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 2

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 February 28, 2022.

Welcome and Review of Web Meeting Objectives

Chuck Amos, NQF senior director, welcomed participants to the second web meeting for this second year and reviewed housekeeping reminders. 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 Teresa Brown, NQF senior manager. Ms. Brown proceeded to take attendance and invited the TEP members that missed the first web meeting to disclose any conflicts of interest. Ms. Brown then conducted attendance of the federal liaisons and thanked those in attendance.

Recap of Web Meeting 1

Ms. Brown provided a recap of the major deliverables that will be completed during Year Two of the project, along with a high-level overview of the themes that came out of Web Meeting 1. Ms. Brown shared that during Web Meeting 1 the TEP raised the importance of aligning the definition of patient-reported outcomes (PROs), PROMs, and PRO-PMs to the CMS' Meaningful Measures System Blueprint, and to include working definitions of eCQMs and dQMs from CMS as shared in previous Requests for Information (RFI). The TEP also discussed the need to highlight considerations for vulnerable populations and the unintended consequences of PROMs and PRO-PMs. Another key theme from Web Meeting 1 was the TEP's suggestion to expand on the assessment of mode of administration and method of data collection within the Environmental Scan Report Update. Ms. Brown expanded on the last two themes by highlighting issues related to the digital divide that prevent some patients from completing PROMs, as well as and consider other factors that may reduce PROM completion (e.g., literacy, language, cognitive functioning, time) in the Environmental Scan Report Update. She also clarified that the Report Update will reflect the project's focus on outcome measures.

Ms. Brown shared the need to refine the Environmental Scan Update to emphasize the current state of digital measurement and include a broad health systems approach that incorporates topics such as interoperability (e.g., FHIR and USCDI). Another recommendation was to incorporate resources in various ways, such as by including information from CMS publications and other public presentations that were delivered in 2021. Ms. Brown concluded this section by encouraging meeting attendees to keep in mind during the discussion what is minimally accepted today and consider the ideal future state of performance measurement five years from now. After providing the meeting recap, Ms. Brown transitioned to Mr. Amos to provide an overview of the preliminary findings from the Key Informant Interviews (KIIs).

Preliminary Findings from Key Informant Interviews

Mr. Amos reminded the TEP that NQF is currently working on the Environmental Scan Report Update and continues incorporating feedback from the KII findings and web meeting discussions. Mr. Amos shared that the scope of Option Year 1 includes the convening of KIIs with a sample audience of measure developers to identify potential improvement opportunities and help guide the TEP and NQF in updating the Technical Guidance Report. Mr. Amos also reminded meeting attendees that the three major project deliverables of the project include the Environmental Report Scan Update, the Developer Feedback Report that will capture the user experience of the Technical Guidance Report that was published in the Base Year, and the third and final report will be the revised version of the Technical Guidance Report, or the Roadmap.

Mr. Amos provided high-level overview of the informants whose experience spanned the career cycle as measure developers from being relatively new to having over a decade of experience. He shared that the interviewees came from a variety of organizations that ranged in capacity, resources, and established relationships with test sites. Mr. Amos also shared that the informants had a range of experience working with electronic clinical quality measures (eCQMs) or digital quality measures (dQMs). He highlighted that the measure developers had a wide range of backgrounds and skill sets, including nurse informaticists, qualitative researchers, data analysts, clinical quality experts, and experts on digital measurement. Mr. Amos concluded describing the informants' background by noting that most are not directly involved with the project, sharing that a few TEP members and federal liaisons with unique expertise were invited to participate.

Mr. Amos provided an overview of the interview topics that were covered, including introductory questions to explain each informant's experience, followed by their preferred topic area to focus on the most important improvement opportunities within the report. In advance of reviewing the findings, Mr. Amos highlighted that the findings on the slide deck were listed at a high-level while NQF continues to synthesize in more detail from the recent completion of the interviews.

The first feedback theme that emerged among the KIIs was the need of standardized data collection, data sharing, and reporting. Mr. Amos noted that while that is a broad topic, the focus is on the need for all stakeholders to approach digital measurement in a unified way. He shared some opportunities to support the recommendation, such as standardized use of Logical Observation Identifiers, Names, and Codes (LOINC) has the potential to encourage PROM developers to include comprehensive LOINC codes that address PROM questions, cut points, targets, and scores. Another emerging opportunity that was raised to support the theme was the use of FHIR (Fast Healthcare Interoperability Resource) for interoperability and other standardized steps throughout the process of creating a digital measure.

Mr. Amos shared that a second feedback theme that emerged was the need to indicate the importance of the patient throughout the entire development process, including activities that go beyond involvement in the stakeholder advisor group. Mr. Amos provided an example of one interviewee that shared his/her experience keeping the patients/caregivers engaged in the development process by holding separate meetings to those of the advisory group to break down the technical topics.

Mr. Amos highlighted that during the interviews there was general support for NQF's approach of listing the stages and tasks, and the experts appreciated that the stages were not too prescriptive and allowed for flexibility depending on the organization and measure developer's approach. One consistent theme of feedback specific to the stages was the need to provide more detail, such as approximate timeline for

key tasks, to better prepare measure developers who do not have experience in PRO-PM development (e.g., stage three can take longer than one year to be completed).

Mr. Amos concluded the overview of findings by sharing that another recurring theme of feedback was to the expand the report and include a broad health information technology systems approach (e.g., Health Information Exchanges [HIEs] and registries). He also shared that a couple of informants suggested additional resources in the report, including a side by side visual comparing a human readable specification and a computer readable specification.

Mr. Amos encouraged the TEP to raise any feedback shared from the KIIs findings that should be incorporated into the Environmental Scan Update as well as the Roadmap later this year.

Discussion: Environmental Scan Updates

Mr. Amos invited Drs. MacLean and Simon to facilitate the TEP discussion and to help inform the Environmental Scan Update.

One theme that emerged among the TEP members was the need to include challenges and considerations when using proprietary PROMs (i.e., if the PROM is not available in the public domain). Dr. MacLean raised that these challenges are largely applicable while using any valid and reliable PROM during PRO-PM development. It was shared that this challenge is not limited to dQMs and emphasized that to specify a measure appropriately, developers need to establish the standardized coding (e.g., LOINC) to support the desired data elements. During the conceptual stage, developers determine if codes exist to support the various elements the measure will be specifying (i.e., simple results versus change scores) and consider the proprietary nature of the PROM(s) to request or negotiate the use of LOINC codes early in the process as needed. Several TEP members also discussed that when developing a dQM, it is important to determine if the definition is supported by available FHIR resources and acknowledged this consideration for the future state of performance measurement.

Another recurring theme centered around the implications of modes and methods among different populations due to a range of accessibility issues (e.g., rural setting, cognitive or physical impairment, digital access, etc.). One TEP member shared that there is evidence that results for certain PROMs may vary via different modes (i.e., difference in results when PROMs are administered such as self-administration or verbal administration) or methods (i.e., how PROM data are collected, such as on paper or via a patient portal). The group discussed and agreed that mode of administration was not built to be captured within the existing EHR structure and this is an opportunity for improvement in the future state. The group discussed that in the future state it will be important to track progress over time and be able to assess whether different modes or methods were used. One future-state data collection element would be the use of proxy respondents, to ensure the validity of results. Other future-state elements would be the data capture around race, ethnicity, language, and social determinants of health (SDOH) as part of the metadata. There was agreement that the capture and use of this data is an opportunity to advance the field to the future state of quality measurement. One TEP member raised that there is a great amount of hesitation in the field towards risk-adjusting social determinants of health (SDOH) but shared that stratification can demonstrate whether a variation exists.

The importance of patient-level involvement throughout the development process was emphasized by a patient and TEP member. Specifically, considerations regarding the involvement targeted patient population and the importance of accurate language translations. This portion of the meeting ended with Mr. Amos sharing the revised definitions for PROs, PROMs, and PRO-PMs that will be included in the Environmental Scan Update in alignment with the CMS Meaningful Measures System Blueprint.

NQF Member and Public Comment

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

Next Steps

Evelyn Thomas, NQF senior analyst, informed the TEP that the next web meeting will be held on May 16, 2022. Ms. Thomas also shared that NQF is currently working on the Environmental Scan Update, which will be posted and available for public comments from April 6 to April 27.

Adjourn

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