Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures Second Year Web Meeting 6

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 October 21, 2022.

Welcome and Review of Web Meeting Objectives

Chuck Amos, NQF senior director, welcomed the participants to the sixth and final web meeting of the project's second year and reviewed housekeeping reminders. Mr. Amos thanked both the Centers for Medicare & Medicaid Services (CMS) and the TEP members for their commitment to elevating patient voices in quality measurement. Mr. Amos reviewed the meeting objectives, the project report (i.e., the Technical Guidance Report [henceforth referred to as the *Roadmap*]), and the agenda. Mr. Amos shared that NQF will release the updated Roadmap on November 30, 2022. Carina Smith, NQF manager, took attendance and reviewed the ground rules for the meeting.

Recap of Web Meeting 5

Ms. Smith summarized the discussion topics from Web Meeting 5, reviewing highlights from the TEP's discussion of the Key Informant Interview (KII) recommendations. Ms. Smith shared that NQF would continue the discussion of the KII recommendations during this meeting, in addition to reviewing public comments and direct TEP and KII feedback on the Roadmap.

Technical Guidance Report: Comments

Mr. Amos shared that three organizations provided 17 comments that spanned a broad range of themes. NQF shared a spreadsheet of the comments and proposed responses with TEP members and federal liaisons in advance of the meeting. Mr. Amos introduced an overview of the public comments, focused this meeting's discussion of public comments on the comments made about health equity, and opened the opportunity for the TEP to bring forward any additional public comments for further discussion. TEP members did not provide any additional comments for further discussion.

Mr. Amos introduced the comments, which encouraged a greater focus on health equity in the Roadmap; the first comment highlighted the urgency of equity in healthcare, and the second comment highlighted the importance of understanding who is left out of digital measurement initiatives. Mr. Amos reviewed existing language in the Roadmap that focused on health equity, pausing for TEP members to read through each section. The co-chairs introduced the discussion, acknowledging that while the Roadmap does include health equity at a high level, opportunities remain to strengthen and elevate health equity considerations within the report.

The TEP explored several suggestions to provide examples, strategies, or guidance related to health equity in the Roadmap. Suggestions include linking to source-of-truth documents for how to approach health equity in measure development, considerations for how the modalities of data collection may influence representation and therefore inclusion, and language improvements to refrain from being overly prescriptive while still being inclusionary. TEP members encouraged collaboration with NQF's Health Equity initiatives to ensure the most up-to-date guidance. TEP members also discussed the potential application of the Roadmap to provide general guidance across programs, though it is driven by guidance for use in CMS' Value-Based Purchasing (VBP) models. Throughout the discussion, TEP members in the chat recognized the importance of the measure developer's due diligence to ensure a selected PROM is inclusionary for the development of a PRO-PM.

In wrapping up the health equity discussion, a federal liaison emphasized the Performance Measure aspect of the PRO-PM, noting the importance of PRO-PMs to guide an organization's understanding of their performance and ability to improve. Overall, the TEP offered several recommendations to include health equity more visibly in the Roadmap. Mr. Amos agreed to explore the recommendations and add language on health equity to the final version of the report.

Mr. Amos again offered an opportunity for TEP members to bring forward any other public comments for discussion. No TEP members responded.

Mr. Amos introduced and summarized the written feedback from TEP members. Mr. Amos focused the TEP's discussion on the feedback to improve guidance on assessing the validity and reliability of crosswalks that harmonize data across PROMs. Dr. MacLean shared that whenever a crosswalk is involved in measure development, the developer should recognize that additional steps are necessary to ensure a measure is reliable and valid with both the original (i.e., non-crosswalked) PROM scores and the crosswalked PROM scores. TEP members discussed storage codes and access for measures as it relates to deriving equivalency, emphasizing that the reliability and validity testing of a measure must be done in tandem with storage. Mr. Amos acknowledged the TEP's suggestions and ensured that NQF will improve the guidance for crosswalks in the Roadmap.

Technical Guidance Report: Additional Recommendations

Mr. Amos introduced and provided a brief overview of the three remaining recommendations from the KIIs. Mr. Amos introduced the first recommendation about addressing the timing considerations of data collection for the PRO-PM. Mr. Amos noted that timing considerations are often designated by the PROM and TEP members agreed that the time intervals did not need to be specifically addressed in the Roadmap because they are dependent on the measure's construct.

Mr. Amos introduced the next recommendation about including guidance for proxies (i.e., someone other than the patient who enters or provides survey responses on the patient's behalf), again noting that guidance is presumably designated by the PROM. Dr. Simon shared that proxies can occur when a clinical team member enters patient responses to a survey during the clinical encounter, or a caregiver or designee enters the responses on behalf of the patient. Dr. Simon agreed that guidance for the use of proxies is typically included in the PROM, suggesting that measure developers defer to the PROM specifications. Although TEP members initially recommended to defer this consideration as part of the PROM specification, a discussion emerged, explaining that the omission of the consideration given to proxies, specifically caregivers or designees, is a gap in the Roadmap. TEP members highlighted that proxies often influence response results during data collection and can influence the performance measure. TEP members discussed the importance of including guidance on proxy response, particularly as it relates to proxies for older populations and populations with cognitive impairment. Additionally, during the opportunity for public comments, a member of the public iterated the importance of

including guidance for proxies in the Roadmap. The member noted that the use of proxies in data collection is often linked with vulnerable populations, pointing to individuals with cognitive impairment and the disability community more broadly. The commenter therefore linked the inclusion of considerations for proxies to an important element of health equity. While NQF initially deferred guidance for proxies to the guidance given by the PROM, NQF also recognizes the importance of inclusion and proxies as part of improving health equity. Mr. Amos agreed to add language about proxies to the Roadmap.

Mr. Amos shared the final recommendation about reframing the semantics of PROMs as instruments and noted this vocabulary adjustment is out of scope for the Roadmap. TEP members discussed the challenges of the terminology in their work and highlighted that a change in terminology potentially warranted discussion in the future. Mr. Amos acknowledged this as an opportunity for future work.

Mr. Amos opened the floor for any additional recommendations to the Roadmap that had not already been discussed and offered to flag any major changes as future opportunities for work. The co-chairs noted the potential for future work as measurement and equity standards evolve but nonetheless supported the Roadmap as it stands. Mr. Amos acknowledged the future considerations to elevate health equity and noted that the TEP did not provide any additional recommendations to the Roadmap.

Future Steps

Mr. Amos congratulated the TEP on two years of work in the development of the Roadmap and shared that it will be published on November 30, 2022. Mr. Amos called on TEP members to aid in the dissemination of the report by promoting and sharing the Roadmap within their respective networks, noting that NQF will provide a publicity kit around the time of publication.

Mr. Amos prompted a discussion with the TEP for additional dissemination strategies for the report, including outreach to organizations that may not be aware of but might benefit from or be interested in the Roadmap. Mr. Amos also prompted discussion with the TEP for opportunities for future work. Dr. MacLean suggested outreach to the International Consortium for Health Outcomes Measurement (ICHOM) and emphasized that CMS and NQF should facilitate periodic updates to the Roadmap in the future. Dr. Simon noted both NQF's Annual Conference and the CMS Quality Conference as opportunities for promotion and suggested the Center for Clinical Standards and Quality (CCSQ) link to this work in the Measure Management System (MMS) Blueprint. TEP members suggested outreach to registries (particularly Quality Clinical Data Registries), the Council of Medical Specialty Societies (CMSS), the National Committee for Quality Assurance (NCQA), and potentially the payer community. TEP members shared that as NQF continues to publicize the report, the TEP could concurrently share within their network. Mr. Amos thanked the TEP for their input and suggestions.

NQF Member and Public Comment

Mr. Amos opened the meeting for comments from the federal liaisons and public participants. As noted above in the discussion of proxies, one member of the public connected the importance of including considerations for proxies to elevating health equity in the Roadmap. Mr. Amos acknowledged the comment. Two members also made comments acknowledging this work and thanking the TEP and those involved for their commitment to the project. There were no further comments.

Next Steps

Ms. Smith informed the TEP that NQF will incorporate their feedback into the Roadmap. In addition, Ms. Smith asked TEP members and the federal liaisons to confirm their credentials before publication. Ms. Smith noted that the Roadmap will be published and available online in late November. Ms. Smith also

announced NQF's Annual Conference and the discussion on Bringing PROMs to Scale: Realizing the Vision of Patient-Centered Care Delivery.

Closing Comments and Adjourn

Mr. Amos welcomed the co-chairs to provide closing remarks. The co-chairs thanked and expressed appreciation for the meaningful contributions of the TEP to accomplish the goals of this project. Mr. Amos thanked the co-chairs, CMS, the TEP, federal liaisons, and members of the public each for their expertise, collaboration, and commitment to developing the Roadmap. The meeting adjourned.