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Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care

ABSTRACT The provision of patient-centered care requires a health care environment that fosters engagement between patients and their health care team. One way to encourage patient-centered care is to incorporate patient-reported outcomes into clinical settings. Collecting these outcomes in routine care ensures that important information only the patient can provide is captured. This provides insights into patients' experiences of symptoms, quality of life, and functioning; values and preferences; and goals for health care. Previously embraced in the research realm, patient-reported outcomes have started to play a role in successful shared decision making, which can enhance the safe and effective delivery of health care. We examine the opportunities for using patient-reported outcomes to enhance care delivery and outcomes as health care information needs and technology platforms change. We highlight emerging practices in which patient-reported outcomes provide value to patients and clinicians and improve care delivery. Finally, we examine present and future challenges to maximizing the use of patient-reported outcomes in the clinic.

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A seminal 2001 report from the Institute of Medicine (IOM), *Crossing the Quality Chasm*, called for a redesign of the US health care system.¹ Indeed, the report used bold language to suggest that patients control health care decisions; knowledge be shared and information flow freely; the system be flexible in accommodating patient preferences and values and encourage shared decision making; and patients have ready access to their own medical information, as well as clinical evidence. Fifteen years later the system has changed surprisingly little, necessitating a further call to action.

The advent of new technologies and accompanying changes in policies and consumer expectations are encouraging, however. A time is approaching when rapid progress and advances are possible.² One approach that supports patient engagement in health care delivery is the use

of patient-reported outcome measures. Patient-reported outcomes, traditionally developed and used in research, are now seeing broader applications in clinical practice.

Patient-reported outcome measures complement existing biological measures and physical examinations by providing standardized assessments of how patients function or feel with respect to their health, quality of life, mental well-being, or health care experience.³ For example, patient-reported outcomes can measure an individual's ability to return to recreational activities or be free of pain following spine surgery. When incorporated into the health care visit, patient-reported outcomes can fuel conversations between patients and providers that lead to shared decision making and result in individualized care.

Moving Patient-Reported Outcomes To Mainstream Care

Many stakeholders are interested in expanding the capture and use of patient-reported outcomes for direct patient care. Efforts to include such feedback in quality measurement, encourage electronic data collection, and include patient-reported outcome measures in value-based payments, as well as calls by the patient community to advance shared decision making, have collectively created an environment that is increasingly ready for the widespread adoption of patient-reported outcomes.

The National Quality Forum,⁴ the International Society for Quality of Life Research,⁵ and a number of professional societies⁶ have established guidance for the collection and reporting of patient-reported outcomes. Most notably, the National Institutes of Health funded the Patient Reported Outcomes Measurement Information System (PROMIS) to establish a bank of patient-reported outcome measures for use across health conditions.⁷ Although PROMIS was established as a research initiative, subsequent funding expanded it to support applications in clinical practice.

Policy facilitators for incorporating patient-reported outcome measures into practice include the enactment of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009. Starting in 2011, HITECH established meaningful-use criteria for eligibility for federal incentives to expand the adoption and use of electronic health records (EHRs).⁸ Beginning in 2017, the focus will shift toward improving health outcomes, with meaningful-use measures ultimately being incorporated into the Medicare Merit-Based Incentive Payment System and other alternative payment models.⁹ Pilot programs of bundled payment for total joint replacement, slated to begin in April 2016, will reimburse providers for collecting patient-reported outcomes and will later include the collection of those outcomes in calculating payments.¹⁰ The Oncology Care Model of the Centers for Medicare and Medicaid Services (CMS) also includes patient-reported outcomes as one of several endorsed quality measures.¹¹

Patient and consumer communities are also driving change.¹² One example is the social media platform PatientsLikeMe. Developed in 2004, PatientsLikeMe disrupted the traditional paradigm of how patients control and manage their health by directly linking patients to each other to share experiences and knowledge. The success of this and similar initiatives has led funders to partner with patient communities to expedite change.

For example, PatientsLikeMe developed a new

project to generate and test new patient-reported outcome measures based on input from its users.¹³ In addition, the Patient-Centered Outcomes Research Institute recently approved the second phase of the National Patient-Centered Clinical Research Network, which supports thirty-four other networks.¹⁴ Eighteen of these are patient-powered research networks led by communities of patients interested in tracking and sharing health information to advance patient care and research.¹⁵

Given substantial changes in the data and research “ecosystems” that support the capture and use of patient-reported outcomes in health care delivery,¹⁶ it is important to identify and understand barriers to and facilitators of the successful implementation of patient-reported outcome measures.

Identifying The Value Of Patient-Reported Outcomes

A project facilitated through AcademyHealth’s Electronic Data Methods Forum and supported by the Agency for Healthcare Research and Quality brought together experts from the following three leading surgical quality and outcome registries: Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR),¹⁷ the Comparative Effectiveness Research Translation Network (CERTAIN),¹⁸ and the Kaiser Permanente National Total Joint Replacement Registry.¹⁹ In a year-long collaboration with diverse stakeholders (clinicians, patients, EHR vendors, hospital administrators, researchers, and policy makers), these experts worked to identify the value of patient-reported outcomes in clinical practice and to glean generalizable lessons that informed the development of a tool kit with examples of successful implementation of patient-reported outcome measures.^{20,21}

Providers report that patient-reported outcomes enhance patient engagement and shared decision making when they are integrated into clinical care, because the outcomes can provide an assessment of the patient’s experience of illness (symptoms, functioning, and well-being), values and preferences, and goals for health care over time. Accordingly, the value of patient-reported outcomes is to support patient-provider engagement by assessing the severity of symptoms, providing information to track the impact of treatments on patient outcomes, helping patients and providers set priorities for office visit discussions, informing treatment decisions by making it possible to compare patient-reported outcomes to population norms, monitoring general health and well-being as part of routine vis-

its, and connecting providers to patient-generated health data collected by patients to track their health independent of the health care encounter (Exhibit 1).

ASSESSING THE SEVERITY OF SYMPTOMS The systematic capture of patient-reported outcomes can highlight patients' experiences of symptoms related to a health condition or treatment. This information is important for assessing health and monitoring treatment effects. For example, in oncology care, collecting patient-reported symptoms through the EHR helps clinicians identify and discuss the impact of treatment and plan for the potential adverse events related to chemotherapy.^{22,23} Similarly, the integration of a web-based patient-reported assessment into routine care in an HIV outpatient clinic helps clinicians identify important issues such as depression, symptom burden, and medication adherence.²⁴

INFORMING TREATMENT DECISIONS Informa-

tion gleaned from patient-reported outcomes has been shown to inform patient-physician discussions in surgical care. In joint replacement surgery, the capture of patient-reported outcomes regarding symptom severity (such as pain and loss of function) helps inform decisions about the approach to and timing for knee surgery.²⁵ The Arthritis and Joint Replacement Center at the UMass Memorial Medical Center shares trends in pain and function measures with patients at each visit to monitor symptomatic changes.²⁶ If medical care and physical therapy do not effectively control symptoms, patients and their surgeons review individual patient measures, in the context of national norms for surgery, to inform decisions about surgery.

TRACKING OUTCOMES Tracking outcomes over time allows patients and providers to observe important trends and adjust care accordingly. The Collaborative Chronic Care Network²⁷ sup-

EXHIBIT 1

Examples of the value of patient-reported outcomes (PROs) for patient-centered care

Study author(s)	Example	Endnote in text
Basch et al, Berry et al.	Assessing the severity of symptoms Provider alerts generated for potential chemotherapy-related toxicities based on patient self-report through an online PRO platform	22, 23
Crane et al.	Routine symptom burden assessment for patients seen in an HIV primary care clinic alerts providers about patients reporting high burdens	24
Ayers et al. (2015), Ayers et al. (2013)	Informing treatment decisions Patient-reported pain and function outcomes over time provide data for patients and providers to assess the effectiveness of physical therapy and medication treatments and determine when surgical care is necessary for knee replacement	25, 26
Simpkins et al, Margolis et al, Cincinnati Children's Hospital Medical Center	Tracking outcomes The Orchestra Project's tracking tool allows pediatric patients with inflammatory bowel disorder to track outcomes over time related to lifestyle and treatment changes	28, 29, 30
Forsberg et al.	Patient-reported pain and function collected for patients cared for at the Spine Clinic at Dartmouth-Hitchcock Medical Center are used to monitor the impact of treatments provided	31
Forsberg et al.	Outcomes relevant to the patient's condition are captured and graphically displayed, showing trends over time in disease course and response to treatments	31
Todd et al, Stover et al.	Prioritizing patient-provider discussions Cancer patients and their providers review a summary of PRO measures to detect health issues that otherwise might have been missed	32, 33
My GI Health	Personalized reports based on reported gastrointestinal symptoms are generated for patients treated at a gastroenterology clinic to prioritize and focus discussions	34
Forsberg et al.	Monitoring general health and well-being Routine assessment of health behaviors and health status (health-related quality of life) through Group Health's electronic health record, MyGroupHealth	31
Katzan et al.	Routine assessment of depression among patients treated at Cleveland Clinic's Neurological Institute through the Knowledge Program	36
Sanger et al.	Connecting providers to patient-generated health data Patient tracking of surgical site using a mobile application (mPOWER) to track and share photos of surgical site and patient-reported symptoms following hospital discharge	38

SOURCE Authors' analysis of data from the items cited.

ports the Orchestra Project, an innovative approach to patient-physician partnership for inflammatory bowel disease.²⁸ Using the Orchestra Project's tracking tool, the patient and physician determine the set of measures the patient will track, inclusive of validated patient-reported outcomes and goal-specific measures tailored to the individual. The patient and physician learn together, both from changes initiated by the individual (for example, related to diet, sleep, or exercise) and from planned changes in care.²⁹ This approach to care has resulted in an increase in pediatric remission rates from 60 percent in 2007 to 79 percent in 2015 across the Improve-CareNow network of over seventy pediatric gastroenterology care centers that treat children and youth with inflammatory bowel disease.³⁰ Similar examples of tracking outcomes have been described in routine care for rheumatology and in spine care.³¹

PRIORITIZING PATIENT-PROVIDER DISCUSSIONS The brevity of health care encounters requires innovative approaches in information sharing to ensure that high-quality care is delivered. Platforms that allow patients to provide information about their health, concerns, and priorities and that facilitate providers' real-time access to this information can help prioritize topics for discussion during the clinical visit.³²⁻³⁴

MONITORING GENERAL HEALTH AND WELL-BEING Routine collection of patient-reported outcomes related to general health and well-being provides important information about an individual's overall health.³⁵ The systematic capture of this information is important in screening for clinical depression, a CMS clinical quality measure. The Knowledge Program, developed by and used in Cleveland Clinic's Neurological Institute, incorporates the capture and use of patient-reported outcomes—including the Patient Health Questionnaire (PHQ-9), a widely used depression screening measure—as part of the comprehensive electronic data system.³⁶ Similar approaches to monitoring overall health have been described at the Spine Center at Dartmouth-Hitchcock Medical Center and at Group Health Cooperative.³¹

CONNECTING PROVIDERS TO PATIENT-GENERATED HEALTH DATA Many patients see value in tracking important outcomes on their own, outside of the health care encounter, using a variety of new technologies available for this purpose. Moreover, patients are increasingly interested in and willing to share this type of information, especially if they are aware that the information will be used in dialogue with the treating provider.³⁷ In a recent consumer survey, 80 percent of the respondents agreed that they would be willing to share their data for improved care.³⁷

For example, a mobile health (mHealth) app called mPOWER provides surgical patients with a tool to track the condition of the surgical site following discharge from the hospital, with the goal of improving early detection and treatment of surgical site infections.³⁸ The app allows discharged patients to securely transmit photos of surgical sites and respond to their health care provider's questions about symptoms and pain. The increased availability of mHealth apps, wearable devices, and sensor technologies allows patients to easily track information about their health and well-being, movement and exercise, diet, and sleep. This information, which is not captured through medical records, presents new opportunities for patient care outside of traditional health care settings.^{39,40}

Although mHealth apps and wearable devices have taken center stage in the movement toward patient-generated health data, other tools can also be used to gather such information, sometimes in ways that require no effort by the user. Embedded sensors that track movement in the home offer the possibility of greater independence for individuals who have ambulatory challenges, cognitive deficits, or other health conditions that frequently require facility-based care.⁴¹ The use of such sensors has significant potential because, unlike wearable devices and mHealth apps, they do not require the user to do anything to gather and transmit data.

Challenges To Using Patient-Reported Outcomes In Routine Care

Despite the groundswell of interest in and support for the use of patient-reported outcomes to enhance patient-centered care, efforts to put theory into practice have met with mixed success.^{42,43} The implementation of patient-reported outcome measures is hampered by logistical concerns, measurement challenges, technological barriers, and lack of focus on the end user.

LOGISTICAL CONCERNS Logistical concerns about capturing patient-reported outcomes include workflow barriers, such as the increased burden on staff members and patients to ensure that patient-reported outcomes are collected and made available, the added time the provider needs to interpret the data, and the increased duration of office visits to discuss them.⁴³⁻⁴⁵ In response to these concerns, health systems have developed several strategies to streamline the collection of patient-reported outcomes. To save time and reduce staff and patient burden, many systems offer multiple mechanisms for data collection, including tablet computers to use in collecting and scoring patient-reported outcomes while patients wait to see the provider.

Mechanisms that allow patients to collect outcomes from home before or after an office visit have proved helpful.

In addition, mechanisms that allow patients to collect outcomes from home before or after an office visit have proved helpful. In one early study about administering patient-reported outcome measures before and after total joint replacement, researchers reported low patient questionnaire completion rates (in the 20–30 percent range).⁴⁴ However, after the joint replacement registry implemented more consistent follow-up procedures outside of the clinic visit (through e-mail, regular mail, or telephone coordinated by a centralized contact center), the completion rate exceeded 80 percent.^{44,46}

Expanding the use of computer adaptive testing is another approach to addressing logistical challenges because it reduces the time needed to collect patient-reported outcomes.^{47,48} Computer adaptive testing uses the responses the patient has already provided to select subsequent questions. In this manner, the questionnaire adapts to the individual patient by eliminating questions that are not relevant to his or her condition. In an ongoing study, patients receiving care for rheumatoid arthritis complete a series of PROMIS measures about their physical, mental, and social health using computer adaptive testing.⁴⁹ A customized report is generated for each patient to discuss with his or her provider. Additional evaluations of the impact of PROMIS and computer adaptive testing are needed.

Technology to support the seamless integration of the collection and review of patient-reported outcomes into patient care needs further development. EHRs organize clinical data (lab and physical exam results and nursing notes), but many EHRs have limited capacity for direct patient input. Portals focus on “read only” patient access to clinical data, which limits providers’ ability to “process” data (for example, score them or search for trends) for patient-provider discussions. This situation may change, however, as more health care institutions take advantage of a provision in the stage 3 meaning-

ful-use criteria that require application-program interfaces that enable patients to view, download, and transmit their health information.

MEASUREMENT CHALLENGES Concerns about how patient-reported outcomes are measured also exist. While shared decision making is assumed to be a “best practice,” some stakeholders believe that focusing on patient-reported outcomes driven solely by clinical practice needs may decrease the likelihood of discussions about issues or concerns that are important to the patient. Engaging patients in the implementation of these measures in health care settings will be necessary to ensure that patient-provider discussions are of value.

The complete and timely capture of patient-reported outcomes is necessary but challenging to implement. The collection of health information, including patient-reported outcomes, is frequently driven by the health care visit. As a result, it may not be possible to capture data beyond health care encounters, unless a patient registry or research initiative exists to support the effort.

Providers and researchers have expressed concerns about the reliability of patient-generated health data as a measure of patient outcomes. In one study, patients who underwent total joint replacement tracked exercise sessions daily and wore an accelerometer, as well as completing patient-reported outcome measures. Scores of the outcomes showed significant pain reduction and increases in the distances patients reported being able to walk (for example, “I am capable of walking five blocks”) after total joint replacement. However, daily steps tracked through the accelerometer showed that many patients did not walk much greater distances after the procedure than they had before.

This discrepancy may reflect a difference between the ability to perform a new task and adopting new patterns of daily activity.⁵⁰ New opportunities to leverage features within mobile devices for research activities, such as those available using Apple’s ResearchKit apps,⁵¹ may make it possible to study such discrepancies and even take advantage of differences in self-reported and sensor data to intervene on behalf of patients whose observed function is not as expected. In the interim, research is needed to understand what applications for patient-generated health data are appropriate, how to preserve patient privacy,⁵² and how to interpret these data.

TECHNOLOGICAL BARRIERS Limited evidence exists about how to make patient-reported outcomes actionable for patient care. Thus, the enthusiasm for modifying clinical practice to collect patient-reported outcomes may be limited

precisely because of providers' inability to act upon the data or easily return them to patients.⁵³ Early efforts to address this limitation include creating visual displays and dashboards showing data over time that can be e-mailed to patients or shared with them via a patient health record or portal; flagging results that require attention, such as a major change in self-reported health status or mental well-being; and connecting patient-reported outcomes with recommended actions for care, such as a call from a nurse or an auto-generated call from a practice to schedule a follow-up visit.^{22-24,26}

Patient-generated health data provide additional information about individual health behaviors, but it is not yet clear how best to integrate this information into health care or existing clinical information systems. Today's EHR does not readily assimilate patient-generated data such as daily activities or diet. Furthermore, some stakeholders have concerns about how to comply with legal and regulatory requirements in collecting and storing these data.⁵⁴ Regulations that reduce the potential for liability, such as the specification of patient and provider responsibilities and the terms to be included in data-sharing agreements, could alleviate these concerns.

LACK OF FOCUS ON THE END USER Efforts to capture and report patient-reported outcomes need to accommodate the end user. These efforts should address issues related to health literacy and numeracy, including the ability to interpret graphical representations of data. User-centered design (that is, design processes that are iteratively conducted with end users) can help create functional tools for patients and providers.^{55,56}

While mobile tools may enhance patients' ability to complete patient-reported outcome measures, lack of access to technology may be a barrier for some patients, who require alternative modes of administration of the measures such as mail or telephone-assisted completion. In addition, people suffering from loss of vision or arthritis and those in poor health may find completing the measures burdensome or challenging. Designing systems to accommodate people with visual impairment or limited mobility can minimize these barriers and is an additional rationale for employing user-centered design principles, including usability testing, to incorporate patients in designing and implementing systems to measure patient-reported outcomes in practice.⁵³

Conclusion

The implementation of new policies, the availability of research funding, payment reform, and

Improving patient engagement continues to be seen as a necessary step for improving the efficiency and safety of care.

consumer- and patient-led efforts to improve health care together have created an environment suitable for the successful implementation of patient-reported outcome measures in clinical practice. As experience with patient-reported outcomes expands and matures, the focus should be on addressing logistical challenges for integrating patient-reported outcome measures into practice, supporting technological advances to seamlessly integrate and report the resulting data to facilitate engagement between patients and providers. It will be necessary to ensure that patients are partners in developing and prioritizing measures for which outcomes can be reported and captured and to implement user-centered design processes to support the meaningful use of the data.

Some specific areas for further exploration include automating workflow to support the implementation of patient-reported outcome measures in clinics, research to support the interpretation of these outcomes to support patient and provider decision making, applications of computer adaptive testing that reduce the burden on patients while producing actionable data for providers, and research on the uses of patient-generated health data. It will also be important to explore efforts to implement patient-reported outcome measures to understand the factors that influence the scale and spread of that implementation in practice.

Patient engagement continues to be seen as a necessary step for improving the efficiency and safety of care as well as outcomes for chronic conditions. Yet unless a health care environment is created in which patients are viewed as partners in care and tools exist to facilitate meaningful discussions between patients and providers, it is unlikely that the goals set forth by the IOM fifteen years ago will be achieved.

Collecting and using patient-reported out-

comes in clinical practice is one practical way to meaningfully transform health care, replacing its narrow focus on clinical outcomes with a more holistic view of the patient. Ultimately, the goal is for a person-centered view of care to drive improvements in practice and in the

health of individuals and populations. Given careful attention to the intended uses of patient-reported outcomes and thoughtful implementation of these measures in practice, that goal is within reach. ■

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