NATIONAL QUALITY FORUM

Meeting Summary

Person and Family Centered Care Standing Committee June 2017 Off-Cycle Quarterly Webinar

The National Quality Forum (NQF) convened a public webinar for the Person and Family Centered Care (PFCC) Standing Committee on June 1, 2017. An archived recording of the webinar is available for playback.

Welcome, Introductions, and Overview of Topic

Suzanne Theberge, Senior Project Manager with NQF, began by welcoming participants to the webinar and providing an overview of NQF's off-cycle work. Ms. Theberge then introduced the topic of this call, to seek input from the PFCC Committee on the evaluation of instrument-based measures, and presented the discussion questions (which were shared with the Committee in advance of the call and are listed below); a brief overview of the history of patient reported outcome - performance measures (PRO-PMs) at NQF; and NQF's current classification system for instrument based measures. She then provided an overview of a proposed new classification system for instrument-based measures. Karen Johnson, Senior Director at NQF, provided additional context on NQF's previous work on patient-reported outcomes and how the field has changed in the last five years. Following the overview, the Committee Co-Chairs, Lee Partridge and Dr. Chris Stille, led the Committee discussion.

Discussion Questions

- Which instrument-based measures should be considered PRO-PMs?
    - Should provider-administered PROM measures be classified as PRO-PMs?
    - Does NQF need to differentiate between provider-solicited information and patient provided information?
    - Should patient self-report (e.g., a measure that asks a patient to report on whether a particular process was done) process measures be considered PRO-PMs? (These measures are currently evaluated as PRO-PMs. Are these still PRO-PMs or do they need to be classified differently)?
- Should the evaluation differentiate between PRO-based outcome and process measures? If so, what are the implications in terms of NQF's measure evaluation criteria? Would patient-reported process measures be held to the criteria for process measures (e.g., a more stringent evidence requirement for quantity, quality, and consistency of the body of evidence rather than a rationale, but no requirement for score-level reliability and validity testing)?
- Is it important to label PRO-PMs (or other instrument-based measures) according to PRO domains? Why or why not?
- Are there additional PRO domains that NQF should consider?
- What should be the implications (if any) of PRO domain on the measure evaluation criteria?

- There are two diagrams below: NQF's current classification of instrument-based measures and a proposed classification. Are there concepts or items missing from the diagram below that would be helpful for NQF to know about and/or incorporate?
- If there is time on the call after discussing the previous questions, NQF staff would like the Committee to discuss these two questions:
    - What are the implications for Feasibility and Usability & Use, particularly with eMeasures?
    - Are there any considerations specific to eMeasures?

Committee Discussion

The Person and Family Centered Care Standing Committee held a wide-ranging discussion. Committee co-chairs Ms. Partridge and Dr. Stille facilitated the discussion portion of the call, with additional facilitation provided by Ms. Johnson. Ms. Theberge began the Committee discussion with the following two questions:

- How should NQF describe the different types of instrument-based measures?
- What are the implications in terms of NQF's endorsement criteria?

Committee members first discussed the range of descriptions proposed by NQF and asked several clarifying questions about NQF's definitions and examples of measures that could be patient-reported process measures. A Committee member proposed, to general agreement, that the key consideration for person and family centered care is whether care is aligned with a patient's health goals, preferences, and priorities. Committee members discussed the difference between a report – a dichotomous yes/no "did this event happen" versus a subjective rating – "did this event happen in a way that worked for the patient" and agreed they are not the same, but are both needed. Committee members also noted the distinction of rating metrics. Oftentimes perception can influence ratings, which can cause discordance between the physician and patient experiences.

NQF's criteria for PRO-PMs require evidence that the measured population values the measure and finds it useful. Committee members agreed that process measures can also be meaningful to patients noting that there is a space for considering process measures as an intermediate step to develop valuable outcome measures. The Committee noted that measure developers need more information on emerging best practices for involving patients in measure development. Specifically, new ways to engage patients in identifying relevant outcomes to measure and the selection of instruments that meaningfully capture the patient experience or condition are key areas for future focus.

NQF's current guidance, from the 2013 NQF report *Patient Reported Outcomes (PROs) in Performance Measurement,* states that "patient" in "patient reported" is a term of art that is intended to be inclusive of all persons, including patients, families, caregivers, and consumers more broadly. It is intended as well to cover all persons receiving support services, such as those with disabilities. There was an extensive discussion on whether NQF should define a new measure category for "observer reported" data. Ultimately, the Committee agreed there are some measures where caregivers must provide information – such as measures of care for small children or measures for patients who have died, but that it was not necessary to create a new categorization. Committee members did note that different data might be provided for the same measure concept depending on whether the patient or caregiver is asked (such as teen versus parent report of a care experience). However, the Committee indicated that the data source (i.e. patient versus family member) does not affect the criteria by which a measure

should be evaluated. The Committee stated it is an issue that should be discussed during the validity criterion, but not something that needs to be used to classify measure types.

Recommendations

Committee members agreed that not all measures collected by patient report are outcomes, and that there is a need for the further classification of instrument-based measures into the following types (see NQF's current and newly proposed classification diagrams on page 4):

- Clinician reported: performance measures that rely on data collected from clinicians
- Patient reported outcome: outcome measures that rely on data collected from patients
- Patient reported process: process measures that rely on data collected from patients
- Patient reported structure: structure measures that rely on data collected from patients
- Patient reported experience of care: measures that assess a patient's experience of care, using data collected directly from the patient.

In agreement with the definition in NQF's 2013 Patient Reported Outcomes report, the Committee agreed that caregivers and parents can be included in the "patient" categorization for the purposes of the measure evaluation criteria, but that Committees should assess, as part of the validity of the measure, who is the best data source when looking at particular measures that rely on proxy reporting. The Committee did reiterate that while "patient reported" can include others such as families and caregivers, it is important the report not be filtered through any clinician interpretation; the data must be collected directly from the patient into the instrument.

Ultimately, the Committee recommended the following changes to NQF's criteria:

- Instrument-based measures that use patients as the data source: Patient reported measures should be split out into patient reported outcomes measures, patient reported process measures, patient reported structure, and patient reported experience of care measures.
- Patient reported process measures should use the evidence requirements for process measures (quantity, quality, and consistency of evidence).

The Committee agreed that for evaluation purposes, it is not necessary to further categorize measures by outcome type (e.g. symptom/symptom burden, health related quality of life, functional status). However, the Committee agreed that there was an opportunity for NQF to further develop nomenclature for PRO-PMs to advance their development, adoption, and implementation.

In addition, the Committee requested that NQF provide further guidance on the exact definition of "instrument", which is not currently defined by NQF.

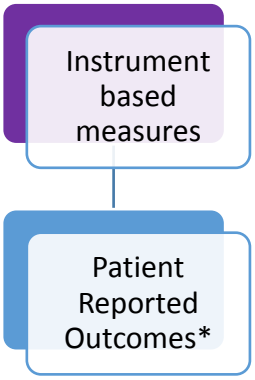
Opportunity for Public Comment

Ms. Theberge opened the call for public comment. Two commenters had questions for the Committee. One commenter asked how financial burden is incorporated into patient experience measures. Committee members agreed this was an excellent, but difficult question, and that financial burden is a key component of experience of care, especially in regards to a patient's ability to access care. The second commenter noted that there are particular areas of clinical care where caregivers, families, and/or parents may be more appropriate than either a patient or clinician to provide information on the quality of care (e.g. patients with cognitive impairments or dementia, or young children).

Closing

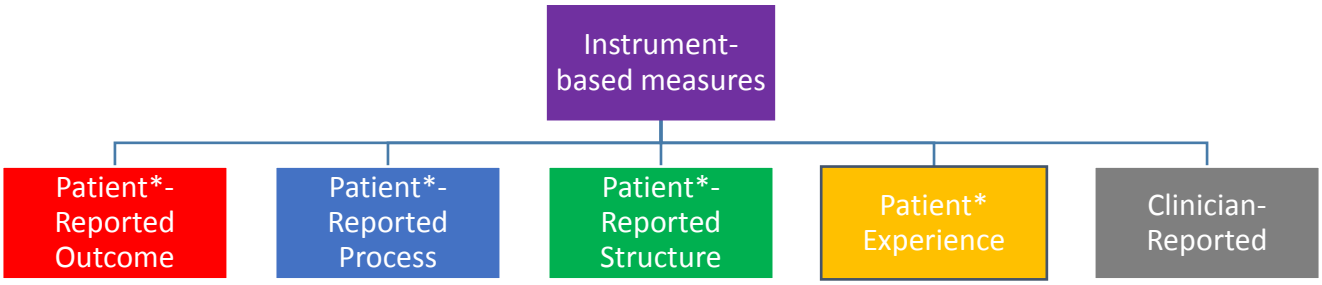
In closing, Ms. Theberge thanked webinar attendees for their participation. Ms. Theberge summarized the next steps, including the creation of this meeting summary, which NQF will share with the Committee. Ms. Theberge also reminded the Committee about the next off-cycle webinar, scheduled for August 2, 2017, in which the Committee will hear updates about NQF's work on shared decision making.

NQF's current classification of instrument-based measures



**NQF's 2012 report on PRO-PMs noted the following key domains of patient-reported outcomes: health-related quality of life (including functional status); symptoms and symptom burden (e.g. pain, fatigue); experience with care; and health behaviors (e.g., smoking, diet, exercise). However, NQF's endorsement requirements do not vary based on domain.*

Newly proposed classification of instrument based measures



**Patient can include family and other caregivers, as appropriate. Measures in each of these categories could be further described according to domain (i.e., health-related quality of life, patient experience, symptoms & symptom burden, and health behaviors).*