Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures Second Year Web Meeting 3

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 May 16, 2022.

Welcome and Review of Web Meeting Objectives

Chuck Amos, NQF senior director, welcomed participants to the third web meeting of the initiative's second year and reviewed housekeeping reminders. Co-Chairs Dr. Cathy MacLean from Hospital for Special Surgery and Dr. Sam Simon from Mathematica made opening remarks to welcome the meeting participants. The co-chairs reminded meeting attendees about the work that was completed after Web Meeting 2, including posting the Environmental Scan Report Draft 2 for public comment, and the completion of key informant interviews (KIIs) to elicit feedback on the Technical Guidance Report published in the Fall of 2021. Mr. Amos then reviewed the meeting objectives, welcomed Allie Herr, NQF senior managing director, and announced the promotion of Teresa Brown to NQF director. Mr. Amos introduced Evelyn Thomas, NQF specialist, who conducted attendance of TEP members and federal liaisons. Mr. Amos thanked those in attendance and reviewed ground rules for the meeting.

Recap of Web Meeting 2

Mr. Amos provided an overview of Web Meeting 2. He reminded the attendees that February's meeting included the introduction of high level themes from the KIIs, and stated that NQF will host a more methodical discussion of these themes during the current meeting. Mr. Amos also noted that Web Meeting 2 included TEP members' suggestions for updates to the Environmental Scan Report, and that the TEP will conclude this discussion in the current meeting during the review of public comments.

Discussion: Environmental Scan Updates and Public Comments

Mr. Amos noted that the NQF team made significant improvements to the Environmental Scan Update prior to undergoing public comments (e.g., simplified the structure of the report, removed redundant information, and rewrote the executive summary to showcase the key takeaways from the report). In addition, he shared that NQF added new information as directed by the TEP (e.g., details on modes and methods, details on equity issues that may affect the use of PROMs and by extension PRO-PMs, the implications of interoperability of PRO-PMs, and links to sources of truth). Mr. Amos shared that NQF's new Chief Scientific Officer, Elizabeth Drye, assisted with the guidance of these revisions, particularly the information on interoperability.

Mr. Amos introduced eight public comments that were submitted by two organizations and provided an overview of six themes from the comments to discuss with the TEP. Mr. Amos shared that the

comments expressed positive feedback and overall support for the report. Mr. Amos opened the discussion and encouraged the TEP to provide feedback to inform the proposed responses.

Perception of Advocacy for New PROMs

Mr. Amos introduced the first comment theme, which stated that the report came across as advocating for the development of new PROMs. Dr. MacLean initiated the discussion by responding that the report should remain agnostic to the development of new PROMs, and discussion included the fact that many excellent PROMs exist but there are not enough PRO-PMs. Various TEP members agreed that it should be up to measure developers to provide a thorough scan of existing PROMs—considering content, validity, specificity, and sensitivity—to find the correct instrument(s) for use with a PRO-PM.

The TEP engaged in a discussion about patient experience and patient outcomes, as measured by patient-reported instruments. While there were comments that existing PROMs are potentially too narrow and can fail to capture patient experience, further discussion elicited that the TEP generally agreed that the Environmental Scan Report and the Technical Guidance Report should remain focused on patient-reported information about health related quality of life (HRQoL), functional status, and symptoms and symptom burden. The discussion concluded with Dr. MacLean's reminder to focus on PRO-PMs as the scope of this project.

Further Clarification of Experience Measures' Role Within This Work

Mr. Amos acknowledged that the second comment theme, which sought clarification on the role of experience measures within the report, was addressed during the previous discussion.

Challenges Relating to Digitizing PRO-PMs

Mr. Amos introduced the third comment theme, which probed whether the Environmental Scan Report offers appropriate guidance on digitizing existing measures. NQF and Drs. Simon and MacLean proposed that this recommendation falls out of the scope of the project. Various TEP members expressed support and agreed with a proposed response recognizing that it is beyond the scope and too broad to address in this report. Mr. Amos suggested adding language to encourage stakeholders across the spectrum to actively engage in and adopt the technologies related to interoperability.

Perception of Holding Patients Accountable for Measurement Burden and Non-Response

Mr. Amos introduced the fourth comment theme, which suggested that a section of the report unintentionally holds patients accountable for measurement burden and non-response. TEP members suggested opportunities to modify the language to reflect a shared responsibility between the patient and the healthcare professionals (e.g., systems, clinicians), such as adding text about including patients in the PRO-PM development process and the PROM instrument selection. The conversation ended with a recommendation from Dr. MacLean to add a sentence explicitly stating it's the responsibility of the care delivery system and measure developers to ensure that when PRO-PMs are developed and implemented, that they're done in a way to reduce the burden on patients.

Existing PRO-PM Utilization

Mr. Amos shared the fifth comment theme, which questioned whether the Environmental Scan Report adequately describes how PRO-PMs are used today. NQF shared a proposed response and approach to include more information and examples of PRO-PM inclusion in existing CMS comparative payment models and value-based purchasing. The TEP members did not raise concerns with the proposed approach.

PROM Qualities Relating to Intended Use

Mr. Amos introduced the sixth and final comment theme, which raised whether the report effectively describes the different intended uses of PROMs. Dr. MacLean launched the conversation by sharing how even data that are intended to inform quality assessment or improvement can ideally be integrated into clinical care to assist with point of care decision making. The TEP discussed how this integration of data in clinical care can reduce patient burden by actively engaging the patient in treatment decisions. TEP members also noted how even when PROM data does not impact a patient's clinical care, those data are useful to inform population-based care. Multiple TEP members agreed that there should not be a distinction between clinical care and performance measurement, because the data ultimately reflect clinical care, whether at the individual or population level.

Mr. Amos concluded the public comment portion of the meeting by sharing that NQF will incorporate the TEP's feedback as well as the responses to public comments in the next draft of the Environmental Scan Report.

Overview of Findings from Key Informant Interviews

Teresa Brown, NQF director, provided an overview of the three major deliverables of the project, followed by a recap of the Technical Guidance Report (henceforth referred to as the Roadmap). Ms. Brown reviewed the graphic that encompasses the various PRO-PM development stages. She also shared an overview of findings from the KIIs and noted that the feedback will be incorporated in the Roadmap that will be published in November 2022. NQF highlighted that the informants listed the following as strengths of the report:

- The report's articulation of the four stages and tasks to communicate the development process for a PRO-PM
- The Roadmap's non-prescriptive approach to measure development, and its presentation of the steps of PRO-PM development in a flexible way
- The focus on three PRO domains of HRQoL, functional status, and symptoms and symptom burden

Following the overview of the report strengths, Ms. Brown opened the discussion for TEP review. One TEP member raised that the report is not prescriptive and therefore may not align with CMS. The TEP member encouraged federal liaisons to share their thoughts on whether it is sufficient in informing public reporting and payment programs. NQF agreed to raise the concern with CMS and confirm if the report should be more prescriptive to meet federal program requirements.

Mr. Amos highlighted that one consistent theme of feedback from the KIIs was to avoid redundancies and link to other existing sources of truth (e.g., CMS Blueprint, FHIR standards, NQF CDP documentation). TEP members shared various resources, including the Regenstrief Institute and the Value Set Authority Center (VSAC), that should be added to the Roadmap. NQF concluded this portion of the discussion by agreeing to reach out to NQF endorsement colleagues to receive more guidance on appropriate resources.

Mr. Amos then encouraged the TEP to review the discussion guide and share guidance on any of the 13 recommendations that the KIIs provided. The TEP discussed the first of the 13 recommendations, which is to add time frames to the roadmap. TEP members discussed that there is limited specificity on how long each task takes, ranging from months to years, but that general timing expectations could help measure developers to understand the long-term commitment required for PRO-PM development. NQF

concluded by sharing that the discussion of improvements to the Roadmap will continue during upcoming web meetings.

NQF Member and Public Comment

Ms. Brown opened the meeting for public comments, and no comments were received.

Next Steps

Evelyn Thomas informed the TEP that the next web meeting will be held on June 14, 2022. Ms. Thomas also shared that the Developer Feedback Report will be posted and available for public comments from May 20 to June 13.

Adjourn

Mr. Amos thanked the TEP, CMS, and NQF staff as the meeting adjourned. He noted that NQF would send the public comments to the TEP on June 13, and apologized in advance that they could not be delivered any sooner.