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

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

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
    o  NQF endorses PRO-PMs, not the individual-level PROs
    o  NQF endorses PRO-PMs for use in accountability applications such as public reporting and payment
    o  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 1st 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 1st 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 1st 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
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:
    o the validity of conclusions about quality; and
    o 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 Perfetto, 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:
    o 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