NATIONAL QUALITY FORUM

Meeting Summary

Prioritizing Measure Gaps: Person-Centered Care and Outcomes Committee Web Meeting

January 30, 2014 | 1:00 pm –3:00 pm ET

The National Quality Forum (NQF) convened a web-based meeting of the Prioritizing Measure Gaps Person-Centered Care and Outcomes Committee members on Thursday, January 30, 2014. An online archive of the meeting is available.

Committee Members In Attendance

Name	Organization
Uma Kotagal, MBBS, MSc (co-chair)	Cincinnati Children's Hospital Medical Center
Sally Okun, RN (co-chair)	PatientsLikeMe
Ethan Basch, MD, MSc	University of North Carolina at Chapel Hill
Dave deBronkart, Jr.	Society for Participatory Medicine
Joyce Dubow, MUP	AARP
Jennifer Eames-Huff, MPH	Consumer-Purchaser Disclosure Project
Troy Fiesinger, MD	Memorial Family Medicine Residency
Lori Frank, PhD	Patient-Centered Outcomes Research Institute
Priti Jhingran, BPharm, PhD	GlaxoSmithKline
Bruce Leff, MD	Johns Hopkins University School of Medicine
Michael Lepore, PhD	Planetree
Mary MacDonald, MS, BA	American Federation of Teachers
Mary Minniti	Institute for Patient-and Family-Centered Care
Eugene Nelson, MPH, DSc	Dartmouth Institute for Health Policy and Clinical Practice
Mark Nyman, MD, FACP	Mayo Clinic
Anne Walling, MD, PhD	University of California-Los Angeles
Cille Kennedy	Government Task Leader, ASPE, HHS
Kevin Larsen	Government Task Leader, ONC, HHS

Welcome, Committee Introductions and Disclosures of Interest

Karen Pace, Senior Director, NQF, welcomed the committee members and the public audience to the web meeting and reviewed the meeting objectives. The meeting objectives articulated were to:

- Review project scope and timeline
- Gain consensus on proposed definition and core concepts
- Seek input on the measurement framework
- Review the environmental scan and identify performance measures

Ann Hammersmith, NQF General Counsel, led the introductions of the committee members along with their disclosures of interest. Uma Kotagal and Sally Okun, Committee co-chairs offered opening remarks.

Background & Project Overview

Wendy Prins, Senior Director, NQF, provided background information on the Priority Setting for Health Care Performance Measurement: Addressing performance Measure Gaps in Priority Areas project. She provided historical context for the project and highlighted the importance of taking a deeper dive on identifying and prioritizing gaps in performance measurement.

Mitra Ghazinour, Project Manager, NQF, reviewed the specific tasks and overall approach to completing the project including:

- Convene a multistakeholder committee of experts including patients and patient advocates.
- Identify existing models and core concepts as a basis for envisioning the ideal state or "north star" of person-centered care.
- Seek input from patients (and families) on what information would be useful for assessing person-centered care.
- Conduct an environmental scan of potential performance measures, status of development, and alignment with concepts of person-centered care.
- At the in-person meeting, review the above inputs and create the vision of the ideal state or "north star" of person-centered care and identify how best to measure performance and progress in the delivery of person-centered care.
- Based on ideal person-centered care, recommend specific measures for implementation or specific concepts for development of performance measures.
- Obtain public comment, and then finalize recommendations.

Draft Conceptual Framework

Karen Pace, Senior Director, NQF, reviewed the proposed definition and core concepts presented in the Draft Conceptual Framework report, noting that they will serve as a starting point for developing a framework which will be a major task of the April in-person meeting. Ms. Pace introduced a draft definition of person and family centered care, drawn from the Institute of Medicine's (IOM's) prior work on patient-centeredness and the Institute for Patient- and Family-Centered Care definition and core concepts. The draft definition states, "Person- and family-centered care is an approach to the planning, delivery, and evaluation of healthcare that is anchored by, respectful of, and responsive to the individual's preferences, needs, and values (including involvement of family) to ensure that individual values guide all clinical decisions". Ms. Pace then reviewed the proposed core concepts, explaining that they are spawned from the basic concepts emerging through various sources such as, the IOM, the Institute for Patient- and Family- Centered Care, and the National quality strategy priorities and goals, et cetera.

Next, Ms. Pace discussed the draft performance measurement framework, highlighting some of the challenges associated with performance measurement related to person and family centered care including: abstract concepts not easily defined by one data point, different definitions and interpretations, multiple strategies for achieving the desired experience, outcome measurement not a sufficient indicator of person- and family- centeredness, and structures that support person-centered care (e.g., extended office hours, email communication) being better suited as standard information

than a formal performance measure. Ms. Pace then discussed the key principles for person-centered performance measurement including the following:

- Meaningful to consumers and built with consumers
- Focused on their entire care experience, rather than a single setting or program
- Measured from the person's perspective and experience (i.e., patient-reported unless not necessary such as information on extended office hours).

Lastly, Ms. Pace reviewed the definition of a Patient-Reported Outcome (PRO) and the PRO's domains of Health-related quality of life including functional status, experience with care, symptom and symptom burden, and health-related behaviors that were developed through the NQF Patient-Reported Outcomes and Performance Measurement Project. She noted that some PROs may not be an explicit indicator of patient-centered care. For example, patient-reported outcome measures on function or symptoms and symptom relief although of great interest to patients, might be considered an indicator of treatment effectiveness rather than person-centered care.

Sally Okun led the committee discussion of the draft definition and core concepts. A number of committee members noted that the last part of the definition that speaks about ensuring that individual's values guide all clinical decisions seems to be more restricted than what precedes it. They recommended that the definition be refined to read "…to ensure that individual preferences, needs, and values guide all clinical decisions". Others expressed that focusing on clinical decisions is limiting and other factors such as access, built environment structures, and care coordination can also indicate person-centered care. A few members inquired as to why the hybrid definition has excluded the reference to mutually beneficial partnerships among health care providers and patients as it was written in the Institute for Patient- and Family-Centered Care definition and highlighted the importance of provider and patient interaction in engaging and empowering patients to be active partners in their own care. The question for further exploration may be what benefit to the provider is essential to person-centered care.

Committee members then discussed expanding the existing core concepts to include other aspects of person-centered care such as treatment burden or over treatment, affordability of care, patient readiness, patient-provider communication, goals of care and follow-up plans, and family support and resources. It was noted that the safety and effectiveness aspects of care should not be entirely excluded from the framework and may be considered in this task in parallel with other work relating to these areas. Committee members also recommended breaking down the core concepts to sub-levels and adding real life examples to illuminate what each core concept potentially mean. One committee member noted that the proposed core concepts primarily focus on the patient experience of care and do not address the outcomes desired by patients including good health and reducing the burden of illness. This will be explored further as the committee envisions ideal person-centered care and the structures, processes, and outcomes that represent ideal person-centered care. Some committee members questioned whether the project is focused on person-centered care or person- and family-centered care and to more explicitly address the family.

Draft Environmental Scan of Measures

Mitra Ghazinour, Project Manager, NQF presented the results of the preliminary environmental scan of measures and measure concepts related to person and family centered care, drawn from several

sources such as the NQF portfolio, the AHRQ National Quality Measures Clearing House. Out of more than 5000 measures and measure concepts that were reviewed, 803 were mapped to the PRO domains. The majority of the measures were related to the patient experience of care domain and a fewer were mapped to the domains of health-related quality of life and symptom and symptom burden. She noted that with limited information on measure specifications, it was difficult to identify if they are patient reported or clinician assess. Lastly, Ms. Ghazinour stated that NQF will be reaching out to the committee members and the previously convened NQF PRO expert panel to identify examples where measurement of performance on person-centered care is occurring.

Uma Kotagal then led the committee discussion regarding the next steps by asking the committee what they would need to be prepared for the in-person meeting. Committee members expressed their preference for further refining the definition and the core concepts in advance of the in-person meeting. They also stated that the environmental scan should not be limited to the identified PRO domains and need to include other quality measures that might be important to drive patient-centered care. Other comments included bringing forward the work that has already been done by a variety of organizations such as the IOM and gathering qualitative information by speaking directly to patients and families. Karen Pace responded that NQF will look to the committee members to provide some of this information based on their expertise and knowledge of the topic area. Lastly, committee members noted that it would help if NQF provided specific instructions and questions regarding the type of input sought from the committee.

Next Steps

NQF will continue refining the definition and core concepts and seek input on identifying measures and concepts related to person and family centered care by reaching out to the committee members. NQF will hold a two-day in-person meeting on April 7-8, 2014. Draft final report will be available for public comment in June/July 2014 and final report will be due to HHS in August 2014.