NATIONAL QUALITY FORUM

Meeting Summary

Prioritizing Measure Gaps: Person-Centered Care and Outcomes Committee
In-Person Meeting
April 7-8, 2014

The National Quality Forum (NQF) convened the Prioritizing Measure Gaps: Person-Centered Care and Outcomes Committee members for a two day in-person meeting on April 7 and April 8, 2014. The meeting materials and transcripts can be accessed online. An online archive of the meeting is also available: (Day 1; Day 2)

This is a brief meeting summary focused on describing the purpose and process of the meeting. The results and recommendations form the meeting will be synthesized in a formal report, which is the primary deliverable for this project.

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
Christopher Forrest, MD, PhD	The Children's Hospital of Philadelphia
Lori Frank, PhD	Patient-Centered Outcomes Research Institute
Priti Jhingran, BPharm, PhD	GlaxoSmithKline
Lisa Latts, MD, MSPH, MBA, FACP (by phone)	LML Health Solutions, LLC, Denver, CO
Bruce Leff, MD	Johns Hopkins University School of Medicine
Michael Lepore, PhD	Planetree
Mary MacDonald, MS, BA	American Federation of Teachers
Maureen Connor (Substitute for 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
Laurel Radwin, RN, PhD	Veterans Administration, Manchester
Anne Walling, MD, PhD	University of California-Los Angeles

HHS and NQF staff in attendance:

- Cille Kennedy, Government Task Leader, ASPE, HHS

- Kevin Larsen, Government Task Leader, ONC, HHS
- Ellen Makar, Senior Policy Advisor, ONC, HHS
- Jennifer Wolff, PhD, Johns Hopkins Bloomberg School of Public Health
- Karen Pace, Senior Director, NQF
- Wendy Prins, Senior Director, NQF
- Mitra Ghazinour, Project Manager, NQF
- Kaitlynn Robinson-Ector, Project Analyst, NQF

Welcome and Introductions

Uma Kotagal and Sally Okun, co-chairs, welcomed the Committee members and the public audience to the meeting and led the introductions of the committee members who shared their views on receiving, delivering, and/or measuring person- and family-centered care.

Setting the Stage

Ms. Kotagal and Ms. Okun reviewed the meeting objectives and the agenda. The meeting objectives were to:

- Finalize definition/core concepts of ideal person- and family-centered care
- Identify how to measure person- and family-centered care (i.e., the core concepts)
- Prioritize opportunities for person-centered care performance measurement, i.e., short term vs. longer-term

Ms. Kotagal and Ms. Okun then laid out the expectations for participation in the meeting which included open sharing of and respect for views, perspectives, agreements, and differences, as well as helping to work toward consensus, meeting objectives, and staying on time. Ms. Kotagal and Ms. Okun provided clarification on the scope of the project and its objectives, noting that other domains of quality which may be related to or affected by person-centered care such as safe, effective, and affordable care will not be addressed under this project. Ms. Kotagal and Ms. Okun also clarified the term “measure”, stating that it could be used to refer to patient-level data such as a blood pressure or lab values, as well as a score on an instrument or scale. Measure can also refer to provider or organization-level measures that are created by aggregating the patient-level data (referred to as performance measures). Ms. Kotagal and Ms. Okun discussed the patient-reported outcomes (PROs) definition and domains and noted that not all PROs indicate person- and family-centered care. Additionally, Ms. Kotagal and Ms. Okun stated that the definition and core concepts will serve as a starting point to describe what it is we are attempting to measure. The core concepts can be thought of as the experience of receiving person- and family-centered care or outcomes and there are various structures and processes of care that can be used to achieve those experiences.

Next, Kevin Larsen, Government Task Lead, provided opening remarks and discussed the context for HHS funding the project. Person- and family-centered care is a priority area in the national quality strategy but there are very few measures. This project can help inform the federal government where to invest in measure development.

Project Overview and Related NQF Projects

Ms. Mitra Ghazinour, Project Manager, NQF, provided a brief overview of the project and discussed the next steps. She then provided a high-level overview of current work at NQF focusing on person- and family-centered care including:

- MAP Person- and Family-Centered Care Measures
- Person- and Family- Centered Care Endorsement Measurement
- Patient and Family Engagement Action Team

A discussion was followed that pointed to how these efforts could be coordinated for cross-fertilization and integration of recommendations when and where appropriate to move the field forward.

Definition and Core Concepts for Person- and Family-Centered Care

Panel- Exemplars of the Core Concepts

Ms. Kotagal presented the draft definition and core concepts for person- and family-centered care that were developed using the foundational works of the National Quality Strategy (NQS) priorities of person- and family-centered care and communication and coordination, the IOM domain of patient-centered, and the Institute for Patient- and family-centered care definition and core concepts. The draft definition and core concepts had further been refined in an iterative process which included a committee web meeting, followed by a committee poll, and additional input from the co-chairs.

Next, a panel of the Committee members presented real-life vignettes that exemplified each draft core concept in the following order:

1. Whole Person, goal, priorities – *Gene Nelson, MPH, DSc,* Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH
2. Care I need, when, where, how I prefer – *Uma Kotagal, MBBS, MSc, Cincinnati Children's Hospital Medical Center, Cincinnati, OH*
3. Respect, dignity, compassion – *Anne Walling, MD, PhD, University of California-Los Angeles, Los Angeles, CA*
4. Collaborate in decisions – *Michael Lepore, PhD, Planetree, Atlanta, GA*
5. Family – *Jennifer Wolff, PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD*
6. Information – *Bruce Leff, MD, Johns Hopkins University School of Medicine, Baltimore, MD*
7. Time valued – *Dave deBronkart, Jr., Society for Participatory Medicine, Nashua, NH*
8. Communication – *Troy Fiesinger, MD, Memorial Family Medicine Residency, Sugar Land, TX*

Some of the points emerging from the vignettes and subsequent discussion included:

- Overlap across core concepts, so could consider combining some.
- Open communication is important.
- Common theme is meeting people where they are. Takes time and constant assessment and reassessment.
- Concepts of empathy, compassion, and humanness of care were emphasized throughout all vignettes.
- Confluence of empathy, caring, capacity for empowering, competence/confidence in self-management.
- The heart of person- and family-centered care is individualization. Think about how you would individualize care for each person and their families with the right kind of information.
- There is a need for "creative collaboration", co-decision making, and co-production of the plan.

- Thinking about a systems approach to which would include micro systems (e.g., compassion and empathy of individual clinician) and macro systems (e.g., infrastructures that support compassionate care).
- Not all aspects may lend themselves to performance measurement. Some information might be appropriate for a standard information “label” for person- and family-centered care.
- Need to be thinking about reconciling the warmth and humanness of person-centered care with the science of measurement (i.e., reliability and validity).
- Person-centered desires could conflict with quality of care as defined by the physician, or system capacity, or with other patients’ needs (e.g., wait time increased because of need of another patient).
- Just ask – how was this visit for you? Did you feel taken care of?

Definition and Core Concepts for Person- and Family-Centered Care

Panel of Patient and Patient/Consumer Representatives

A panel of patient and patient/consumer representatives addressed the following question in a series of brief presentations. “Do the definition and core concepts capture your view of ideal person-and family-centered care?”

The panel consisted of the following Committee members:

- *Dave deBronkart, Jr., Society for Participatory Medicine, Nashua, NH*
- *Joyce Dubow, MUP, AARP, Washington, D.C.*
- *Jennifer Eames-Huff, MPH, Consumer-Purchaser Disclosure Project, San Francisco, CA*
- *Mary MacDonald, MS, BA, American Federation of Teachers, Washington, D.C.*
- *Maureen Connor, RN, MPH, Institute for Patient-and Family-Centered Care, Eugene, OR*
- *Sally Okun, RN, PatientsLikeMe, Cambridge, MA*

The panel presentations and the discussion that followed indicated the desire for further refinement and simplification of the draft definition and core concepts and additional considerations such as:

- In core concept #1, remove “strive” and just know me.
- Simplify core concept #6 – provide “any” information
- System perspective is needed as healthcare system is interconnected and complex.
- When defining person and family centered care, consider adding this notion, “when patient and family centered care is happening, the patient and family feel cared for.”
- What we are trying to describe is the outcomes that patients really want.
- Need to stay away from processes as not to stifle innovation; also could tend to be “check the box”.
- Need to tailor communication to individuals. One size does not fit all. Concept #6 needs to say “I want communication the way I want and understand”.
- Patients being prepared to be engaged.
- A partnership is a coming together of patients, families, and physicians. Families are the stewards of patient safety.
- Need to determine who will be ultimately responsible and accountable for providing person-centered care and thinking about attribution when speaking about systems.

Definition and Core Concepts for Person- and Family-Centered Care

Ms. Karen Pace, Senior Director, NQF, facilitated further committee discussion on the draft definition and core concepts to identify level of support or any objections that would prevent moving forward. Committee members stated that although the last core concept addresses the communication element and communication goes a long way towards coordination, coordination of care involves more than communication and another group is focusing on care coordination. Committee members felt the term “care partners”, which was meant to be inclusive of providers of care and family members, was confusing and suggested using family separately and defining care partners to include all providers of care – health professionals and all healthcare workers. Some members thought concepts could be combined, others suggested splitting some out – for example prepared for self-care management. However, there was general agreement that the core concepts captured all the major ideas for the committee to continue its work to identify potential performance measure concepts.

Measurement Framework

In this segment of the meeting, Ms. Pace provided an overview of the NQF Endorsement Criteria. She then defined and provided examples of a Patient-Reported Outcome (PRO) performance measure vs. PRO-based practice and instrument/tool. Ms. Pace described PRO-PMs in relation to person- and family-centered care, stating that identified core concepts for person- and family-centered care would represent the PRO domain of experience with care and PRO-PMs for other domains (health-related quality of life/functional status, symptom/symptom burden and health/related behaviors) are primarily indicators of treatment effectiveness and not necessarily delineate person-centered care. Next, Ms. Pace discussed the draft measurement framework and illustrated the type of structures, processes, and outcomes that could be measured to address the core concepts. Lastly, Ms. Pace explained the notion of label for person- and family-centered care which could be analogous to the idea of “Nutrition Label”. A potential label would include: standard set of items, standard definitions, standard ways to present information, and standard format/layout.

Innovative Approaches

Two presentations on innovative approaches to person-centered care were used to stimulate new ideas before the committee began to identify performance measure concepts. Dr. James L. Holly from SETMA discussed the idea of convenience (e.g., schedule visits with multiple providers on the same day) and how it directly correlates with higher quality of care. Dr. Yount provided an overview of the Patient-Reported Outcomes Measurement Information System (PROMIS) and discussed its unique features as well as describing the PROMIS frameworks and measures. Dr. Eisenstein presented on a study that uses PROMIS measures to individualize goals and measurement of PROs that are most relevant to the individual (Standardizing and Personalizing Patient-Centered Rheumatoid Arthritis Treatment Targets).

Small Group Work: Identify Measure Concepts

With the goal of identifying potential performance measure concepts for each core concept, the Committee was divided into four groups. Members of each group were asked to identify potential measure concepts and discuss with the group. Each group then was asked to recommend 2-5 measure concepts for each core concept. The Committee members were also asked to identify any items that might be useful for a standardized label.

Next, each group presented suggested measure concepts to the full committee for discussion. Following are some of the initial suggestions. However these will be modified based on the committee discussion of the core concepts and potential measure concepts, the potential for a standard label, existing CAHPS measures, and discussion of short and long-term recommendations. The final recommendations for performance measurement will be presented in the final report.

Group 1 addressed concepts 1 and 2. The group included: Gene Nelson, Uma Kotagal, Ethan Bash, Jennifer Eames-Huff, and Priti Jhingran

Core Concept #1: My care partners strive to know me as a whole person and take into account my priorities and goals for physical, mental, spiritual, and social health.

- See patient as whole person
- Care centered on goals and preferences
- Systematic assessment of PROs and well-being
- Staff training in patient engagement

Core Concept #2: I receive the care I need – no more, no less – when, where, ad how I prefer.

- Global measure of care I need, when, where, how I prefer
- Convenience of communication
- Convenience of scheduling
- Care coordination and interdisciplinary care

Group 2 addressed concepts 3 and 4. The group included: Michael Lepore, Anne Walling, Christopher Forrest, Mary MacDonald, and Sally Okun

Core Concept #3: My care partners treat me and my family with respect, dignity, and compassion.

- Culture of respect: system treats clinicians with respect and dignity
- Respectful environmental design: Support for privacy (for patients and families) as well as being welcoming for family
- High levels of elicitation, checking for understanding, open-ended questions
- Structure [Time management (System), Checking systems are respectful of patients and clinicians time; patients are able to access providers; Providers are not rushed, have time to answer all questions]

Core Concept #4: I collaborate in decisions about my care to the extent I desire or am able, or I choose the care partner I prefer to collaborate in those decisions for me.

- Information Commons and Information sharing architecture
- Recertification requirements for providers tied to family engagement as part of the evaluation process. Institution has clear requirements for patient engagement
- Elicitation of preferences for collaborative decision-making
- Preferences match care received

Group 3 addressed concepts 5 and 6. The group included: Bruce Leff, Jennifer Wolff, Maureen Connor, Joyce Dubow, and Laurel Radwin

Core Concept #5: My family care partners include those I choose and their role is supported by other care partners. (The group recommended splitting this core concept into two)

- Assessing the family care partners about their experiences and burnouts
- Practice infrastructure (e.g. Relationship with appropriate services to support – practice and non-practice based)
- Assessment of experience of support of family care partners by other care partners

Core Concept #6: My care partners provide information, in a format I prefer, to: answer my questions and help me understand my choices – about my health, health problem, treatment, care, costs, or providers; and increase my confidence and capacity to care for myself to the extent I am able.

- Did you get the information you needed
- System ability to deliver information in a flexible manner to patients and caregivers

Group 4 addressed concepts 7 and 8. The group included: Troy Fiesinger, Dave deBronkart, Lori Frank, Mark Nyman, and Kevin Larsen

Core Concept #7: My care partners value my time and use it efficiently and effectively.

- My care team demonstrated they valued/cared about my time – when I have to wait, I am given an explanation
- At a system level, time is considered important

Core Concept #8: Communication with and among my care partners is honest, transparent, and coordinated across settings and time.

- Right Information at right time to right patient --did you understand?
- Patient perception of communication quality
- Care Team/Patient Communication
- Information access (e.g., patient has access to clinical notes and record)

Identify Short-Term and Long-Term Recommendations

A round-robin discussion from the Committee members regarding short and longer-term recommendations identified several key points including the following:

- Long-term recommendations- Develop a "Person-centered Care 10" measure (like PROMIS 10)
- The priority for measurement should be on the patient-reported information over and above structures and process.
- Form a group that brings together people working on PROMIS and CAHPS for mutual learning and measure development, looking at short-term existing CAHPS measures vs. longer-term for measure development.
- When thinking about measurement, be mindful of the delivery system that is evolving quickly (e.g., Walgreens the new primary care).

- Consider food label notion for a standardized way of communicating information related to person- and family-centered care, particularly for structures.
- Start at a baseline with a simple question about how it’s working out; talk to people in grocery stores. To find out what quality is, need to ask the ultimate end-user.
- Don’t try to untangle, but transform—some of these things have already been solved. Figure out what they did and spread it.

Next Steps

The meeting concluded with a discussion of immediate next steps including preparing a draft report of the Committee’s measure gap priorities and recommendations, review of the draft report by the Committee, and a public comment period June 23 through July 14, 2014. A public web meeting will be held on June 30th, 3pm-5pm EST to discuss the projects findings and address any further areas for improvement. The final report will be due to HHS on August 15, 2014.