quality Forum (NQF) has identified the following five guiding principles for selecting PROMs in the context of performance measurement. Measure should be:[1]

- **Psychometrically Sound.** The following characteristics should be considered in selecting PROMs for use in PRO-PMs:
  - Documentation of the measurement concept and model;
  - Reliability;
  - Validity;
  - Interpretability of scores;
  - Burden;
  - Alternative modes and methods of administration;
  - Cultural and language adaptations; and
  - Electronic health record capability.
- **Person-Centered.** Using PROMs is an important step toward engaging patients, health professionals, and other entities in creating a person-centered health system.
- **Meaningful.** Meaningfulness encompasses the relevance and degree of importance of the concepts measured by the PROM from the perspective of patients, their families, and caregivers as well as clinicians and other health professionals who serve them. The following framework, coined as the three "Cs," are three aspects of meaningfulness on which to seek patient input:
  - *Conceptual*—Engaging people in dialogue about what matters most to them to define concepts that PROs should address.
  - *Contextual*—Learning how individuals use the information derived from PROMs and PRO-PMs.
  - *Consequential*—Determining what happens when PRO-PM information is used in accountability applications or performance improvement.
- **Amenable to Change.** There is evidence that the outcome of interest is responsive to a specific healthcare or support service or intervention.

[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.

- **Implementable.** Many diverse factors affect a PROM's practical use in quality or accountability programs, including but not limited to:
    - addressing literacy and health literacy of respondents;
    - addressing cultural competency of clinicians and other service providers;
    - dealing with the potential for unintended consequences related to patient selection;
    - covering costs associated with using PROMS (especially those not available in the public domain); and
    - adapting PROMs to computer-based platforms or other formats.

CMS SUMMARY OF PATIENT FEEDBACK FOR PROMS AND PRO-PMS

While not guidelines per se, the Centers for Medicare and Medicaid Services (CMS) has gathered stakeholder feedback on existing ESRD PROs and suggestions for future PRO investigation from the renal community. Key take away messages from stakeholders include:

- PROs are regarded as important and there is significant interest in further work in this area.
- Both patients and providers expressed concerns about the existing ICH-CAHPS and KDQoL-36 measures. These include survey burden (due to administration frequency/length and unnecessary questions); low response rates; and limited actionability for providers.
- Feedback was mixed about the level of evidence to support use of most of the current measures as quality measures; stakeholders emphasized that measures need to be reliable, valid, and practical for implementation.
- Patient and provider perspectives diverge on important PROs:
    - Patient groups specified that they care about a combination of both health-related outcomes and facility operational characteristics.
    - Providers stated that health-related outcomes are important, while facility characteristics like cleanliness or staff attentiveness are issues that have been addressed or can be easily remedied, and should not be included in performance measures of care quality.
- Providers and patients stated that PRO measures and assessments should incorporate patients' goals for their care in order to reflect outcomes important to the individual patient.
- One instrument or shorter instrument(s) should be used to measure PROs.
- More work is needed for development of PRO measures, owing to the complexities in defining and measuring PROs and data collection sources.
- Some patients and providers expressed interest in recovery time as a PRO, and similarly, a measure of patient experience of treatment.