NATIONAL QUALITY FORUM
Driving measurable health improvements together

Meeting Summary

Building a Roadmap from Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures

Web Meeting #2

The National Quality Forum (NQF) convened a public web meeting for the Building a Roadmap from PROMs to PRO-PMs Technical Expert Panel on February 26, 2021.

Welcome, Introductions, and Review of Web Meeting Objectives

Charles Amos, NQF Director, Quality Innovation, began by welcoming participants to the web meeting. Mr. Amos thanked CMS for their support of this work and provided an opportunity for the co-chairs to provide additional opening remarks. Dr. MacLean thanked the Technical Expert Panel (TEP) for their participation and the NQF project team for their support. Dr. Simon thanked the TEP for their contributions during the previous web meeting and shared his excitement for using the PRO Report from September 2020 as a point to move forward in this current work. Mr. Amos reviewed the following meeting objectives: Web Meeting #1 recap, Environmental Scan Discussion, Defining "High Quality", and Review of the PRO Attributes Grid. Roll call was taken and Mr. Amos discussed ground rules for the meeting.

Web Meeting #1 Recap

Mr. Amos thanked attendees for their participation during Web Meeting #1. Additionally, Mr. Amos thanked the TEP for the responses they provided within the post-web meeting survey. Mr. Amos shared that, at a high level, two themes emerged from discussion during the first web meeting: (1) Challenges to interoperability and (2) The need to consider advantages and disadvantages of having one-to-one ratio of a PROM to PRO-PM versus a many-to-one ratio. Upon review of the survey results, the following themes emerged: (1) Challenges of operationalizing PROs within a clinic environment and the downstream effects of this challenge, and (2) Measuring what is most important to patients and working to avoid patient survey burnout. Mr. Amos informed attendees that the PRO project from 2019 addressed the first challenge regarding operationalization and ensured that this past work will influence and support the current project and the focus on moving towards performance measures.

Mr. Amos shared that additional comments that were mentioned repeatedly in the post-web meeting 1 survey related to clinical relevance and accountability. To this end, Mr. Amos asked that TEP members keep the following question in mind during discussion: How actionable does a PROM need to be in clinical setting in order for it to be meaningful in performance measure?

Definition of "High Quality" PROMs for Use in Developing Performance Measures

Mr. Amos began this section by again thanking the TEP for the ample and varied feedback to the survey, and summarized responses to the strawman definition of "high quality". The definition as presented was "a PROM that is suitable to be the foundation for a digital PRO-PM, that can be used to evaluate the performance of healthcare entities." Mr. Amos shared several additional themes that emerged from the

post-web meeting survey centered on the use of “high quality” to define PROMs for performance measures, and potential consideration of alternate descriptors, such as “high utility” and “trustworthy”. The emerging themes included the importance to capture and acknowledge outcomes that are important to patients; to include psychometric soundness; to go above and beyond reliable, valid, feasible low burden, and low or no cost; to be tested and reliable in real-world settings with different collection modes; to include readily interpretable and actionable in the definition; and to incorporate the quality of PRO-PMs, emphasizing the intersection of PROMs and PRO-PMs.

To lead this discussion, Dr. Simon, co-chair, reviewed the definition of high quality that was discussed during Web Meeting #1, and oriented the TEP to the attribute grid. Dr. Simon asked the TEP to provide feedback on aspects that were missing from the attribute grid, and what is applicable to the work being done within this project. Dr. Simon shared his thoughts to start the discussion, to include whether or not PROMs have defined anchors and recommended timing, as well as the availability of standardized codes such as LOINC codes. Dr. Simon then opened the discussion up to the group.

It was suggested to consider use of a framework for defining high quality as opposed to having a check-list approach given the different properties of PROMs, further suggesting that the framework would assist in the decision-making process to help determine if the properties and instruments are appropriate for their specific context of use. There was strong agreement among the TEP to ensure that what the PROM is capturing is related to a relevant clinical care, and that the utility of a performance measure from a clinical perspective is vital for use and buy-in from clinicians. Additionally, the importance of the availability of the outcomes at the point of care is important for buy-in and continued use by clinicians.

Benefits from the patient perspective were shared, including PROM-based performance measures as a byproduct of delivering better care and improving patient engagement related to their treatment, the benefits to alleviating symptoms, and improving quality of life. The importance of goals for patients were also discussed, including the individualized goals to be considered in PROM selection. A patient member of the TEP emphasized that clarity of the PROM was one of the most important pieces, including the intent and weight behind the questions being asked. This statement was supported by other TEP members.

Specifically related to the Attribute Grid, discussion revealed that burden and effort may not be appropriately considered within the category of psychometric soundness. Discussion occurred around determining the correct PROM related to a particular quality aspect to be measured (e.g., depression or a total knee replacement would use different PROMs), as well as determining the correct unit of attribution (e.g., appropriate level of analysis). Data collection methods were emphasized as a potential prompt for those collecting the data to see or consider something they may not have otherwise considered. Data collection methods also specifically relate to the validity and reliability attribute included within the Grid, as it is possible for an instrument to be used in two different collection systems that may render the data collected by the same instrument incomparable for the purpose of performance measurement. It was stated that inter-unit reliability or signal-to-noise ratio may be missing from the test-retest attribute in the previous grid.

Historical perspective was provided related to including goal attainment as one of the attributes related to PROM selection. It was stated that there are not many good indications of measuring goal attainment, creating an issue for including this attribute related to PRO-PMs. When building performance measures, there was agreement among TEP members that there is a need to define cut-points and use PROMs with comparable cut-points and scores. The TEP discussed from a practical

standpoint whether to consider if training materials or administration procedures are available when selecting a PROM.

Mr. Amos and Dr. Simon thanked the TEP for the discussion provided during this portion of the meeting.

One TEP member asked if the PROM was narrowed to the clinical setting, or might the PROM be focused on the episode of care or the person's experience across care settings over a duration of time. A co-chair responded that existing patient experience of care measures (CAHPS), as well as PRO-PMs could be specified to collect a patient's experience related to a specific procedure, to capture the outcomes of care over time. These procedure-specific performance measures are generally more short term, while issues of attribution arise in long-term measurement. The original TEP member stated that due to family and caregiver experiences, clinical performance measures may not capture the full picture of patient care. The co-chair provided the example of Healthy Days, a measure by Humana, that captures a wider picture of the patient's full care but would likely not be appropriate to be attributed to a primary care provider. Such a measure could easily be attributed on the health plan level.

Environmental Scan Discussion

Teresa Brown, NQF Senior Manager, shared that public commenting on draft two of the environmental scan opened on February 25 and will close on March 17. The TEP, federal liaisons, and public are encouraged to review the scan and provide their comments. The federal liaisons associated with this project are encouraged to review the environmental scan and ensure that the information included aligns with the work of their respective federal agency.

Ms. Brown reminded attendees that the environmental scan focused on the literature review process, value-based payment and alternative payment models, and the NQF endorsement process for performance measures. Based on discussion and input from Web Meeting #1, edits and updates were made to the environmental scan, as discussed during the Web Meeting #1 recap. The sections that were added to the environmental scan include interoperability and the topic of standardized codes for PRO-PM values (e.g., LOINC).

Dr. MacLean, co-chair, provided additional insights on the intersection of PROMs and performance measures, and the importance of considering a one-to-one ratio of a PROM to PRO-PM versus a many-to-one ratio. Background on the PROM and PRO-PM intersection included logistical challenges, standard practice, publicly available crosswalks, cut-points or scores, licensing costs, burden and response rates, and interoperability. Dr. MacLean shared that PROMs should remain important to patients, focus on outcome measures, provide utility to clinicians, and consider collection and completion burden. A table was shared with the TEP comparing many-to-one and one-to-one relationships, and it showed similarities and differences related to the following categories: quality standard, interface with care, administration, and licensing costs. Overall, the many-to-one relationship allows for more flexibility in use and licensing costs and comes with potential difficulties in development, whereas the one PROM to one PRO-PM would be a relatively simple measure to develop but would be less universally accessible and may exclude additional users and clinicians.

Dr. MacLean then discussed the Key Considerations at the Intersection of PROMs to PRO-PMs, to include the definition of a quality standard (i.e., thresholds, change scores, or a combination), and collection and completion burden.

Discussion from the TEP revealed that defining positive changes in clinical care should be considered as an important component when considering cut points for the performance measurement. Cut points as an example relate back to actionability, having the same consensus-based scoring threshold to trigger an

action to be taken by the clinician. By using minimal clinically important difference (MCID) movement in the right direction related to actionability and cut points has been made but may be only the beginning of some of the work in this area. Discussion continued related to MCID specifics and the percent improvements in deemed significant different clinical scenarios, with a benchmark for determining average change deemed helpful in determining minimal acceptable clinical difference for patients. TEP members highlighted the need for more guidance on score interpretation for a PROM as this impacts cut point determination. It was discussed that focusing strictly on outcome-specific measures may become restrictive to both the provider and the patient, such as only looking at patient improvement on blood pressure or depression. Distribution-based measures were discussed as a solution to the many-to-one ratio and would allow for single measurement, even though there are challenges with this method. TEP members also discussed the need for tools that include risk adjustment modeling and specificity of measures for specific conditions. Additional discussion from the TEP highlighted the need to:

- Focus on clinical relevance and applicability, ensuring that measurement strategy is based on clinical relevance,
- Utilize PROMs that will inform the clinician, collecting on several aspects of health that allows for measures to be valuable across specialties; and
- Select PROMs that allow for clear interpretation of the cause of a score change at the individual patient level.

Ms. Brown informed TEP members that there is still an opportunity to share literature and anecdotal information that will inform the work of this project. TEP members were reminded to connect to the project team via email with such information.

A technical issue disrupted the call, but the majority of TEP members were able to rejoin. Emails were sent to TEP members following the meeting, and additional themes raised via email involved the importance of ensuring that PROMs used for performance measurement actually improve the quality of things that matter most to patients and whether patient input was received during the development of the PROM, as well as the relevance of MCID to different diseases and conditions (e.g., hip replacement vs. rheumatoid arthritis) and how they can very depending on the patient's baseline.

Public Comment

Mr. Amos opened the web meeting to allow for public comment. One comment from a Federal Liaison revealed that it is important to consider what patients believe are meaningful metrics and to add appropriate data that supports this point within the environmental scan and any future reports for this project. It was also noted that maintaining focus on PROs as it relates to this project, specifically, will be imperative to providing useful information within the environmental scan and additional project reports. Mr. Amos thanked the public for their comments.

Next Steps

Mr. Amos provided a reminder that the public commenting period for Version 2 of the Environmental Scan will be available until Wednesday, March 17. Mr. Amos encouraged meeting attendees to share the Environmental Scan with their colleagues as the public is welcomed to provide their comments. Attendees were reminded that Web Meeting #3 will occur on March 25, 2021 from 3:00-4:00pm ET.