NATIONAL QUALITY FORUM
Driving measurable health improvements together

Meeting Summary

Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures Second Year Web Meeting 4

The National Quality Forum (NQF) convened a public web meeting for the Building a Roadmap From Patient-Reported Outcome Measures (PROMs) to Patient-Reported Outcome Performance Measures (PRO-PMs) Technical Expert Panel (TEP) on June 14, 2022.

Welcome and Review of Web Meeting Objectives

Chuck Amos, NQF senior director, welcomed participants to Web Meeting 4 of the project's second year and reviewed housekeeping reminders. Mr. Amos thanked both Centers for Medicare & Medicaid Services (CMS) and the TEP members for their time and commitment to this work and introduced the Co-Chairs to make introductory statements. Co-Chairs Dr. Cathy MacLean and Dr. Sam Simon acknowledged the robust conversation during Web Meeting 3 and asked for continued input from TEP members.

Mr. Amos reviewed the meeting objectives, the project reports – including the Technical Guidance Report, or Roadmap, and the Developer Feedback Report – and the agenda. Mr. Amos and Carina Smith, NQF manager, took attendance. Mr. Amos thanked those in attendance and reviewed ground rules for the meeting.

Recap of Web Meeting 3

Mr. Amos summarized key themes from Web Meeting 3, which included a discussion of the Environmental Scan updates and an overview of public comments. Mr. Amos announced that NQF will publish the updated Environmental Scan at the end of June. Web Meeting 3 included an overview of findings from the Key Informant Interviews (KII) and Mr. Amos stated that NQF will continue the conversation about the KIIs during this, and future meetings.

Discussion: Developer Feedback Report Updates and Public Comments

Mr. Amos reminded the TEP that the Developer Feedback Report is intended to capture recommendations from the KIIs about changes NQF should make to the Roadmap. He introduced the public comments – six comments, all submitted by one organization – for discussion with the TEP. Mr. Amos also noted that the KIIs included positive feedback for the report.

Mr. Amos began by sharing public comments that recommended that NQF add the following to the Roadmap: (1) a link to the Council of Medical Specialty Societies (CMSS) as a resource for registry-based developers, and (2) the inclusion of visuals (i.e., tables, charts, and graphics) to improve the readability of the report. The TEP did not raise any concerns and agreed that these suggestions should be incorporated into the updated Roadmap.

Mr. Amos then shared a public comment addressing challenges with low response rates to PROMs and the need to add solutions to improve response rates. He noted that the comment applies more directly to the Roadmap than to the Developer Feedback Report. Dr. MacLean shared that response rates tend to be higher when mechanisms are in place to gather responses during a clinical encounter. TEP members agreed that the factors associated with low response rates are a challenge to PRO-PM development and use. Dr. MacLean recommended that measure developers should consider this during development of PRO-PMs. The TEP discussed the impact of using representative sampling in the development of PRO-PMs, the possibility of integrating the patient response mechanism into the clinical care process, strategies to encourage patient engagement (e.g., progress reports, incentives), and considerations for collection burden. The TEP agreed with the public comment and suggested that NQF update the Roadmap to address the comment. In addition, the TEP suggested including examples of sample collection strategies, with an emphasis on obtaining a representative sample, to address low response rates. Mr. Amos agreed to add detail about sampling to the Roadmap, with guidance from CMS, and noted that this may require continued discussion.

Mr. Amos reviewed a final comment that highlighted the potential for bias resulting from selecting members of the TEP and federal liaisons for the KIIs. Mr. Amos shared that NQF selected some members of the TEP to gather more depth and detail than is possible during the limited time available in web meetings. NQF also mitigated the risk for bias by keeping suggestions within the Developer Feedback Report and the Roadmap anonymous. Mr. Amos suggested that NQF will flesh out the methodology section of the Developer Feedback Report to address this comment. The TEP agreed to the addition of detail in the methodology section of the report.

Mr. Amos began to close this part of the meeting by describing themes emerging from the entire body of feedback, from interviewees, federal liaisons, and TEP members. He highlighted recommendations to edit and add detail to clarify the content of the Developer Feedback Report. The TEP did not raise any concerns about the suggestions. Mr. Amos also mentioned a comment about improving the balance of patient burden versus clinician burden in both the Developer Feedback Report and the Roadmap. NQF will continue to elevate patient voices and improve the balance of patient and clinical burden in the reports. Mr. Amos concluded the public comment portion of the meeting.

Overview of Findings from Key Informant Interviews

Mr. Amos provided a high-level overview of the Roadmap, noting that each of the four stages, with discrete tasks, are intended to provide general guidance for measure developers. Mr. Amos emphasized the non-prescriptive nature of the Roadmap and the fluidity of the tasks in each stage. In addition, Mr. Amos introduced the discussion guide sent before the web meeting to facilitate the TEP's conversation about the recommendations from the KIIs. He encouraged the TEP to refer to the guide throughout the discussion.

Since the first recommendation was reviewed during Web Meeting 3, Mr. Amos opened the discussion with the second recommendation: include meaningful examples of engaging patients in measurement development. The TEP suggested that patients contribute to development of PRO-PMs at specific times in the process; measure developers should consider at what point(s) they can best leverage the voice of the patient. The TEP discussed how patient contributions can be captured via surveys, interviews, or focus groups, and suggested that NQF offer guidance for when and how to engage patients within the measure development process. Mr. Amos offered to follow up with NQF senior leadership to determine next steps.

Mr. Amos shared the third recommendation: include PRO-PM specific challenges and solutions. The TEP briefly reviewed common PRO-PM specific challenges like measure selection and low response rates to

PROMs. To address some of these challenges, Dr. MacLean discussed test site participation and incentives that provide meaningful feedback to the test site while contributing to measure development. Dr. Simon noted the importance of developers considering how to administer a PROM and include patients in the testing phase of measure development.

Mr. Amos introduced the fourth recommendation: include rural perspectives. The TEP noted that developers of measures for any underrepresented community, including but not limited to rural communities, face similar challenges. The TEP supported the need to include not just rural communities, but underrepresented voices more generally (e.g., non-English speakers, older populations) in the development of a PRO-PM. The TEP agreed that sampling could potentially prevent underrepresentation but only if it meets the criteria for representative sampling. The TEP agreed that sampling is an important consideration for the developer of a PRO-PM and NQF should add it to the Roadmap.

Mr. Amos reviewed the fifth recommendation to clearly define the measure concept and the sixth recommendation to add detail about including PROM developers in the PRO-PM development process. The TEP agreed that both recommendations are integral in the early stages of measure development and should be included in the Roadmap.

Mr. Amos introduced the seventh recommendation to include more guidance on assessing, requesting, and using Logical Observation Identifiers Names and Codes (LOINC). The TEP discussed the importance of linking digital measures with LOINC and agreed that guidance on using LOINC is important to include in the Roadmap.

Mr. Amos shared the eighth recommendation to include side by side comparisons of traditional and digital specifications. Dr. Simon agreed with the recommendation and suggested NQF add examples with links from the Electronic Clinical Quality Improvement (eCQI) Resource Center and other publicly available resources.

Mr. Amos shared the ninth recommendation, to include PRO-PM specific information about alpha and beta testing within the Roadmap. Dr. MacLean noted the importance of finding testing sites for PRO-PM development and ensuring that participation benefits the site, as well as measure development. Dr. Simon described the purpose and importance of alpha testing when developing a PRO-PM and agreed with including detail about alpha and beta testing in the Roadmap.

Mr. Amos thanked the TEP for their feedback and shared that the discussion would continue during the next web meeting.

NQF Member and Public Comment

Mr. Amos opened the meeting for comments from the federal liaison and public participants.

A federal liaison commented about including information on digital measurement while balancing the focus on expanding use of PRO-PMs with the push for data standardization as a fundamental aspect of digital measurement. The federal liaison noted that PRO-PMs are complex measures and require greater awareness in the development process. Mr. Amos acknowledged that this comment warranted more discussion and noted that the TEP will have an opportunity for a more in-depth discussion of recommendations for digital measurement guidance in the next web meeting.

There were no further comments.

Next Steps

Evelyn Thomas, NQF Specialist, informed the TEP that the next web meeting will be held on August 3, 2022. Ms. Thomas announced that NQF will publish the final Environmental Scan Report at the end of June. NQF will send a notification when the report is available on the project page.

Adjourn

Mr. Amos thanked the Co-Chairs, TEP, CMS, and NQF staff as the meeting adjourned.