National Quality Forum
Patient Reported Outcomes Workshop #1
July 30-31

1030 15th Street NW, 9th Floor Conference Center

Audience dial-in: (877) 303-9138; Passcode: 95535825

URL: http://nqf.commpartners.com, Type **408010 i**n the "Enter a Meeting" box
Wifi Network: guest; Password: NQFguest

Draft 07/25/12

Meeting Objectives:

1. Identify best practices and lessons learned from initiatives that have implemented individual-level PROs in performance measurement;
2. Discuss the major methodological issues related to the selection, administration and use of individual-level PROs in performance measures;
3. Discuss key considerations for inclusion of PROs into EHRs and policy implications;
4. Identify the characteristics of individual-level PROs suitable for potential use in performance measures; and
5. Identify an initial set of PROs most suitable for development and testing of performance measures.

AGENDA

Day 1

8:30-9:00 Breakfast (Expert Panel only)

9:00-9:30 Welcome & Setting the Stage

Patricia Brennan*, University of Wisconsin-Madison &* Joyce Dubow*, AARP, Co-chairs*

Helen Burstin*, Senior Vice President, Performance Measures, National Quality Forum*

- Overview of project scope and acknowledgment of sponsor
  - How this project fits into the broader Quality Measurement Enterprise and NQF portfolio of performance metrics
  - Distinctions and connections between PROs and performance measures
- Value of PROs to patients and clinicians
  - Duplicity of uses of PROs: quality improvement and accountability (e.g., public reporting and payment)
- Defining PROs – parameters of what's in and what's out
  - Framing PROs within the NQF endorsed patient-focused episode of care measurement framework including health behaviors
  - End game: Objectives and desired outcomes of today's meeting

Audience engagement and feedback

9:35-10:45 Acknowledging the Patient as an Authoritative Data Source

Moderator: Joyce Dubow

David Cella, *Northwestern University Feinberg School of Medicine, Commission Paper Author tee-up key issues for discussion*

Reactor Panel: Charles Mosley, *National Association of State Directors of Developmental Disability Services;* Stephan Fihn*, Veterans Health Administration;* Jennifer-Eames Huff, *Pacific Business Group on Health*

- How do we best build the value proposition for clinicians and policy makers that patient input is credible? (e.g., evidence-base linking PROs to improved outcomes; PROs informing care processes)
- How do we ensure PRO data is useful to patients as well as other end users?
- What are best practices to minimize barriers to individuals being able to self-report outcomes (e.g., age, functional status, cognition, language/culture) and implications on performance measurement?

Audience engagement and feedback

10:45-11:00 **BREAK**

11:00-11:40 Promise of PROs in Improving Patient Outcomes: Lessons from the Field

Moderator: Greg Pawlson, *BlueCross BlueShield Association*

- Partners Healthcare (*Elizabeth Mort, Massachusetts General Hospital*)
- Dartmouth Spine Center (*Eugene Nelson, Dartmouth- Hitchcock Medical Center*)

Audience engagement and feedback

11:45-1:00 Methodological Issues: Method of Administration/Collection & Response
Moderator: Ethan Basch, *Memorial Sloan-Kettering Cancer Center*
David Cella, *Commission Paper Author tee-up key issues for discussion*
Brief demo of CAT (e.g., PROMIS) by David Cella

Reactor Panel: Lewis Kazis, *Boston University School of Public Health*;
Richard Bankowitz, *Premier Healthcare Alliance*;
Lori Frank, *Patient Centered Outcomes Research Institute*

- What is the relationship between static and adaptive approaches to measurement? How do we bridge these approaches (e.g., hybrid approaches)?
- What are the implications of different types of administration (e.g., in-person, mail, web, CAT, IRT, tablet in the waiting room/exam room, provider vs. third party) on response rate, reliability, and validity/bias?
- What are the implications for reliability and validity of using a different method of administration than originally validated, or using multiple methods of administration?
- What are the implications of low response rates and potential bias in responders versus non-responders for usefulness in performance measurement?
- Are responses by proxies allowed, under what circumstances, and what are the implications for reliability and validity of the reported outcome?
- What are the implications of response shift (adaptation) in the measurement of PROs?

Audience engagement and feedback

1:00-1:45 **LUNCH BREAK (lunch provided to Expert Panel on-site)**

1:50-3:00 Methodological Issues: Selecting Patient-level PROs

David Cella, *Commission Paper Author tee-up key issues for discussion*

Moderator: Albert Wu, *Johns Hopkins Health System*

Reactor Panel: Jim Bellows, *Kaiser Permanente*; Eugene Nelson, *Dartmouth-Hitchcock Medical Center*; Kalahn Taylor-Clark, *National Partnership for Women & Families*; Kenneth Ottenbacher, *The University of Texas Medical Branch and Galveston*

- What characteristics identify PROs that are suitable for potential use in performance measures?
- What is the relevance of PROs used in controlled research conditions to use in real-life clinical practice? (e.g. , large clinical trial versus small clinic setting)
- When can general health status measures be utilized and when should condition-specific measures be utilized? Are there any setting-specific issues for selection of PROs?
- What conditions would be most sensitive to measuring changes in patient health status/outcomes? What is the variation in patient-level scores related to clinical interventions (e.g., hip replacement)?
- What are meaningful (clinically and to the patient), not just statistically significant changes (effect size) in patient-reported outcomes?
- What is the impact of patient baseline characteristics and baseline PRO scores on change in scores?
- Under what circumstances is stabilization (no change) a desired outcome?

Audience engagement and feedback

3:00-3:15 **BREAK**

3:20-4:30 Key Considerations for Incorporating PROs into Electronic Health Records

Moderator: Patricia Brennan

David Cella, *Commission Paper Author tee-up key issues for discussion*

Reactor Panel: Uma Kotagal*, Cincinnati Children's Hospital Medical Center;* Kevin Larsen, *Office of the National Coordinator for Health Information Technology*; Ted Rooney, *Maine Quality Counts*

- How does the use of EHRs enable PROs to be used in performance measurement?
- To what extent should different types of patient-reported information be incorporated into EHRs (e.g., function, health status vs. health behaviors, experience with care)? How will patient privacy be safeguarded?
- How can existing programs/initiatives be leveraged (e.g., meaningful use)?
- What are the essential conditions (e.g., EHR structure, technology, data integration, data standards) to integrate PROs into the electronic health record?

Audience engagement and feedback

4:35-5:00 Closing Comments and Prep for Day 2 Activities
Patricia Brennan & Joyce Dubow, Co-chairs

Day 2

1030 15th Street NW, 9th Floor Conference Center

Audience dial-in: (877) 303-9138; Passcode: 95551282

URL: http://nqf.commpartners.com, Type **837858** in the "Enter a Meeting" box
Wifi Network: guest; Password: NQFguest

8:00-8:30 Breakfast (Expert Panel only)

8:30-9:00 Recap of Key Themes from Day 1
Joyce Dubow & Patricia Brennan, Co-chairs ()

Audience engagement feedback

9:05-9:20 Break- out Session: Selecting Individual-level PROs for Performance Measures
Session Overview: Eugene Nelson*, Dartmouth- Hitchcock Medical Center*
& Karen Adams, *Vice President of National Priorities, National Quality Forum*

9:20-9:30 Travel to breakout groups

Logistics:

- *Participants will breakout into workgroups addressing the following 4 categories of PROs:*
  - *HRQoL/Functional Status:* Facilitator: Kathleen Lohr, *Research Triangle Institute*
  - *Health-Related Behaviors:* Facilitator: Eugene Nelson, *Dartmouth- Hitchcock Medical Center*
  - *Symptoms & Symptom Burden:* Facilitator: Debra Saliba, *University of California- Los Angeles Borun Center*
  - *Patient Experience with healthcare:* Facilitator: Robert Weech-Maldonado, *University of Alabama at Birmingham*
- *Participants will be pre-assigned to a group before the meeting based on preference as feasible.*
- *Participants will be charged to apply the emerging characteristics from the meeting discussion (and informed by the background paper) to select PROs in their designated category to determine readiness to consider for performance measurement.*
- *A facilitator from the planning committee will be pre- assigned to each group*

- *The Expert Panel will be dispersed amongst the groups.*
- *NQF staff will be assigned to each break out group to help with transfer and note taking.*
- *Each group will self-identify a spokesperson to report back to the full group & a scribe who will assist the assigned NQF staff with populating the template.*

9:35-11:30 Breakout group work (not available through webinar or conference call)

Based on the background paper & workshop discussion thus far:

- What characteristics should be used to identify PROs for potential use in performance measures? Will these differ based on the needs of the end-user?
- What existing individual-level PROs have these identified characteristics and are candidates for potential development of performance measures?

11:30-12:15 **LUNCH**

12:20-1:30 Report Back & Iterative Discussion

Characteristics are captured real time by staff and projected on the screen for validation & additional feedback. List of potential PROs is compiled.

David Cella, *Northwestern University Feinberg School of Medicine, Commission paper author*

- Discussion of emerging characteristics and list of eligible PROs for potential development of performance measures

1:30-2:00 Recap & Next Steps for 2nd Workshop

Joyce Dubow & Patricia Brennan (virtually), Co-chairs

2:00 Adjourn