



**National Quality Forum  
Patient Reported Outcomes Workshop #2  
September 11-12**

**DRAFT 08/27/12**

**1030 15th Street NW, 9th Floor Conference Center**

Wifi Network: guest; Password: NQFguest

Audience/General Registration number: (877) 303-9138 (both days)

Conference ID **Day 1**: 20945526 Conference ID **Day 2**: 21017521

Webinar Link **Day 1**: <http://nqf.commpartners.com/se/NQFLogin/> Webinar Meeting ID Day 1: 323476

Webinar Link **Day 2**: <http://nqf.commpartners.com/se/NQFLogin/> Webinar Meeting ID Day 2: 391249

**Meeting Objectives:**

1. Discuss the major methodological issues related to reliability and validity when aggregating individual-level PRO data into a performance measure;
2. Identify unique considerations in relation to the NQF endorsement criteria for PRO-based performance measures (PRO-PM) (as compared to other quality outcome performance measures); and
3. Lay out the critical path from individual-level PRO to aggregate-level PRO-PM endorsed by NQF for use in accountability and performance improvement.

**Terms**

**PRO** – refers to the individual-level patient-reported outcome (person-reported outcome)

**PRO-PM** – refers to the aggregate-level performance measure

**AGENDA**

**Day 1 – September 11**

8:30-9:00 Continental Breakfast & Networking (provided for Expert Panel/Authors)

9:00-9:30 Welcome & Setting the Stage **(15 min)**

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

- Context
  - NQF endorses PRO-PMs, not the individual-level PROs
  - NQF endorses PRO-PMs for use in accountability applications such as public reporting and payment
  - NQF evaluates suitability for endorsement based on a set of [evaluation criteria](#)

- Product of the workshop: Pathway from individual-level PRO to NQF-endorsed PRO-PM for use in accountability applications, including unique considerations in relation to the NQF endorsement criteria taking into account the key methodological issues
- Draft pathway from PRO to PRO-PM  
*Drawing from the commissioned papers and groundwork from 1<sup>st</sup> workshop, a “strawman” pathway (represented in a flow schematic) serves as a starting point and will be refined on Day 2.*

**Expert Panel and Audience Engagement (15 min)**

9:35-11:05

**Lessons from the field – using PRO-PMs for accountability (public reporting, payment)**

*Our international experts will be joining via webinar/skype.*

**Moderator:** Greg Pawlson, *BlueCross BlueShield Association (5 min)*

**Panel:** UK–David Nuttall, *Branch Head - Choice, AQP & PROMs, Strategy, Finance and NHS Directorate, Department of Health*; Medicare Advantage –Elizabeth Goldstein, *Director Division of Consumer Assessment and Plan Performance, Center for Medicare* ; Sweden–Stefan Larsson, MD, PhD, Senior Partner & Managing Director Stockholm Office, Boston Consulting Group **(15 min each – total 45 min)**

- What individual-level PROs were implemented for performance measurement and accountability and what were the key characteristics or considerations used for selection?
- How were the individual-level PRO data aggregated into performance measures (e.g., average/median amount of change; percentage who improve/reach benchmark/ have meaningful change)?
- How were reliability and validity of the aggregate- level performance measure demonstrated (beyond reliability and validity of the individual-level PRO)?
- How were threats to validity addressed (e.g., risk adjustment, response rate, missing data)?
- How are the PRO-PMs being used and what are their impact?

**Expert Panel and Audience Engagement (40 min)**

11:05-11:20

**BREAK**

11:25-12:45

**Recap of Key Characteristics for Selecting Individual-level PROs for Use in Performance Measurement**

- Key Characteristics (**Joyce Dubow –10 min**)  
*Prior to the workshop, the Expert Panel will review potential additions to the characteristics identified in Table 3 from the 1<sup>st</sup> paper.*
- Overview of related NQF endorsement criteria: evidence; usability and use; feasibility (**Karen Pace, National Quality Forum – 5 min**)
- **Panel:** Elizabeth Mort, *Massachusetts General Hospital*; Laurie Burke, *Food and Drug Administration*; other pending **(10 min each – total 30 min)**
  - Psychometric properties (Table 3 from 1<sup>st</sup> paper)
  - Actionability – responsiveness to healthcare intervention; facilitates buy-in from healthcare providers/clinicians  
What evidence is suggested – clinical interventions affect the PRO, or that the patient/ person is the best source for assessing the PRO?
  - Meaningfulness to patient/person and engagement in selecting individual-level PROs  
How is patient/person engagement in selecting individual-level PRO implemented and demonstrated?

- Implementable –individual-level PRO first used successfully in clinical care, not just collected for performance measurement  
How is this implemented and demonstrated?

**Expert Panel and Audience Engagement (30 min)**

12:45-1:30 **LUNCH** (provided for Expert Panel/Authors)

1:30-2:50 **Methods that Contribute to Trust– Demonstrating Reliability of PRO-PMs**

*This discussion is based on the premise that the performance measure is based on an individual-level PRO that meets selection characteristics identified in Workshop#1.*

- Overview of NQF endorsement criteria on reliability and differentiation between PRO & PRO-PM (**Karen Pace – 5 min**)
- Commissioned paper authors tee-up key issues and best practices or strengths/weaknesses of approaches (**15 min**)
- **Reactor Panel:** Lewis Kazis, *Boston University School of Public Health*; Lori Frank, *Patient Centered Outcomes Research Institute*; other (pending) (**10 min each – total of 30 min**)
  - What methods for reliability testing would support the demonstration of reliability of the PRO-PM scores (e.g., signal to noise)?
  - Are there any differences or unique considerations for demonstrating and evaluating the reliability of a PRO-PM (as compared to other quality performance measures)? Is reliability of the PRO-PM score needed in addition to reliability of the individual-level PRO?
  - What are the implications of various approaches to aggregating PRO data (e.g., average/median amount of change; percentage who improve/reach benchmark/ have meaningful change) on reliability of the PRO-PM score?
  - What impact does poor reliability of the PRO-PM score have on validity of the PRO-PM as an indicator of quality?

**Expert Panel and Audience Engagement (30 min)**

2:50-3:05 **BREAK**

3:10-4:30 **Methods that Contribute to Trust– Demonstrating Validity of PRO-PMs as Indicators of Quality**

*This discussion is based on the premise that the performance measure is based on an individual-level PRO that meets selection characteristics identified in Workshop#1.*

*Specific threats to validity are addressed in the next panel.*

- Overview of NQF endorsement criteria on validity and differentiation between PRO & PRO-PM (**Karen Pace – 5 min**)
- Commissioned paper authors tee-up key issues and best practices or strengths/weaknesses of approaches (**15 min**)
- **Reactor Panel:** Steve Fihn, *Veterans Health Administration*; other (pending) (**10 min each – total of 30 min**)
  - What methods for validity testing would support the demonstration of validity of the performance score for making conclusions about quality of care?
  - Are there any differences or unique considerations for demonstrating and evaluating the validity of PRO-PMs (as compared to other quality performance measures)?
  - Is validity of the performance score as an indicator of quality needed in addition to validity of the individual-level PRO?

**Expert Panel and Audience Engagement (30 min)**

4:30-5:00 **Identification of Unique Considerations Related to NQF Endorsement of PRO-PMs**

Each table asked to identify unique considerations (as compared to other quality performance measures) for evaluating PRO-PMs as suitable for NQF endorsement

5:00

**Adjourn for the Day**

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## Day 2 – September 12

8:00-8:30 Continental Breakfast & Networking (provided for Expert Panel/Authors)

8:30-8:40 **Intro to Day 2**

Joyce Dubow

8:45-10:05 **Methods that Contribute to Trust – Addressing Threats to Validity**

*This discussion is based on the premise that the performance measure is based on an individual-level PRO that meets selection characteristics identified in Workshop#1.*

- Overview of NQF endorsement criteria on threats to validity of conclusions about quality and differentiation between PRO & PRO-PM (**Karen Pace – 5 min**)
- Commissioned paper authors tee-up key issues and best practices or strengths/weaknesses of approaches to aggregating individual-level PRO data and specifying PRO-PMs (**15 min**)
- **Reactor Panel:** Kenneth Ottenbacher, *The University of Texas Medical Branch at Galveston*; Albert Wu, *Johns Hopkins Health System*; Robert Weech-Maldonado, *University of Alabama at Birmingham* (**10 min each – total of 30 min**)
  - What are the implications of various approaches to aggregating PRO data (e.g., average/median amount of change; percentage who improve/reach benchmark/have meaningful change) on:
    - the validity of conclusions about quality; and
    - the ability to discriminate performance among accountable entities?
  - Are there any differences or unique considerations for risk adjustment of a PRO-PM (as compared to other quality outcome performance measures)?
  - What are the implications of using proxies on the validity of the performance measure and the testing needed to assess impact on validity?
  - What are the implications of exclusions, incomplete/missing data, and response rate/bias on validity of the performance measure and the testing needed to assess impact on validity?
  - What are the implications of specifying more than one PRO (i.e., instrument/scale) in a performance measure and the testing needed to assess impact on validity?

**Expert Panel and Audience Engagement (30 min)**

10:05-10:30 **Identification of Unique Consideration Related to NQF Endorsement of PRO-PMs**

Each table asked to identify unique considerations (as compared to other quality outcome performance measures)

10:30-10:40 **BREAK**

10:45-12:00 **Revisit pathway from individual-level PRO to NQF-endorsed PRO-PM**

- **Moderators:** Ethan Basch, *Memorial Sloan-Kettering Cancer Center*, (Steps 4-7)Eleanor Peretto, *Pfizer* (Steps 8-11), others pending
- **Expert Panel and Audience Engagement**
  - Are all the steps in the pathway identified and in the correct order?
  - Should performance measures begin with process measures (vs. outcome measures)?
  - Is there flexibility in specifying multiple individual-level PROs for process measures? Outcome measures?
  - Along the various steps of the pathway identify:
    - Any unique considerations for endorsement of PRO-PMs (as compared to other quality outcome performance measures)

- Guiding principles

12:00-12:45 **LUNCH** (provided for Expert Panel/Authors)

12:50-1:50 **Future Directions**

- **Moderator:** Patti Brennan
- **Expert Panel and Audience Engagement**
  - How do you see use of PROs and PRO-PMs evolving in the future? (e.g., multiple individual-level PROs calibrated to a standard scale; use in composite measures)
  - Do the foundations being built now (e.g., IT, evaluation criteria, pathway) support the future?

1:50-2:00 **Closing Remarks and Next Steps**  
Patti Brennan

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