

# Toward a Better Understanding of Patient-Reported Outcomes in Clinical Practice

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Current shifts toward patient-centered healthcare, and changes in payment structures point to the more personalized production of better *health*, not just *healthcare*, as a next organizational paradigm. A critical question exists around how to redesign systems to promote more meaningful patient involvement in their health, especially around modifiable risk factors, the use of preventive care, understanding personal risk, and patient-reported functional outcomes. Clinicians see most patients for a total of 30 to 90 minutes per year, over the course of a few visits—what patients do outside of these often-rushed visits is where health will be largely created and promoted.<sup>1</sup> Transformation to a system geared toward promoting health and improving care requires us to reimagine what it means to engage patients meaningfully, to give them a real voice in their health and care,<sup>2</sup> and to capture more of their varied experience and attitudes beyond the 20-minute provider visit. Further, patients only retain 10% of what they are told during office visits, with communication made worse by sometimes distracted clinicians staring at poorly structured electronic health records (EHRs), typing notes, and performing quick protocol-driven symptom reviews and screening recommendations. Notably, due to new and sometimes conflicting data casting many screening tests in a more questionable light, current guidelines for prevention and screening are increasingly moving from a “one size fits all” approach toward more tailored recommendations based on specific patient characteristics and preferences.<sup>3</sup> These nuanced and complex screening discussions require more comprehensive patient-specific information to achieve their intended goal.

The collection and use of patient-reported outcome (PRO) data into EHRs represents an important step forward for the transition to a more patient-centered, personalized health system. The initial rationale for PROs in healthcare revolved around assessing the patient’s functional status and healing/recovery timeline, often for research. Subsequent work has expanded these uses. Bennett and colleagues described a typology for the use of PROs to include the following areas: (1) platforms for regularly inputting patient perceptions of their care or health;

(2) a longitudinal patient care monitor; (3) a way to coordinate advanced symptom management for complex disease; (4) a system for vital symptom tracking at

Current shifts toward patient-centered healthcare and accountable payment options point to the more personalized production of better health, not just healthcare, as a next organizational paradigm. Transformation to a system geared toward promoting health requires us to think broadly about what it means to engage patients meaningfully, to give them a voice in their health and care, and to capture more of their varied experience and attitudes beyond the provider visit. The collection and use of patient-reported outcome data into electronic health records represents an important step forward for the transition to a more patient-centered health system. We set out an agenda for better understanding how and when patient-reported outcomes may improve patient health and care experience.

*Am J Manag Care.* 2014;20(4):281-283

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### Take-Away Points

- Current shifts in incentive structures, patient-centered healthcare, and payer policies point to the more personalized production of better health, not just healthcare, as a next organizational paradigm.
- The collection and use of patient-reported outcome (PRO) data into electronic health records represents an important step forward for the transition to a more patient-centered health system.
- We propose an agenda for better understanding how and when PROs may, or may not, improve patient health and care experience.

home; and (5) a shared interface to communicate changes in symptoms and need for care.<sup>4</sup>

Another important application of PROs is in the area of generating individualized screening and prevention recommendations. PROs have the potential to create more accurate prediction models to estimate the value of a particular screening test. They can do so through the use of electronic interfaces to capture patient-reported information about family history, past medical conditions, lifestyle habits, and preferences around screening and risk tolerance within structured and clinician-vetted EHR fields. PROs can also inform recommendations for optimal screening decisions for an individual. This in turn can provide patients the opportunity to discuss their goals, values, risks, and preferences with their providers. Enhanced shared decision making between patient and provider can thus be promoted with the addition of updated, organized patient-derived information.

The National Cancer Institute's PROSPR (Population-based Research Optimizing Screening through Personalized Regimens) initiative supports the study of patient-specific information as it relates to processes of care and decision making across the cancer continuum, from screening through treatment. Our experience implementing this research initiative in 2 large health systems suggests that the collection and use of PROs holds large potential benefit, but also brings forward many operational challenges and questions. We believe that to realize the full promise of PROs, a number of key facets warrant attention. We outline them below and set out an agenda for better understanding how and when PROs may, or may not, improve patient health and care experience.

First, patients need to be willing to provide this information. This implies that they buy in to the rationale that these novel metrics should be employed in routine care. While there has been a fair amount of study on the use of PROs in pathway-driven perioperative care, research is needed on patient perceptions of PROs into other areas, particularly primary care and prevention. Other research needs to better understand how patients would ideally want to communicate with their providers around PROs,

and whether they would feel pressure to provide "socially desirable" responses.

Second, patients need to have reliable, attractive platforms to provide PROs. Initial measurement of PROs occurred on paper forms. As the transition occurs toward electronic capture of PROs through kiosks, tablets, patient portals, e-mail, or other options, this opens up the possibility of longitudinal and integrated tracking. While good evidence exists around the equivalence of electronic and paper-based PROs,<sup>5</sup> more data are needed to discern which modes of input fit best in different clinical contexts and for individual patients. A related area of research and development centers around optimizing the flow of PRO data to providers. Most EHRs do not have standardized fields to accept and track PROs. New work flows are necessary to optimize provider effort and the personnel responsible for tracking and managing these metrics. This type of operational, process-based research is a key next step in implementing PROs in ambulatory settings.

Third, data derived from PROs must be relevant and actionable. This raises a series of interrelated questions. Which PROs have the highest likelihood of changing clinical management, and in what settings might this be most useful? We posit that PROs that promote better screening and preventive health decisions through collection of fine-grain personalized risk data are high-value targets. There are many other potential areas, such as common chronic diseases, in which existing process and outcome measures do not capture fully the spectrum of the illness and healthcare experience. Functional physical and mental health PROs may prove to be attractive in these areas.

Providers are already burdened by the collection of numerous measures; for PROs to have uptake in this stakeholder group, they would need to show validity and utility. More understanding of provider perceptions and concerns about PROs is urgently needed. Investigation is necessary around their support for the concept and any underlying fears about the accuracy of, and responsibility for, data input by the patient.

Further questions exist around the best ways to collect PROs in practice. Does real-time collection of data in the office impede provider work flow, or create logistical and efficiency hurdles? If the data are collected asynchronously through patient portals or kiosks, how can providers ensure that they see and act on the data in a timely manner? In the move toward team-based care, we need to

understand which team members should manage specific PROs. For most PROs, whether they are computed risk scores or physical and mental health functional scores, we need to better understand what small score changes mean, and when providers should act on them.

As the structure of the healthcare system changes rapidly, patient-reported outcomes provide clinicians with a different set of tools for promoting health that can better incorporate patient information and perspectives. Early innovations with PROs offer some hope for their eventual utility and success, along with cautions around challenges with managing and standardizing PROs.<sup>6</sup> Incorporating PROs into clinical practice may begin to fundamentally alter our relationship with EHRs for the better, prompting a move from restrictive unilateral documentation by providers to shared, dynamic dashboards for managing health and health risks with timely information on patient preferences for screening and disease management.<sup>3</sup> Ultimately, PROs have to show that they provide value to patients and providers in daily practice. While their promise is large, many operational questions need to be addressed before the use of PROs can be widely disseminated.

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**Source of Funding:** This project was supported by award number U54CA163307 from the National Cancer Institute Population-based Research Optimizing Screening through Personalized Regimens initiative.

**Author Disclosures:** The authors report no relationship or financial interest with any entity that would pose a conflict of interest with the subject matter of this article.

**Authorship Information:** Concept and design (AB, TO, JSH); acquisition of data (AB, TO, JSH); analysis and interpretation of data (AB, TO); drafting of the manuscript (AB, JSH); critical revision of the manuscript for important intellectual content (AB, TO, ANAT, JSH); obtaining funding (JSH, TO, ANAT); administrative, technical, or logistic support (AB); supervision (AB).

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