NATIONAL QUALITY FORUM
Driving measurable health improvements together

Web Meeting #5: Discussion Guide

Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures

Context on this Discussion Guide

This Discussion Guide is designed to help prepare the members of the Technical Expert Panel (TEP) for Web Meeting #5, on Wednesday, August 3, from 11:00am – 12:30pm ET. Web Meeting #5 will focus on findings elicited from key informant interviews (KIIs). The findings address recommendations for how the original version of the Technical Guidance Report (i.e., *the Roadmap*) can be improved when an updated version is published in November 2022.

This discussion guide is broken into five sections: (1) Updates to the existing tasks in the Roadmap, (2) Issues related to burden and workflow, (3) Improved guidance on digital measurement, (4) Trade-offs of data collection strategies for a PRO-PM, and (5) Other Recommendations.

Organization of the Roadmap

The Roadmap provides guidance on the development of patient-reported outcome performance measures (PRO-PMs). The Roadmap is organized into four stages with 16 tasks.

- **Stage 1: Definition of Measurement Goals**
- **Stage 2: Exploration and Assessment of patient-reported outcome measures (PROMs)**
- **Stage 3: Development and Testing of the PRO-PM**
- **Stage 4: Finalization and Implementation of the PRO-PM**

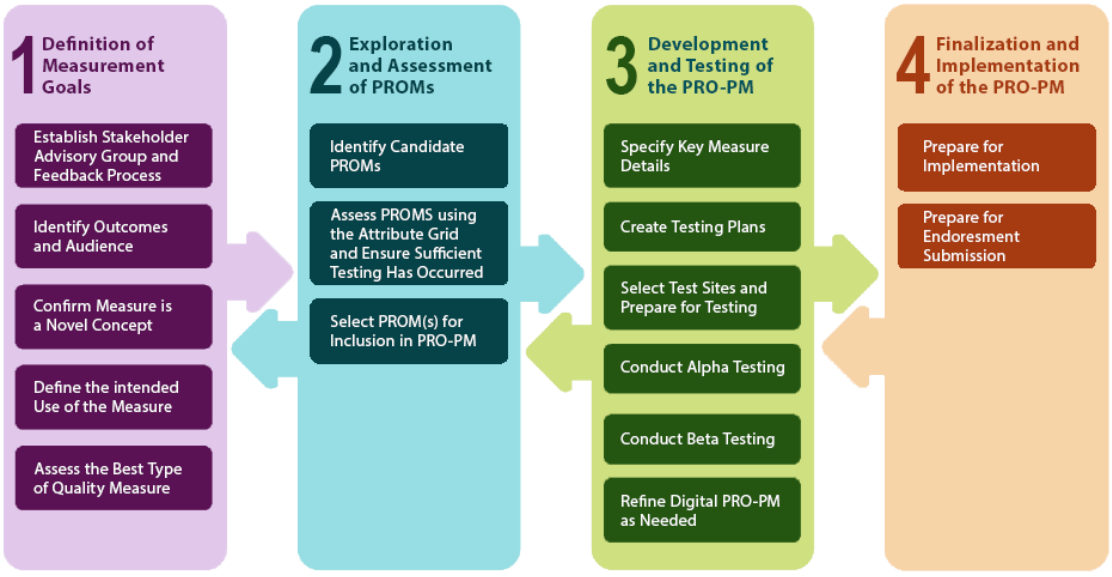

Figure 1. PRO-PM Roadmap: Each column contains one stage, and the bidirectional arrows indicate that tasks can move freely and be iterated across stages.

Discussion: Updates to existing tasks in the Roadmap

The interviewees supported the Roadmap's presentation of existing tasks and did not flag any of the 16 tasks in the November 2021 version of the Roadmap for removal or deletion. However, the interviewees did share several opportunities for improving the tasks. In Web Meeting #3 and #4 the TEP discussed nine of the 13 recommendations.

Discussion Questions

The following discussion questions will be posed **for each recommendation**

- Does the TEP agree with this suggestion?
- What information does the TEP recommend adding to the Roadmap to address this suggestion?

Recommendations from the KIIs (Continued from Web Meeting #4)

9. **Stage 3: Include PRO-PM Specific Information on Alpha and Beta Testing.** Describe the differences of PRO-PM testing compared to other type of quality measures and offer guidance on how to overcome challenges. (e.g., build PROMs in the test sites' EHRs, implement PROM-specific workflows and train staff on how to accomplish them). (Note to TEP: This discussion began at the end of Web Meeting #4 and will be completed during Web Meeting #5.)
10. **Stage 3 and Stage 4: Reduce Redundancies with Source-of-Truth CDP Documentation.** Include links to external source-of-truth documents to reduce redundancies.
11. **Stage 4: Include Guidance on Preparing for Measure Maintenance.** Provide more detail about preparing for maintenance (with a specific focus on maintenance of PRO-PMs) and/or add links to relevant NQF documentation.
12. **Stage 4: Include Information on the Purpose and Importance of NQF Endorsement.** Add a brief explanation of considerations and benefits of NQF endorsement.
13. **Stage 4: Add Guidance on the NQF Intent to Submit.** Describe the NQF Intent to Submit process, along with any guidance specific to PRO-PMs.

Discussion: Issues Related to Burden and Workflow

Nearly every interviewee commented on how the Roadmap presents information related to measurement burden, from both the clinician and patient perspectives. Key informants recommended additional guidance on beta testing (discussed in #9, above) as well as potential improvements to stage 2 of the Roadmap.

Stage 2 Recommendations

The Roadmap should acknowledge and offer solutions that address both clinician and patient burden related to data collection. While the TEP has extensively discussed these topics, the recommendation is to better reflect these discussions in the Roadmap. The interviewees suggested three potential approaches.

1. Expand the Roadmap's guidance on PROMs that minimize patient burden (e.g., prioritizing short forms or computerized adaptive testing [CAT]).
2. Discuss opportunities to reduce clinical burden (e.g., licensed versus unlicensed PROMs, PROMs that include LOINC, and PROMs that are already built into EHR systems).

3. Include links to the Environmental Scan Report and the Interim Report, as well as NQF's 2020 report on Best Practices on Selection and Data Collection, which all cover these topics.

Discussion Questions

- Does the TEP agree with the recommendations?
- Does the TEP have any additional input for how to address the recommendation?

Discussion: Improved Guidance on Digital Measurement

When the first version of the Roadmap was published in November 2021, NQF, CMS, and the TEP agreed on the need for improved guidance on digital measurement. The KIIs confirmed this stance and outlined eleven improvement opportunities. Because NQF addressed many of these recommendations in the updated Environmental Scan Report, discussion in Web Meeting #5 will focus on suggestions marked with an asterisk (*).

Discussion Questions

The following discussion questions will be posed for each of the eleven improvement opportunities

- Does the TEP agree with this suggestion?
- What information does the TEP recommend adding to the Roadmap to address this suggestion?

Eleven Improvement Opportunities From the KIIs

1. **Define and differentiate dQMs and eCQMs.** Include up-to-date CMS definitions of dQMs, an explanation of the relationship between eCQMs and dQMs, and information on data sources for dQMs that include novel devices (e.g., wearable technology).
2. ***Emphasize digital technology earlier and more consistently.** Digital measurement should be established as a theme early in the Roadmap and maintained throughout in call-outs or side-by-side comparisons.
3. **Explain and describe the use of digital technologies.** Include improved explanations of dQMs, FHIR, USCDI, and USCDI+, along with links to corresponding "sources of truth."
4. **Discuss interoperability standards.** Add high level information on compliance with ONC's Health IT Certification Program and CMS' reporting program requirements.
5. **Offer guidance on translating measures to digital.** Consider including guidance on how to convert existing measures to digital, but interviewees acknowledged that this is so novel that NQF and the TEP might not be able to provide accurate and timely evidence on the topic. (During Web Meeting #3, the TEP recommended that this is out of scope.)
6. ***Give specific examples of digital measure specifications.** Improve the description of digital measure specifications to "connect the dots" for the audience. Examples could include side-by-side comparison of traditional and digital specifications, or a use case explaining how a digital specification answers specific measurement questions.
7. **Address trade-offs with digital modes of PROM administration and methods of data collection.** The existing Roadmap only discusses modes and methods as they refer to the development and testing of PRO-PMs in stage 3. Include discussion of the modes and methods as they relate to measure design in stage 1 and PROM selection in stage 2.

8. ***Discuss privacy and security.** Offer information and guidance on privacy and security implications of digital measurement, including how the sharing of protected health information (PHI) is addressed in digital specifications.
9. ***Represent diverse health technology systems, not just EHRs.** Improve the overview of key data sources beyond the EHR (e.g., health information exchanges [HIEs], qualified clinical data registries [QCDRs], patient portals, wearable devices, remote monitoring devices, patient symptom trackers and other apps, and claims data).
10. ***Remove discussion of outdated standards.** Update discussions of Quality Data Model (QDM) and Bonnie.
11. ***Consider inclusion of case studies/promising practices.** Include examples of excellence that could benefit readers of the Roadmap.

Discussion: Explain Trade-offs in Data Collection Strategies for a PRO-PM

The Roadmap contains a summary of pertinent environmental scan findings, including a discussion on the trade-offs of using one PROM or multiple different PROMs to collect data for a single PRO-PM. The interviewees recommended moving this information into either stage 1 or stage 2, since this decision is critical to the early stages of developing a PRO-PM.

Discussion Questions

- Does the TEP agree with this suggestion?
- What information does the TEP recommend adding to the Roadmap to address this suggestion?
- Should it be added as a new task or folded into an existing task?

Discussion: Other Recommendations

Although the following recommendations do not have the ubiquity of the previously discussed recommendations, they were raised by at least one expert and highlight important issues that might not always be at the forefront of conversations regarding PRO-PM development.

Discussion Questions

The following discussion questions will be posed for each of the recommendations.

- Does the TEP agree with the suggestion?
- What information does the TEP recommend adding to the Roadmap to address this suggestion?

Describe Opportunities to Engage Patients

Interviewees suggested adding guidance in the Roadmap on how to engage patients. Suggestions include:

- Expanding the role of the patient advisors in PROM selection and timing of data collection
- Engaging patients in designing workflows at test sites and during implementation guidance
- Creating patient-specific workgroups within the stakeholder advisory group

Identify and Address Health Equity Issues

Although there is currently limited literature on health equity, it is an issue that NQF and the TEP should consider as they prioritize improvements to the Roadmap. Suggestions include:

- Explain and identify inequitable differences in care in the measure design portion of stage 1
- Consider how factors such as race, ethnicity, gender, weight, and comorbidities are reflected in PROs
- Include challenges of capturing and addressing social risk factors due to limitations in coded data (e.g., LOINC, International Classification of Diseases, 10th Revision [ICD-10])
- Identify the challenge and impact of the digital divide (i.e., when promising health IT solutions are adopted, available to, or used by vulnerable populations) on data collection.

Discuss the Timing of PROM Data Collection and PRO-PM Measurement

Interviewees pointed out that the intervals at which PROM data are collected can impact patient burden, clinical workflows, and response rate, which ultimately affects the effectiveness of the PRO-PM. Interviewees suggested adding detail about timing in stage 1 of the Roadmap.

Establish New Terminology to Reframe PROMs as Instruments, not Measures

Stakeholders across the healthcare industry use confusing language to describe PROs, PROMs, and PRO-PMs. One interviewee suggested that NQF use the Roadmap as an opportunity to propose a new and more accurate acronym, such as patient-reported outcome instruments (PROIs).

Address Proxies

One interviewee noted challenges related to proxies (i.e., one person completing a PROM on behalf of another person), such as when a parent completes PROMs on behalf of an adolescent, or a caregiver submits a questionnaire for a cognitively impaired patient. It was suggested to include details about this challenge in the Roadmap.