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The science of collecting and analyzing patient-reported outcomes (PROs) is well developed in clinical research.¹ Almost a quarter of US drug labels include information about treatment benefits based on patient symptom questionnaires.² International organizations and regulatory agencies have developed methodological standards for the use of PROs in clinical trials.^{1,3}

But this work has largely occurred outside the workflows of those delivering care and the vocabulary of performance measurement. Although data about patients' impressions of or experiences with care delivery (ie, satisfaction) are routinely collected, reports about symptoms, functional status, or quality of life are not.

To close this gap, recent initiatives by several major US organizations involved with the development, endorsement, and implementation of performance measures have converged on approaches for collecting, analyzing, and reporting outcomes that patients notice and care about (ie, patient-centered).

The National Quality Forum (NQF), the National Committee for Quality Assurance (NCQA), and a number of US medical specialty societies have moved forward with initiatives to promote the use of PROs as a basis for performance measurement. These efforts recognize the need to move from a PRO measure (PROM) to a PRO-based performance measure (PRO-PM), which specifies how patient-reported data are aggregated and interpreted to reflect performance ([Box](#)).

Box.

Definitions Related to Assessing Performance Using Patient-Reported Outcome Measures

- **Patient-reported outcome (PRO):** The concept of any report of the status of a patient's health condition that comes directly from the patient (or in some cases a caregiver or surrogate), without interpretation of the patient's response by a clinician or anyone else. An example is the concept of depression.
- **PRO measure (PROM):** An instrument, scale, or single-item measure used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient (or in some cases a caregiver or surrogate) to self-report. An example is the Patient Health Questionnaire-9 (PHQ-9).
- **PRO-based performance measure (PRO-PM):** A performance measure that is based on PROM data aggregated for an accountable health care entity. An example is the proportion of patients with depression or dysthymia and an initial PHQ-9 score >9 who after 6 months of management from mental health professionals have a PHQ 9 score <5 at follow-up.

In January 2013, the NQF produced a report outlining a pathway to the endorsement of PRO-PMs and criteria for evaluating them for endorsement as US national voluntary consensus standards.⁴ This report was based on a series of multidisciplinary stakeholder workshops that included patient advocates, clinicians, experts in performance assessment, and PRO experts and was informed by 2 commissioned methods papers and a public comment period.

Approaches used in several existing performance evaluation programs that integrate PROs also informed the report. Some examples include a program for universal reporting of symptoms and functional status by patients in England after selected elective surgeries⁵; administration of a symptom and functional status questionnaire to patients enrolled in Medicare Advantage plans⁶; and a state-sponsored program for

collection of patient-reported depression scores by primary care and psychiatric practices across Minnesota.⁷

A pathway has been generated through this effort for developing methodologically robust and actionable PRO-PMs (eFigure in Supplement). This pathway begins with establishing a rationale for using a PRO to measure performance in a particular context—including a process for identifying outcomes that are meaningful to patients. It carries through to selecting or developing an appropriate PROM, then to identifying and testing an approach for aggregating and interpreting the patient-reported data as a PRO-PM. The PRO-PM can then be used for purposes of accountability and quality improvement. In addition, there is periodic evaluation of the PRO-PM as part of ongoing feedback and refinement.

These recommendations are already being used. The NCQA has prior experience with PRO performance measurement through its involvement with the Medicare Advantage program (and provided input in the development of the NQF recommendations). Now, the NCQA is working with the US Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services (CMS) to identify PRO measurement strategies supported by electronic health records. This includes developing consensus on which PROMs are appropriate in specific clinical situations; the timing of administration of PROMs; definitions of meaningful improvements; and risk adjustment methods.

A number of professional organizations are also developing condition-specific PRO-PMs. For example, the American Society of Clinical Oncology is creating PRO-PMs for specific symptoms and functional status relevant to the treatment of cancers toward implementation in its Quality Oncology Practice Initiative network, and is basing its work on the NQF model. The Society of Thoracic Surgeons and American College of Cardiology recently developed a registry including assessment of patient-reported health-related quality of life as part of a CMS National Coverage Determination program for percutaneous transcatheter aortic valve replacement.

The American Medical Association–convened Physician Consortium for Performance Improvement (PCPI) recently hosted a technical expert panel to identify best practices for developing PRO-PMs. Similar to the NQF recommendations, key PCPI themes included the importance of engaging patients and consumers to help identify quality performance problems and corresponding meaningful outcomes that are amenable to change by health care intervention; to determine when PROs are appropriate; and to test the clarity, interpretability, and psychometric properties of potential PRO-PMs. Pilot testing was viewed as essential to evaluate feasibility of a measurement strategy and to obtain data for developing and testing the PRO-PM. The panel harmonized its work with the NQF recommendations through a collaborative effort.

Challenges for early PRO-PM programs will include the cost of new infrastructure and pilot testing; the logistics of collecting data from patients in a “real world” setting while minimizing missing data; and the development of analytic techniques that risk adjust and yield results that are meaningful to clinical practice. As programs move forward, these challenges should be periodically reconsidered.

A rationale for PRO-PM programs is that better symptom control and quality of life are associated with reduced costs and use of medical services and improved medication compliance, patient satisfaction, and survival.⁸⁻⁹ Availability of PRO-PM information will help clinicians evaluate whether they are optimizing symptom control and learn how they might improve; can allow health systems or quality assessment programs to identify practices for which educational interventions or outreach programs could be beneficial; and, ultimately, may assist patients in understanding which practices best manage issues related to symptoms and functioning.

Now that a pathway has been outlined (with an understanding that it will be refined as experience accumulates from continuous feedback), the next step is wider integration of PROs into delivery of care.

To date, this takes place in very few practices. In the near future, electronic health records will need to include fields to collect structured data and define data elements that can be represented with appropriate codes for this information.

Research funding and engagement of stakeholders across the quality enterprise—including payers, health systems, professional societies, researchers, and patient groups—are essential for fostering priority setting, rigorous measure development, and integration of PRO-PMs into accountability programs. Such efforts will help bring patients' perspectives to the center of care delivery and the center of performance measurement, where they belong.

ARTICLE INFORMATION

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