



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

Web Meeting #3

The National Quality Forum (NQF) convened a public [web meeting](#) for the Building a Roadmap from PROMs to PRO-PMs Technical Expert Panel on March 25, 2021.

Welcome, Introductions, and Review of Web Meeting Objectives

Chuck 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.

Co-chair Dr. Sam Simon mentioned the useful Technical Expert Panel (TEP) discussion during Web Meeting #2, including the need to capture the voice of the patient and the need to have actionable anchors and cut points. Dr. Simon believes the last meeting helped move the project work forward. Co-chair Dr. Cathy MacLean agreed with Dr. Simon's comments and shared that the importance of this project work continues to arise and that she appreciates the TEP's constructive comments and discussions. Mr. Amos informed the TEP that a monthly Measures Management Systems Information Session hosted by CMS was held on March 24. This meeting was an opportunity for Mr. Amos and Teresa Brown, NQF Senior Manager, Quality Measurement, to present on NQF work related to the Patient Reported Outcomes: Best Practices on Selection and Data Collection technical report that was published in September 2020. Mr. Amos reinforced that the work being completed on this project is useful and interconnected within the field and appreciates the TEP's continued feedback.

Roll call was taken and Mr. Amos reviewed the following meeting objectives: to determine which public commenting themes contribute to improvements in the environmental scan report; to clarify scope of Interim Report and ensure TEP is well-positioned to guide its development, and to review recommended changes to the PRO-PM version of the Attribute Grid (based on the grid from the PRO Best Practices report) and identify additional revisions to support performance measurement. Mr. Amos shared a visual representation of the project timeline and discussed that we are currently completing base year activities, including the three main deliverables for the base year of the project: the environmental scan report, an interim report, and a technical guidance document. TEP members were reminded that the environmental scan report will be published in May, the interim report is being outlined and will be finalized in the Summer of 2021, and that the Technical Guidance document will be finalized in November 2021. Mr. Amos discussed ground rules for the meeting.

Web Meeting #2 Recap

Mr. Amos did not offer additional summarization of Web Meeting #2 beyond what Drs. Simon and MacLean shared at the beginning of the meeting. There were no questions or concerns from the TEP regarding the Web Meeting #2 recap.

Review of Environmental Scan Public Comments

Mr. Amos updated the TEP and shared that 25 comments were received from 6 organizations. Many of the comments received focus on data implications of caregivers and the burden that caregivers and patients must complete. Some public comments received raise important points about PRO-PMs that go beyond the scope of this project. Mr. Amos asked that the TEP keep the scope of work at the forefront as we consider proposed responses. Mr. Amos explained the process of sharing public comments with the TEP, then opened discussion to ensure that TEP members' suggestions were considered for proposed responses.

Mr. Amos noted that within the public comments there were several remarks related to caregivers or proxies completing PROMs on behalf of a patient, and the difference between a PROM being completed by a patient versus a caregiver. The following highlights key discussion points that emerged in response to this overarching theme:

- Would a PROM need to obtain an increased amount of patient data before being considered as a PRO-PM, and if a performance measurement data set should include how well the patients are doing, or if such information is inherent to the PROMs themselves. Mr. Amos responded that the project needs to keep in scope for the CMS task order, agreeing that one of the goals include how we approach PROM measurement and the importance from the patient's perspective. Dr. MacLean shared in response that the patient voice is already gleaned from the PROM, but the patient voice is still needed for developing PROM-based performance measures.
- Would there be value in looking at how to address multiple or quasi-themes related to the importance of individualized goal setting, shared care planning, and shared decision making as related to PROMs? Mr. Amos reiterated that we have deferred to the previous NQF work in some of those areas ([Patient-Reported Outcomes: Best Practices on Selection and Data Collection](#)) and have focused on the attributes of high quality PROMs rather than on what each PROM is measuring. Drs. Simon and MacLean shared that addressing multiple themes in the context of individualized goal setting is out of scope but helpful to discussions related to shared decision making.
- There may be a test or template for measure developers that can be provided to determine what is a meaningful PRO to the patient or patient groups, to have specific outcome measures that match what is desired for the patient.
- It is important to maintain realistic expectations regarding individualized and goal setting measures. Person-driven outcomes in the context of setting care goals are still in the research phase. There was TEP agreement with this comment and that a template, as previously mentioned, could be developed and considered for future understanding of the measurability of PROM results related to individual goal setting.
- The same or similar terminology is being used among developers and psychometricians, but with different meanings. More clarity in language and terminology, especially around interoperability, is needed. NQF staff agreed that this is a point to consider and apply to future reports.

Mr. Amos began sharing the public comments received and asked that the TEP also review the proposed responses that the project team developed. The review of comments began with those from the American Academy of Physical Medicine and Rehabilitation (AAPMR). The proposed response was acceptable to the TEP with the addition of language that clarifies patients' voices will be included at all phases of the project.

A TEP member posed a question related to a dedicated patient perspective being represented, and if a provider or vendor could reasonably provide both a professional viewpoint, as well as a personal perspective as a patient (i.e., that most healthcare professionals have been patients at some point in their lives and could speak as both professional experts and as patients). Mr. Amos responded that the dedicated patient perspective is important to represent those that are not versed in the medical ecosystem and who have lived experience managing a difficult and time-consuming condition as a patient or caregiver rather than as a healthcare professional. A patient representative agreed with this statement. Another TEP member emphasized the importance to determine the explicit aspect in which the patient perspective would be most valuable. Drs. MacLean and Simon further emphasized the importance of measured outcomes to the patient, and that the development of attribute related to the characteristics of a PRO-PM need to ensure this information is included.

Review of the initial comments garnered robust conversation which required an adjustment in approach in order to keep the meeting on schedule. Mr. Amos provided two options for the TEP: 1) Review proposed responses today with TEP comments limited to major concerns about those responses, or 2) Continue robust discussion and seek TEP feedback on proposed responses via email. Responses provided during the meeting showed that the TEP wished to review the proposed responses as a group during the meeting. Overall, there were no concerns from the TEP members regarding the proposed responses.

Related to comments from American College of Medical Quality (ACMQ) and criterion 1, Mr. Amos asked if this is something to add to our report. The public comment read as follows:

“The Scan completely skipped over Criterion 1: Importance to Measure and Report: Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-impact aspect of healthcare where there is variation in or overall less-than-optimal performance. This is both surprising and very concerning. The initial process circa 2011 that NQF developed and adopted for evaluating evidence related measures going through the CDP has not been updated. The current process here is loose and very unscientific and requires significant updating. Measure developers typically skirt around this step with provision of a narrative and bibliographic references, but no structured or explicit scientific approach to evaluating the effectiveness and impact on actual health outcomes related to the measure in question. In the case of PRO-PMs, the evidence that is presented usually is only related to the PRO instrument and not the effectiveness of the actual use of the related PRO-PM in the field. Change scores in PRO scores can be statistically significant but clinically insignificant. Another concern is how/if/when the results of generating PRO scores are actually used at the point of care during clinician/patient interactions. From my own experience having had several spine and hip surgeries, while I have filled out endless PRO instruments related to these procedures, I have never had a discussion or been made aware of these scores by the clinicians who have done these procedures or been involved with post procedural physical therapy. Thank you.”

Mr. Amos shared that the comment relates to the endorsement process and will be shared with the appropriate NQF department, and that point of care issues are discussed in the 2020 PRO Best Practices report. He also noted that Criterion 1 is addressed in a previous section of the environmental scan report but not in the “Challenges” section. Finally, he asked if the TEP had any additional recommendations for either revising the environmental scan report in light of these observations or responding to this comment, and none were noted.

Mr. Amos went through each remaining comment and proposed response. A TEP member shared insight about interoperability and wondered to what degree there will be language that addresses

equivalency and explained that there is a desire to select from more than one instrument, so having equivalent meaning is useful and important to consider. Mr. Amos shared that language in the environmental scan does include information about interoperability, but the project team would welcome additional information to add to the report if necessary. TEP members shared that they would review this aspect of the scan and share appropriate information with the project team.

Mr. Amos thanked the TEP for their patience and adjustment to the approach for reviewing the public comments.

Discuss Interim Report Draft Outline

Mr. Amos provided a brief update regarding the interim draft report outline by sharing that the final outline will be provided to CMS on March 26. In the Interim Report, the project team will continue updates to the attribute grid and determine if any attributes have been missed, review current PRO-PMs in use.

Discuss Revisions Made to the PRO Attributes Grid

Mr. Amos reviewed the changes that have been made to the attributes grid. We are looking at attributes of PROMs that are well-suited for a performance measure. Dr. Simon led discussion to glean from the TEP if any attributes are missing or need to be updated. TEP discussion included a desire to determine if sensitivity in changes to a PROM score are related to changes in care or if there is an impact from other factors. Additional proposed revisions discussed among the TEP included:

- Separating the final bullet point to reflect “language/translations” and “standardized codes”
- Add language that will help to determine if a PROM is being used at point of care, and if so, if physicians know how to use and interpret the score, and
- Changing language within the second point to be more inclusive and read as “actionable cut points or targets, anchors, and/or defined meaningful change”
- Remove “clear documentation on how to interpret scores” due to redundancy
- Elaborate to what is meant by cultural congruency

Additionally, standardized scaling at the PRO-PM level was emphasized, to ensure when more than one PROM is used there is equivalence of those various instruments. “Normalize, standardize, harmonize” was used as an example from a separate perspective to further stress the importance of ensuring scaling and cut points are accurate and consistent throughout. No additional revisions were proposed by the TEP. Mr. Amos shared that a brief survey will be shared with the TEP in order to determine which additional revisions to the attribute grid the TEP believe are necessary.

Public Comment

Ms. Brown opened the web meeting to allow for public comment. Sandy Mitchell, Federal Liaison, opened further conversation related to change scores and meaningful change within the attribute list. Girma Alemu, Federal Liaison, requested that there be clarification in any terminology used. Mr. Amos shared that a comprehensive glossary will specifically be incorporated into the Technical Guidance document, which is intended for developers at all levels, as well as the Interim Report. No additional public comments were offered. Mr. Amos requested that this time be used to revisit the TEP members that had questions early in the meeting when there was minimal time for discussion.

Next Steps

Ms. Brown closed the meeting by reminding the TEP that a brief survey will be sent by mid-day on Friday, March 26 to determine what, if any, additional changes need to be made to the attribute table discussed during today's web meeting. Additionally, the Interim Report will be shared with the TEP in mid-to-late-April for review and feedback. Ms. Brown closed the meeting by reminding attendees that Web Meeting #4 will occur on April 29, 2021 from 1:30-3:00pm ET.