NATIONAL QUALITY FORUM

Memo

TO: NQF Members and Public

FR: NQF Staff

RE: Review of *Patient Reported Outcomes in Performance Measurement*

DA: October 24, 2012

Background

Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy, including performance improvement and accountability, in achieving a high quality, affordable health system. Emerging evidence affirms patients who are engaged in their care tend to experience better outcomes and choose less costly but effective interventions, such as physical therapy for low back pain, after undergoing a process of share decision-making. Promising approaches to authentically involve patients and their families at multiple levels are being implemented across the country including serving on governance boards at hospitals and contributing to system and practice redesign to make care safer and more patient-centric.

Historically, with the exception of collecting feedback on satisfaction or experience with care, patients remain an untapped resource in the assessment of the quality of care and that of long-term support services. Patients are a valuable and arguably the authoritative source of information on other outcomes beyond experience including: health-related quality of life, symptom and symptom burden, and health-related behaviors. Therefore, interest in performance measures based on patient- reported outcomes is increasing.

The project goals were to:

- Identify key characteristics for selecting PRO instruments (PROMs) to be used in performance measures (PRO-PMs);
- Identify any unique considerations for evaluating PRO-PMs for NQF endorsement and use in accountability and performance improvement applications; and
- Lay out the pathway to move from PROMs to NQF-endorsed PRO-PMs.

Review and Comment

The Expert Panel's recommendations are included in the draft document, *Patient Reported Outcomes in Performance Measurements*. The draft report is posted on the NQF web site for review and comment only—not voting. The recommendations include a suggested pathway to move from PRO concept to an endorsed PRO-PM and some modifications related to NQF criteria for evaluating performance measures when considering PRO-PMs for NQF endorsement. Of particular note are recommendations to require: evidence that persons form the target population find the PRO meaningful; evidence that a PRO is responsive to intervention; and reliability and validity testing of both the PROM and the PRO-PM.

You may post your comments and view the comments of others on the NQF website.

NQF Member and Public comments must be submitted no later than 6:00 PM ET, November 22, 2012.

NQF is now using a program that facilitates electronic submission of comments on this draft report. **All comments must be submitted using the online submission process.**

Supporting documents related to your comments may be submitted by e-mail to pro@qualityforum.org with "PRO Report" in the subject line and your contact information in the body of the e-mail.

Thank you for your interest in the NQF's work. We look forward to your review and comments.

National Quality Forum

Patient Reported Outcomes (PROs) in Performance Measurement

Draft Report for Comment

10/24/12

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INTRODUCTION

US Healthcare: Performance Improvement & Accountability

Widespread variation in the quality of healthcare in the United States is well documented.[1,2,3,4,5,6] Although there are many laudable examples across the country where safe, effective, affordable care and support services are consistently provided serious gaps persist. Coupled with the need to constrain escalating healthcare costs—threatening the livelihoods of individuals and families and the overall national economy— intense focus is being placed on performance improvement and holding providers accountable to tackle the double edged sword of achieving the highest quality care at the lowest possible costs. The Affordable Care Act has several provisions targeting this challenge including the creation of a National Quality Strategy (NQS) to serve as a blueprint to *improve the delivery of health care services, patient health outcomes, and population health.*[7] Released in March 2011 and updated yearly, the NQS identifies three overarching aims of better care, healthy people and communities, and affordable care and six priority areas[8] for collective action to ultimately drive towards a high-value health system.[9,10]

Achieving Performance Improvement & Accountability through Patient Reported Outcomes

Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy, including performance improvement and accountability, in achieving a high quality, affordable health system. Emerging evidence affirms patients who are engaged in their care tend to experience better outcomes[11] and choose less costly but effective interventions, such as physical therapy for low back pain, after undergoing a process of share decision-making.[12] Promising approaches to authentically involve patients and their families at multiple levels are being implemented across the country including serving on governance boards at hospitals and contributing to system and practice redesign to make care safer and more patient-centric.[13,14]

Historically, with the exception of collecting feedback on satisfaction or experience with care, patients remain an untapped resource in the assessment of the quality of care and that of long-term support services. Patients are a valuable and arguably the authoritative source of information on other outcomes beyond experience including: health-related quality of life, functional status, symptom and symptom burden, and health-related behaviors. For example, in the case of long- term support services for persons with disabilities, asking about valued outcomes such as increased communication and self help skills, and improved social interactions. Hence, it is critically important to engage patients by building capacity and infrastructure to routinely capture patient-reported outcomes and then use this data to develop performance measures to allow for accurate appraisals of quality and efficiency.

NQF Role in Promoting Accountability & Performance Improvement

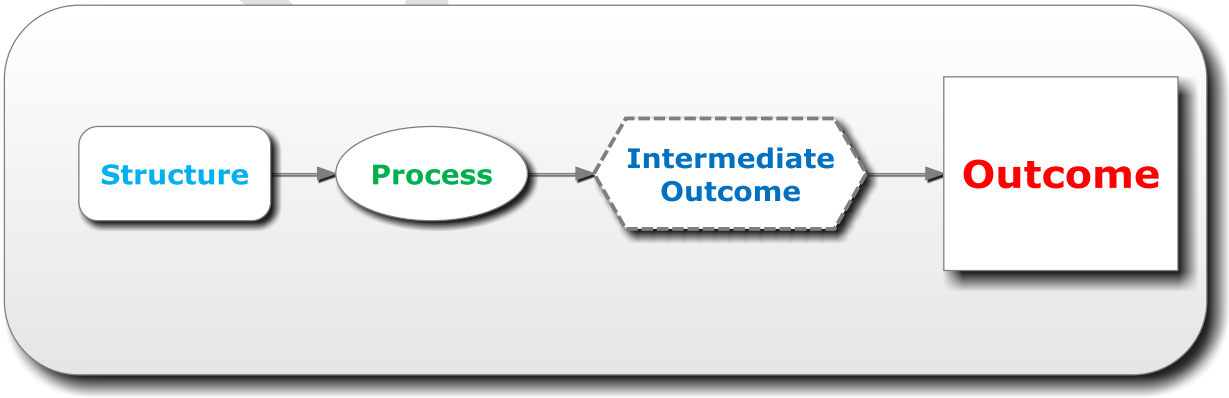
Valid, reliable measures are foundational for evaluating and monitoring performance and fostering accountability. The National Quality Forum (NQF) is a voluntary consensus standard setting organization recognized under the National Technology Transfer and Advancement Act.[15] In this role NQF endorses performance measures as consensus standards to assess the quality of healthcare for use in accountability applications such as public reporting and payment as well as performance improvement. NQF is a neutral evaluator of performance measures but is not a measure developer. NQF convenes diverse stakeholders to evaluate measures based on the well-vetted criteria (available here).

The field of performance measurement is evolving to meet the demands of increased accountability to improve outcomes in both quality and costs. In tandem, the direction for NQF-endorsed performance measures includes:

- a drive toward higher performance reflected in more outcome measures rather than very basic processes such as assessment;
- measuring disparities;
- a shift toward composite measures that summarize multiple aspects of care;
- harmonization of measures across sites and providers; and
- measurement across longitudinal patient-focused episodes including outcome measures, process measures with direct evidence of impact on desired outcomes; appropriateness measures; and cost/resource use measures coupled with quality measures, including overuse.

Figure 1 depicts the relationship between structure, process, and outcome. For NQF endorsement, there is a hierarchical preference for performance measures of health outcomes that are linked to evidence-based processes or structures; or outcomes of substantial importance with a plausible link to healthcare processes. Next in the preferred hierarchy are measures of intermediate outcomes and processes closely linked to desired outcomes. Measures of processes that are distal to desired outcomes (e.g., assess patient) and those that are satisfied by a "checkbox" are considered to have the least impact on the goal of improving healthcare and health.

Figure 1. Structure-Process-Outcome



	Characteristic	Specific issues to address for performance measures	Example: The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)[354] for use in hip arthroplasty
		measure to detect changes in the construct being measured over time), would you accept use of the PRO measure to provide valid data over time in a longitudinal study if no other PRO measure was available?	
		• Important to emphasize responsiveness because there is an expectation of consequences. Need to be able to demonstrate responsiveness if action is to be taken.	
		• PRO must be sensitive to detect change in response to the specific healthcare intervention	
4.	**Interpretability of Scores**		
	A PRO measure should have documentation to support interpretation of scores, including: • what low and high scores represent for the measured concept • representative mean(s) and standard deviation(s) in the reference population • guidance on the minimally important difference in scores between groups and/or over time that can be considered meaningful from the patient and/or clinical perspective	• If different PROs are used, it is important to establish a link or cross-walk between them. • Because the criteria for assessing clinically important change in individuals does not directly translate to evaluating clinically important group differences, [327] a useful strategy is to calculate the proportion of patients who experience a clinically significant change[271,327]	• Availability of population-based, age- and gender-normative values[363] • Availability of minimal clinically important improvement values[364] • Can be translated into a utility score for use in economic and accountability evaluations[365]
5.	**Burden**		
	The time, effort, and other demands on the respondent and the administrator.	• In a busy clinic setting, PRO assessment should be as brief as possible, and reporting should be done in real-time. • Patient engagement should inform what constitutes "burden."	• Short form available[366] • Average time to complete mobile phone WOMAC = 4.8 minutes[367]
6.	**Alternatives modes and methods of administration**	• The use of multiple modes and methods can be useful for diverse populations. However, there should be evidence regarding their equivalence.	• Validated mobile phone and touchscreen based platforms[368,369]

	Characteristic	Specific issues to address for performance measures	Example: The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)[354] for use in hip arthroplasty
7.	**Cultural and language adaptations**	• The mode, method and question wording must yield equivalent estimates of PRO measures.	• Available in over 65 languages[370]
8.	**Electronic health records (EHR)**	Critical features: ▪ interoperability ▪ automated, real-time measurement and reporting ▪ sophisticated analytic capacities	▪ Electronic data capture may allow for integration within EHR[367]

Appendix C—Glossary

Patient-reported outcome (PRO): The concept of any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else. PRO domains included in this project encompass:

- health-related quality of life including functional status;
- symptom and symptom burden;
- experience with care; and
- health-related behaviors.

PRO measure (PROM): Instrument, scale, or single-item measure used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient to self-report (e.g., PHQ-9).

Performance measure: Numeric quantification of healthcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, clinician, etc.

PRO-based performance measure (PRO-PM): A performance measure that is based on PROM data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved