Meeting Summary

Building a Roadmap From Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures 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 26, 2021.

Welcome, Introductions, and Review of Web Meeting Objectives

Chuck Amos, NQF director, Quality Innovation, began by welcoming participants to the initial web meeting for this project and stating housekeeping reminders. Sheri Winsper, NQF senior vice president, Quality Measurement, provided opening remarks on the importance of this work and thanked the Centers for Medicare & Medicaid Services (CMS). Mr. Amos then reviewed the meeting agenda and objectives. Following this review, he introduced the NQF staff, and then Teresa Brown, NQF senior manager, Quality Measurement, proceeded to take role and disclosures of interest from the TEP members and role from the Federal Liaisons.

Project Overview and Timeline

Mr. Amos began by sharing a brief history of NQF as a neutral convener and consensus-based entity. He then shared a high-level overview of the project, along with the True North statement that will serve to center the TEP's work and ensure that it remains in-scope: "There is currently a gap between hundreds of existing PROMs and only a few dozen PROM-based Patient-Reported Outcome-Performance Measures. This project will provide guidance to developing PROM-based PRO-PMs for use in CMS accountability programs by identifying key attributes of high-quality PROMs and creating step-by-step guidance on utilizing these PROMs to develop fully tested digital PRO-PMs."

Mr. Amos highlighted NQF's approach to this project, including the convening of the TEP and Federal Liaisons, the dates of eight 90-minute meetings, facilitating supplemental means of gathering information (e.g., surveys, key informant interviews, and focus groups), and developing reports and recommendations. He introduced the project's three deliverables and draft stages of development for each: (1) an Environmental Scan Report, (2) an Interim Report, and (3) the Technical Guidance Report. Mr. Amos concluded this section by describing an optional second year to the project that would include six additional web meetings and three additional deliverables.

Roles and Responsibilities

Mr. Amos 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. Mr. Amos noted that discussions will be facilitated by Co-Chairs Cathy MacLean (Hospital for Special Surgery) and Sam Simon (Mathematica). The co-chairs will also assist in reaching consensus,

identifying paths forward when consensus cannot be reached, keeping the TEP discussion on-scope, and prioritizing discussion topic and key issues.

Mr. Amos 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 the way TEP members do but will provide additional information and insights as needed. Mr. Amos 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. He then acknowledged CMS as the funder of the project and the agency that defined the scope of the work, noting that CMS will attend the meetings and review materials but will respect the independence of both NQF and the TEP.

SharePoint Tutorial

Ms. Brown introduced the SharePoint page that the TEP will use to share and provide feedback on meeting materials, such as draft reports, slides, and agendas. Included in the overview was a screenshot of the SharePoint site and recommendations for suggested browser use. She noted that the TEP should have recently received instructions on accessing SharePoint, although the site is currently down due to technical issues. The TEP would be notified when it is available.

Environmental Scan Overview and Discussion

Mr. Amos reminded the TEP that NQF shared a draft/strawman version of the Environmental Scan Report with them several days before the meeting and clarified that the report is intended to elicit TEP feedback. He noted that NQF performed a literature review and searched for publicly available guidance on developing digital PRO-PMs; however, due to the novel nature of the topic, few sources were identified. He noted that the Report includes some sources that measure developers can utilize when attempting to identify PROMs that are suitable as the base of a PRO-PM, including CMS' Value-Based Purchasing (VBP) Programs and Alternative Payment Models (APMs), the International Consortium for Health Outcomes' (ICHOM) standard sets, and recommendations from specialty societies.

The first discussion with the TEP was facilitated by Co-Chair Cathy MacLean and focused on identifying candidate PROMs for performance measures. The second discussion was facilitated by Co-Chair Sam Simon, and while it focused on challenges of measure development, Dr. Simon noted that the two discussion topics possessed enough overlap so that they were closely interrelated. Dr. MacLean began the discussion by focusing the TEP on identifying attributes of high quality performance measures and ensuring the candidate PROMs were designed in an adequate manner to support performance measurement. The following 35 minutes of the TEP's discussion centered around a few themes, including attributes of high quality PROMs that are suitable for performance measures; the respective advantages and drawbacks of a 1:1 relationship between PROMs and PRO-PMs versus a many:1 relationship; the unique responsibilities of different measurement stakeholders; and literature recommendations.

One theme centered around tentative attributes of high quality PROMs that are suitable for performance measures. The TEP discussed the value of reviewing the Attribute Grid that was developed and presented in the final report for the *Patient-Reported Outcomes: Best Practices on Selection and Data Collection* initiative. NQF agreed to send the link to the final report following the meeting. While burden was a common discussion point, one measure developer pointed out that some level of burden is inherent to performance measurement, particularly with regard to workflow and technical changes. One health information technology (IT) expert suggested that some of the challenges might be

addressed by working backwards from what we want to measure rather than by beginning with assessments of data collection instruments. Other points that were raised by TEP members consisted of the following questions:

- Does the PROM address the specific elements of the condition being measured?
- Does the PROM assess longitudinal changes over time?
- Does the PROM assess Minimal Clinically Important Difference (MCID)?
- Does the PROM have a score or other quantitative elements?
- Can PROMs with different scores or cut points be used in a single measure?
- Can data from different PROMs in the same clinical domain be used within a single measure?
- Is the PROM easy to collect?
- Is the PROM burdensome to patients with the number of questions?
- Is the PROM burdensome to clinical practice?
- Does the PROM have clinical utility?
- Is the PROM usable with disparate populations?
- Does the PROM have strong psychometric and/or econometric properties, as appropriate?
- Does the PROM have licensing fees or other proprietary elements?
- Is the PROM widely used and is extensive data available for measure testing?
- Is the PROM easy to implement in an electronic health record (EHR)?
- Does the PROM have codes from the Logical Observation Identifiers Names and Codes (LOINC) or other characteristics to support interoperability?
- Is the PROM data collected electronically or on paper, via Excel, etc.?

Another related theme discussed the value of choosing one PROM as the foundation for a performance measure, as opposed to developing a PRO-PM that is PROM-agnostic and can utilize data from many different PROMs in the same domain. One developer on the TEP mentioned a digital PRO-PM developed by his organization that accepts data from 28 different PROMs with no implementation other than using the PROM in clinical practice.

A third theme that emerged related to the unique responsibilities of different stakeholders. Multiple health IT specialists acknowledged the importance of engaging health IT professionals early in the implementation process so that their involvement is proactive rather than reactive. A measure developer noted that interoperability should not be considered as the responsibility of measure developers; it involves active engagement from different stakeholder perspectives. Interpretability and actionability were highlighted by clinicians as important, as was the ability to explain the value of patient-reported outcomes (PROs) to patients and discuss PROM results in real time. Meanwhile, patients must be engaged and willing to answer PROM questionnaires in order for measurement to occur. One TEP member noted the importance of "measuring once and cutting twice" as a metaphor emphasizing that stakeholders must accept responsibility for creating systems in which patients can complete questionnaires one time, and then those data can be used for both clinical care and quality measurement.

Lastly, during both the call and the in-meeting chat, the TEP members identified several peer-reviewed articles and government publications that they recommend NQF staff to review.

Public Comment

Mr. Amos opened the web meeting to allow for public comment. No public comments were offered.

Next Steps

Ms. Brown covered the next steps, including a survey to be distributed after the meeting, the next web meeting date and topics, and the upcoming environmental scan comment period. Mr. Amos then thanked everyone for their attendance and participation and closed the meeting.