



NATIONAL
QUALITY FORUM

Fast Forward

BRIEFS ON NEW WORK BY NQF

ISSUE NO. 1

Creating Valid and Reliable Patient-Reported
Outcome Measures

WHERE WE ARE

- Patients remain untapped resources, but their views and experiences are seen as important
- Clinicians are concerned about use of patient-reported information in measurement programs

NQF'S NEW WORK

- Brings critical stakeholders together to hash out complex methods issues
- Lays out 12-step path from measure idea to reliable, valid patient-reported outcome performance measures
- Provides measure developers with practical and immediately useful tool to fill critical measure gaps

FAST FORWARD

- New patient-reported outcome performance measures are developed, tested, endorsed, and used nationally by private and public sectors
- Patients become a much more prominent voice in improving healthcare value
- Health information technology and electronic measurement advance, making adoption of these measures easier

Patients are an authoritative source of information on health outcomes; they can answer the questions “was I able to return to work as scheduled?,” “did I experience prolonged pain?,” “did I understand my doctor’s discharge orders?”

Patient-reported outcomes (PROs) are defined as any report of the status of a patient’s health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else. PROs include health-related quality of life, including functional status; symptoms and symptom burden, such as pain or fatigue; patient experience with care; and health behaviors, such as smoking, diet, or exercise.

There is broad agreement that valid and reliable performance measures are foundational to achieving quality in healthcare, and that patient-reported outcomes are an important, largely untapped source of information. But a large gap remains between the perceived value of patient-generated information and the trust of using it as part of quality measurement, public reporting, and payments to providers.

PRO → PROM → PRO-PM

patient-reported outcomes

information on the patient, told by the patient, without interpretation

instrument, tool, single-item measure

way to collect information told by the patient without interpretation

PRO-based performance measure

way to aggregate the information that has been shared and collected into a reliable, valid measure of performance

EXAMPLE: Patients with Clinical Depression

Symptom: depression

Patient Health Questionnaire (PHQ-9[®]), a standardized tool to assess depression

Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711)

NQF is contributing to this leap forward in performance measurement. Its new report, **Patient-Reported Outcomes in Performance Measurement**, details the specific steps on how to move from patient-reported outcome information all the way to evidence-based, valid, and reliable performance measures that can help healthcare providers continually improve the care they give. Those who fund, develop, and test performance measures can immediately use this new report to more rapidly create these much needed, next generation measures.

As referenced in a January 2013 *New England Journal of Medicine* piece, important methodological issues must be solved to more rapidly develop, use, and encourage widespread acceptance of patient-reported outcome performance measures, or PRO-PMs. NQF recently worked with a group of leading national experts to address these complex methods and other technical issues. The end result of NQF's work—a practical, actionable roadmap for advancing patient-centered performance measurement—will help us see the healthcare system through patients' eyes, focusing on what matters most to them.

Many challenges must still be addressed before PROMs are used widely in practice and PRO-PMs become the standard for measuring quality. How do the frail, children, or others who may face communication challenges respond when asked to provide information? How do we better integrate measurement tools into an electronic measurement environment, and what data infrastructure changes are needed? NQF looks forward to ongoing partnership with others in the field to tackle these challenges moving forward.

CURRENT DEBATE

“Do patients' reports of their health care experiences reflect the quality of care? Despite the increasing role of such measures in research and policy, there's no consensus regarding their legitimacy in quality assessment.”

“..as physician and hospital compensation becomes increasingly tied to patient feedback, health care providers and academics are raising strong objections...”

“We believe that when designed and administered appropriately, patient-experience surveys provide robust measures of quality and our efforts to assess patient experiences should be redoubled.”

“A common measure of patients' overall assessment of care—grounded in sound research—would facilitate cross-study comparisons and might reduce confusion and skepticism regarding what patient 'satisfaction' actually measures.”

ABOVE EXCERPTED FROM *The Patient Experience And Health Outcomes*, *New England Journal Of Medicine*, January 17, 2013

EXPERT PANEL AND FUNDER

NQF is thankful for the support of the Department of Health and Human Services that funded this work, and its panel of wonderful experts that committed themselves to this project.

Patricia Brennan, RN, PhD – Co-chair
Professor, School of Nursing and College of Engineering, University of Wisconsin-Madison

Joyce Dubow, MUP – Co-chair
Senior Director, Health Care Reform, AARP

NQF SUBJECT MATTER EXPERTS

Helen Burstin, MD, MPH

Karen Adams, PhD, MT

Karen Pace, PhD, MSN

[> Full Expert Panel List](#)

QUICK LINKS

[> Patient-Reported Outcomes in Performance Measurement: Final Report](#)

[> NQF Commissioned Paper:](#)

[Methodological Issues In The Selection, Administration And Use Of Patient-Reported Outcomes In Performance Measurement In Healthcare Settings](#)

[> NQF Commissioned Paper:](#)

[PRO-based Performance Measures for Accountable Healthcare Entities](#)



ABOUT NQF

The National Quality Forum (NQF) is a private organization recognized and funded in part by Congress to do public service work aimed at making healthcare of the highest value. Non-profit, non-partisan, and member-driven, NQF specializes in performance measures that enable standardized measurement of healthcare services. Its unique consensus model for making decisions and recommendations allows everyone invested in healthcare's future to have a say in its direction; NQF-endorsed measures are seen as the 'gold standard' given the rigor and multi-stakeholder decision-making that go into them. NQF earns its public trust through this commitment to consensus, having a seat at the table for all-comers, and by making its entire body of work transparent to the public.