

# **Meeting Summary**

# Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures Second Year Web Meeting 1

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 January 28, 2022.

# Welcome and Review of Web Meeting Objectives

Chuck Amos, NQF director, began by welcoming participants to the initial web meeting for this second year and reviewing housekeeping reminders. Kathleen Giblin, NQF senior vice president, provided opening remarks on the importance of this work and thanked the Centers for Medicare & Medicaid Services (CMS) for their continuation and support of this work. Co-Chairs Dr. Cathy MacLean from Hospital for Special Surgery and Dr. Sam Simon from Mathematica made brief opening remarks to welcome the meeting participants. Mr. Amos then reviewed the meeting objectives and introduced NQF staff.

# **Attendance and Disclosures of Interest**

Following the NQF staff introductions, Teresa Brown, NQF senior manager, proceeded to take attendance and invited the TEP members to disclose any conflicts of interest. Ms. Brown then conducted attendance of the federal liaisons and thanked those in attendance.

# **Recap of Year One and Goals for Year Two**

Mr. Amos began by sharing a high-level recap of Year One of the project, along with the major deliverables that were completed. Mr. Amos shared that the definitions of patient-reported outcomes (PROs), PROMs, and PRO-PMs within the project and deliverables will follow CMS' <u>Meaningful Measures</u> <u>System Blueprint</u> for consistency. Following the recap of the first year, Mr. Amos presented the scope of Year Two, which aims to build upon the foundational work established in the Base Year and will primarily focus on digital PRO-PMs. Mr. Amos emphasized NQF's approach to this second year of the project, including the convening of the TEP and federal liaisons through six 90-minute meetings, facilitating supplemental methods of gathering information (e.g., surveys, key informant interviews [KIIs]), and developing reports and recommendations. He introduced the project's three deliverables that will follow a developmental life cycle through CMS' review, public commenting, revisions, and final drafts: (1) updated Environmental Scan Report, (2) Developer Feedback Report, and (3) updated Technical Guidance Report.

Mr. Amos shared that the update to the Environmental Scan Report will include revisions to reflect the current state of PROMs and digital PRO-PMs, and the primary focus for updates will be the current state of digital measurement. After the update to the Environmental Scan Report is completed, the Developer Feedback Report will be developed to capture the user experience of the Technical Guidance Report published in the Base Year. The third and final report will be the revised version of the Technical

Guidance Report, or the Roadmap. Key changes will be based on recommendations from measure developers and expanded information on digital measure development. Mr. Amos concluded this section by adding that during Year Two, measure developers will be engaged to provide improvement opportunities for the Technical Guidance Report through a series of KIIs.

NQF will look to the TEP to share expertise, guidance, and the latest resources to ensure all deliverables help to create guidance for developing digital PRO-PMs.

### **Roles and Responsibilities**

Ms. Brown began this section by highlighting the ground rules for web meetings and introducing roles and responsibilities. The TEP's roles and responsibilities were described and include using each person's experience and diversity to advance the role of PROM-based performance measures, reviewing meeting materials in advance, participating during meeting discussions and in supplemental information gathering, reviewing and commenting on draft documents, and providing additional feedback as needed. Ms. Brown noted that discussions will be facilitated by Co-Chairs Drs. Cathy MacLean and Sam Simon. The co-chairs will also assist the TEP in reaching consensus, identifying paths forward when consensus cannot be reached, keeping the discussion within the scope of the project, and prioritizing discussion topics and key issues.

Ms. Brown shared the responsibilities of the federal liaisons, who will join meetings as experts representing different federal agencies and will provide guidance on how those agencies utilize PROMs and PRO-PMs. The federal liaisons will not engage in meetings in the manner TEP members do but will work with CMS representatives to provide additional information and insights as needed. Ms. Brown then shared that NQF staff will be responsible for all logistics related to the project (e.g., scheduling meetings, developing slides) and will develop all reports based on feedback from the TEP as well as published literature, measures, and other materials. Ms. Brown then acknowledged CMS as the funder of the project and the agency that defined the scope of this work, noting that CMS will attend the meetings and review materials but will respect the independence of both NQF and the TEP. Ms. Brown opened the opportunity for TEP members to ask questions and share any feedback on the responsibilities of NQF staff. During this section of the meeting, one TEP member shared a recent experience with NQF staff not responding to recent correspondence in a timely manner. Mr. Amos apologized to the TEP member and reassured participants that NQF staff will be prompt in acknowledging communications moving forward.

#### **Environmental Scan Overview and Discussion**

Mr. Amos provided an overview of the Environmental Scan Report and noted that digital measurement is a priority for the updates. Mr. Amos then invited Drs. MacLean and Simon to facilitate a conversation with the TEP that included discussions of sections of the Environmental Scan Report that require significant revision, sections that might be removed, or additional information that could be included.

One theme that emerged from among the TEP members was the need to further distinguish between experience-focused performance measures (i.e., those based on patient satisfaction or experience data, such as Consumer Assessment of Healthcare Providers and Systems [CAHPS] surveys) and outcome-focused performance measures. The TEP recommended that this work remain focused on the latter. A related discussion addressed definitions in the Environmental Scan Report, and several TEP members suggested revisiting the definitions of PROs, PROMs, and PRO-PMs. The TEP also suggested including a more detailed explanation of the differences between electronic clinical quality measures (eCQMs) and digital quality measures (dQMs). This portion of the discussion also found several TEP members agreeing on the importance of standardized specifications and their influence on capturing consistent and

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reproducible data. TEP members raised the importance of capturing and storing coded PROM data (e.g., using Logical Observation Identifiers Names and Codes [LOINC]), particularly when using multiple different PROMs to capture data on overlapping domains (e.g., functioning or mental health status), and sharing these data via interoperable health information technology (IT) systems.

Another theme of discussion centered around data collection. One topic addressed the potential impact on vulnerable populations and the importance of including these populations in testing and feedback efforts. TEP members discussed recent research and publications related to possible unintended consequences of using PROMs across different subgroups of patients, noting how a question on a PROM (e.g., pain while bowling) may be well understood by one population but not another, which could lead to errors in outcome scores or poor response rates. The TEP spent a significant proportion of the available time discussing the disparate modes (i.e., how a PROM is administered, such as selfadministration or verbal administration) and methods (i.e., how PROM data are collected, such as on paper or via a patient portal) of PROM administration and the potential to unintentionally misrepresent health outcomes. The mode and method of data collection were introduced as possible factors in the definition of a digital PRO-PM (i.e., Does the source of the data need to be electronically captured to qualify as a digital measure?). The TEP also discussed different ways in which patients can complete PROMs, and a few TEP members noted anecdotal examples in which oral administration of a PROM performed by a nurse or other clinician appeared to result in higher scores. Several TEP members agreed that both the mode of administration and method of collection can impact PROM results; however, they also noted that metadata on mode typically do not exist. There was a sense within the TEP that patients ideally submit PROM data without any involvement or oral administration from clinicians or staff, and this is the best way to minimize social acceptability bias or other biases in the data. Several TEP members, including patient representatives, emphasized that data extracted from the patient record via natural language processing or similar technologies should not be considered "patient-reported" data because they are documented and interpreted by a clinician. Based on this discussion, NQF should consider including an expanded discussion on mode of administration in the Environmental Scan Report.

A TEP member suggested that the project deliverables should describe both the ideal state of digital PRO-PMs and the current state of the industry, with the latter description containing an explanation of what is minimally acceptable in the current state. This suggestion garnered a positive reaction from several TEP members.

This portion of the meeting ended with Mr. Amos reiterating that deliverables during Year Two will focus on digital measurement before introducing the NQF member and public commenting portion.

#### **NQF** Member and Public Comment

Ms. Brown opened the meeting for public comments. The federal liaisons echoed the importance of including precise definitions to drive this work and noted the importance of avoiding social acceptability bias, particularly in specialties and disease states (e.g., oncology) with a documented reluctance of patients to criticize clinician performance. A federal liaison also commented on the use of interactive voice response with PROM data collection and potential differences with tablet-based collection, further highlighting the importance of addressing mode of administration and method of collection in the Environmental Scan Report.

#### **Next Steps**

Evelyn Thomas, NQF senior analyst, informed the TEP that the next web meeting will be held on February 28, 2022. During this meeting, the updated Environmental Scan Report will continue to be discussed. Ms. Thomas then turned the meeting over to Mr. Amos for closing remarks. Mr. Amos

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encouraged the meeting participants to send any recommendations on measure developers that can serve as key informant interviewees to the project mailbox.

# Adjourn

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