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Advancing the use of patient-reported outcomes in practice: understanding challenges, opportunities, and the potential of health information technology

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Abstract

Purpose The effective use of patient-reported outcomes (PROs) can play a critical role in improving health care delivery and patient experience with care. However, PROs are not widely collected and used in clinical practice. This study aims to understand current opportunities and challenges with the use of PROs and the potential for health information technology (IT) to advance their use.

Methods The Agency for Healthcare Research and Quality held two technical expert panel (TEP) meetings to discuss the current use of PROs, challenges, and opportunities in implementation, and how health IT can be leveraged to support effective PRO use in clinical practice. Results were synthesized to identify major themes and takeaways based on different stages of PRO data utilization.

Results Findings from the TEP meetings indicated varying degrees of PRO usage in ambulatory care settings. Practices often lack a business case to collect PROs. Primary care physicians face more challenges than specialists in selecting appropriate PRO measures due to extensive variation in their patient populations. Providers also need training to use PRO data for shared decision making and population health management. Potential research areas to address PRO implementation challenges include measures harmonization, implementation process and workflow, electronic data collection and integration, and user-friendly data displays.

Conclusions Opportunities exist during different stages of PRO implementation to advance the use of PROs in clinical practice. Health IT can be utilized to address challenges in data collection, integration, and visualization to make PRO data accessible and understandable to patients and providers.

Keywords Health information technology · Patient-reported outcomes · Ambulatory care · Primary care

Introduction

The effective use of patient-reported outcomes (PROs) can play a critical role in improving health care delivery and patient experience with care [1–4]. Use of PROs for guiding and improving care is especially important for patients with multiple chronic conditions, older adults, and people with

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disabilities as PROs can reflect outcomes of care for multiple conditions, treated by multiple providers, across multiple settings of care. PRO measures that capture domains across conditions would better reflect overall health for these patients [5].

The U.S. Food and Drug Administration defines a PRO as "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" [6]. The patient's perspective complements clinical assessments to provide a holistic view of the care received [7]. Validated PRO measures exist for a variety of conditions as exemplified by the Patient-Reported Outcomes Measurement Information System® (PROMIS®) [8], the Knee injury and Osteoarthritis Outcome Score (KOOS) [9], and the Hip disability and Osteoarthritis Outcome Score (HOOS) [10].

While various efforts promote the use of PRO measures [11–14], the uptake is far from universal. Given that PROs have the potential to play an increasingly important role in value-based care [15], there is a clear need to understand implementation challenges and find methods to mitigate them.

The Agency for Healthcare Research and Quality (AHRQ) is committed to improving the safety and quality of America's healthcare system. AHRQ's Center for Evidence and Practice Improvement has a strategic focus around advancing the use of PROs in clinical practice, and was interested in understanding how health information technology (IT), as well as other interventions, might advance the use of PROs in ambulatory care settings. Therefore, AHRQ held two expert panel meetings in May 2016 to understand PRO implementation opportunities and challenges as well as the potential for health IT to advance the use of PROs. AHRQ incorporated findings from these two meetings in developing recent PRO initiatives including grant funding opportunity announcements [16, 17], a federal prize competition [18], and a pilot test study.

The purpose of this paper is to recount meeting findings and discuss a potential research agenda, including health IT research, based on the findings. This paper is not intended to capture results from a typical qualitative study; rather, it provides a summary of two expert panel meetings in order to share insight into research areas that could advance PRO use. In this paper, use of PROs is defined broadly to include the use of PRO measures as well as the use of PRO data. PRO measures can be generic or disease-specific.

Methods

AHRQ convened two meetings on PROs with the second meeting building upon the learnings of the first. Participants were invited to participate according to their knowledge, experience, and recognized clinical and research expertise in health IT and PROs. Table 1 provides an overview of the two meetings including meeting objectives and participants' area of work.

The first meeting was a 2-h virtual technical expert panel (TEP) meeting. The TEP was comprised of eight individuals from health systems, academic institutions, and a health IT research group. Prior to the meeting, participants were presented with five questions (Table 2) relating to the current use of PRO measures and opportunities to improve their use in ambulatory care settings. The five questions were determined by AHRQ leaders based on the meeting objectives delineated in Table 1. Each participant was asked to discuss three or more of these questions with other colleagues to garner a more complete perspective. Responses to these questions were gathered and distributed prior to the meeting. Discussion during the meeting provided additional input on the current use of PROs as well as challenges and opportunities in implementation, particularly on how health IT could better support implementation in practice.

The second meeting was a full-day in-person meeting facilitated by AcademyHealth's electronic data methods (EDM) forum. This meeting included critical perspectives from electronic health record (EHR) system vendors, software developers, and patient advocates that were not represented in the first TEP. The focus of this meeting was to discuss how health IT can be leveraged so that PROs can be effectively used in clinical practice, particularly in primary care and for individuals with multiple chronic conditions. The meeting was structured to include short presentations followed by extensive discussions in the morning and topical breakout sessions in the afternoon. The breakout sessions' topics included (1) opportunities to use new technology to promote the collection and use of PROs and patient generated data; (2) scale and spread opportunities to move evidence-based applications of PROs into practice; and (3) opportunities for PROs to support care for individuals with multiple chronic conditions. The breakout groups presented back to share their suggestions.

The content in each of the two meetings was documented by audio recording and note takers. For the first meeting, AHRQ staff produced a summary document that was disseminated to TEP members to review for accuracy and additional thoughts. For the second meeting, AcademyHealth's EDM Forum generated meeting notes for AHRQ staff's review. AHRQ did not employ typical qualitative research methods because the meetings were not designed as a qualitative study. An AHRQ working group synthesized the results across both meetings to identify major themes and takeaways.

The AHRQ working group categorized participants' comments by different PRO implementation stages (i.e., pre-implementation, data collection, and post-data collection).

Table 1 Overview of the meetings

Meeting information	Technical expert panel meeting	Stakeholder meeting
Meeting title	The use of patient-reported outcome (PRO) measures	Using health information technology to advance the use of patient-reported outcomes (PROs) in practice
Meeting date	May 2, 2016	May 23, 2016
Participants (*N*)	8	31
	Clinicians and quality improvement specialists with experience using PRO measures in ambulatory settings	A diverse group of stakeholders including representatives from professional associations, health care delivery systems, health plans, government agencies, an electronic health record system vendor, software developer, academic researchers, and patient advocates
Objectives	• Improve understanding of how PRO measures are being implemented and used in ambulatory care settings to improve the quality and outcomes of care • Identify and assess PRO measure usage within the electronic health record • Identify the range of current practices to inform future research	• Review the current state of PROs in clinical practice and opportunities to leverage health information technology for their more effective use • Deliberate opportunities to make the most effective use of PROs in the care process and discuss the remaining barriers to their effective integration into clinical workflows • Prioritize areas for potential investment to scale and spread the effective use of PRO tools in practice, particularly in primary and ambulatory care and for individuals with multiple chronic conditions • Discuss the use of PROs from the patient perspective and using PROs to improve patient-centered care

Since each stage of PRO implementation involves a different set of activities and meeting participants provided ample feedback on challenges, opportunities, and potential research areas within each stage, this seemed a reasonable method for organizing meeting output. This organizing framework also provides implementers and researchers with the ability to consider challenges, opportunities, and potential research areas within one stage before moving to the next temporal stage. In this paper, the pre-implementation stage covers all of the activities before a practice actually collects PRO data. The data collection stage involves patient's submission of PRO data and how the process fits in the clinical visit. The post-data collection stage includes activities after PRO data are collected. The results presented in this paper, unless otherwise noted, are based on comments from meeting participants.

Results

Current use of PROs

Participants indicated variable use of PROs in ambulatory care settings. Traditionally, PRO data collection is conducted through paper-based surveys, which could be difficult for patients and providers to access and use. Certain specialties (e.g., orthopedics, urology, and rheumatology) employ greater use of PROs. Within primary care, PROs are used most frequently for depression. Participants also commented that the Patient Health Questionnaire-9 (PHQ-9) is commonly used as a screening measure, and is one of the few PRO measures used as an outcome measure. The PHQ-9 for depression screening has established thresholds so that clinicians can easily interpret results and take action. In many other areas where PROs are collected, there are no evidence thresholds for action.

While there are initiatives underway to electronically collect and record PROs within the EHR system, participants observed that PROs are not routinely utilized in direct patient care management by most clinicians in ambulatory care. One of the main reasons is that many EHR systems were not designed to systematically incorporate PRO data for clinical use. However, there is growing interest in doing so.

One EHR vendor that has successfully integrated PROs collects PRO measures via a patient portal that allows patients to track their health, communicate with their health care teams, review test results, and request medical appointments. Data resulting from the PRO measures are presented within the clinical record alongside information on other indicators being used at the same time. Several standardized measures are pre-installed in the EHR system. Despite the integration, the collected PRO data have limited utilization

Table 2 List of questions provided to participants prior to the technical expert meeting

Question 1: How are patient-reported outcome (PRO) measures being used for clinical and care management, quality improvement, patient self-management support, and goal-setting in diverse ambulatory settings? Are there other important uses?
Question 2: To what extent have PRO measures been integrated into the electronic health record systems? What has been the experience with their use?
Question 3: What characteristics enable this information to be effectively used in the course of care?
Question 4: What are the most pressing and time-sensitive challenges and opportunities to consider for healthcare providers to successfully adopt and integrate PRO measures into their practices?
Question 5: What research would advance the field and implementation of PRO measures in practice?

in clinical practice. Many patients are not enrolled for patient portal use, or are not using it consistently. In addition, physicians often do not know where to find the PRO data and have not been trained on how to use it. Therefore, even though some EHR systems are capable of incorporating PROs, the uptake from providers is low.

Participants mentioned several challenges and opportunities for advancing the use of PROs. They also identified potential research areas—some of which relate to health IT—that correspond to the challenges and opportunities. Results (Table 3) are summarized below by PRO implementation stages.

Pre-implementation

Challenges

For many practices, there is no business case to utilize PROs—the value proposition has been difficult to ascertain especially under a fee-for-service payment model. In addition, providers and patients may not understand if and how PROs are relevant for clinical care. Providers who are motivated to use PROs often struggle with selecting the right measures, especially for primary care physicians who take care of patients with a wide range of diseases and conditions. Some PRO measures were developed for research rather than clinical use. Also, patients' different perspectives and preferences add another layer of challenge for physicians. There is little evidence to help guide providers on the use and interpretation of PRO measures in primary care settings. Moreover, physicians feel many PRO surveys are too long and breaking the surveys up would render them invalid.

Opportunities

To advance PRO implementation, participants highlighted the importance of determining a business model and involving the organization's senior leadership in developing a vision for PRO use. Also, team-based training on the benefits (to whom and under what circumstances) of PROs is essential to help physicians and other team members better use PROs. When seeing individual patients, providers need to give patients the option to specify and select symptoms of primary concern. Aligning PROs with patients' concerns and goals then makes PRO data immediately relevant to patients and clinicians, resulting in a patient-centered course of action.

When selecting measures, participants suggested that providers should take advantage of existing PRO data to harmonize measures where applicable and gain consensus around the best measure to use for a particular purpose. Existing PRO data could provide information regarding whether a measure can be used to distinguish desirable outcomes. Participants mentioned the need to adapt existing measures to primary care settings or develop new measures specifically for primary care. When asked about whether there are any PROs that are ready for scale and spread in primary care settings, the participants felt the PHQ-9 is most ready followed by the Childhood Asthma Control Test. There is consensus that physical function and pain are important outcomes; however, there is no consensus on the actual measures that should be used to assess those outcomes. Participants also noted that when developing a new measure, patient communities should be included in the measure development process so that the new measure can reflect what is important for patients.

Potential research areas

Participants agreed that one critical research area is measure development. Research is needed to identify, standardize, and build consensus on specific measures to be collected in primary care, especially for general functional status measures that assess activities of daily living and measures of health-related quality of life. For each measure, research is also needed to develop appropriate criteria or cutoff points for action as well as the accompanying action plans. This necessitates standard definitions of terms (e.g., patient goals, outcomes, care plans) as well as clearly identified criteria to distinguish improved vs. worsened outcomes.

Participants also proposed the potential for use case ideas to shift from collecting PRO data once every few months to ongoing PRO data collection for preventive care,

Table 3 Challenges, opportunities, and potential research areas by stages of patient-reported outcome (PRO) implementation in clinical practice

	Challenges	Opportunities	Potential research areas[a]
Pre-implementation	• Lack of a business case to collect PROs	• Create a business model to promote the use of PROs	• Validate the benefits (to whom and under what circumstances) of PRO use
	• Patients and providers may not understand if and how PROs are relevant for clinical care	• Provide training about the benefits (to whom and under what circumstances) of PRO use	
	• Lack of harmonized and widely accepted measures	• Harmonize measures where applicable and gain consensus around the best measure and frequency of use for a particular purpose	• Understand which specific PRO measures work best and the optimal frequency of administration for specific primary care purposes
	• PRO measures were developed for research, not for clinical practice	• Adapt existing measures or develop new measures specifically for clinical practice	
	• Lack of disease-specific measures	• Develop disease-specific measures	
	• More evidence is needed about the use and interpretation of PRO measures in primary care settings	• Develop evidence for the interpretation of PRO measure scores and resulting action plans in primary care settings	• Identify appropriate criteria or cutoff points for action
Data collection	• PRO data collection may be burdensome for patients and clinicians	• Develop and test strategies to maximize and integrate PRO data collection into clinical workflow • Utilize computer adaptive testing where applicable	• *Understand how electronic PRO collection can best be integrated into clinical workflow*
	• Accessibility of PRO data collection tools	• Provide multiple data collection modalities with easy to use technologies	• *Distinguish best modalities for collecting PROs by patient population and care setting* • *Identify best practices to engage patients for PRO collection over time*
	• Liability and privacy concerns exist (particularly when collecting depression PRO measures)	• Address liability and privacy concerns and ensure HIPAA compliancy	• *Identify best practices to address privacy and liability concerns for collecting PRO data electronically*
	• Copyright restrictions may exist when transitioning from paper instruments to digital tools	• Consult legal experts to address copyright concerns when transitioning from paper instruments to digital tools	• *Identify best health IT-related practices to address copyright and intellectual property issues for use of PRO measures*
Post-data collection	• PRO data are not readily available in the electronic health records (EHRs)	• Develop a process to integrate data into the EHRs	• *Develop standards for storage/retrieval of PRO data, including PRO data collected over time*
	• Patients and clinicians may not know how to interpret PRO data and changes in scores	• Provide training for providers and patients on how to interpret PRO data	• *Develop and evaluate data analytics that can reduce clinician/patient burden in understanding PROs* • *Identify best practices to train both patients and clinicians to use PROs effectively*
	• PRO data displays may not be patient-friendly	• Develop patient-friendly data displays	• *Develop and evaluate effective visualizations of PRO data over time to enable shared decision making*
	• If patients provide PRO data but the data are not utilized for shared decision making, this may act as a disincentive to provide PRO data in the future	• Educate providers on the use of PRO data for shared decision making and population health management	• *Understand how PROs can be analyzed together with patient preferences and goals in order to optimize patient-centered care* • *Identify best practices to integrate conversations about PRO data into clinical workflows and resulting care plans*

This table items refer to generic PROs unless specifically mentioned

[a]Potential research areas related to health information technology are in italics

intermittent issues (e.g., low back pain), and chronic conditions (e.g., diabetes, congestive heart failure). Research would be needed, however, to determine which use cases would most benefit from ongoing PRO data collection.

Another area of research is on the exploration of value. Existing data on value are not ubiquitous and more research is needed to examine whether PRO data collection brings value to patient care in terms of efficiency, experience of care, and effectiveness. What benefits (to whom and in what circumstances) would justify the use of PROs? There is a need to conduct research to connect PROs to cost and quality as well as identifying PRO measures that add the most value to clinical care.

Data collection

Challenges

Participants pointed out a few challenges in collecting PRO data. One challenge is the burden of data collection, especially for patients with multiple chronic conditions (MCCs). Patients with MCCs may need to answer similar PRO questions when they see different providers in addition to repeated data submission over time for one provider.

Some challenges arise when providers choose to move from paper surveys to electronic data collection. One concern is that some patient populations (e.g., people without smartphones, people who are less digitally literate) may be missed. Another concern relates to copyright restriction. Electronic surveys are often quite different from the original paper instruments and users are unsure whether initial copyright should apply.

Questions also arise over how PRO data are used and what action is required based on the data. For example, if a person reports suicidal thoughts when completing an online questionnaire during the middle of the night, how must an organization respond? Some legal teams are more conservative and would suggest not even asking the question via the portal for liability reasons, while others may decide that a reliable follow-up the next morning is sufficient.

Opportunities

Participants suggested opportunities to mitigate challenges and achieve robust data collection which involves patients, front-line staff, and providers. Technology must work seamlessly to provide full integration and real-time connection with providers' workflow. Data must be collected and processed prior to the patient–clinician encounter. Computer adaptive testing could be used, where appropriate, to reduce data collection burden for patients.

Also, providers should offer multiple data collection modalities (e.g., paper, patient portal, wearables) to accommodate patients' reporting preferences. With electronic data collection, providers need to address security and privacy concerns to ensure technology and all communications are HIPAA compliant. When transitioning from paper instruments to digital tools, providers should consult with legal experts to address copyright concerns.

Potential research areas

Conducting research on the data collection process is essential to guide incorporation of PROs into clinical workflow. Research could apply the socio-technical systems model [19] to understand patient and provider needs for effective PRO data collection. Another potential research area includes identifying best modalities for PRO data collection by patient populations and care settings. Research is also needed to identify best practices to address privacy and copyright concerns for electronic data collection.

Post-data collection

Challenges

For providers who collect PRO data, many of them did not use the data for clinical care. One common reason is that the PRO data are not available or easily retrievable at the point of care, if they are only available via scanned versions of paper questionnaires [20].

Another common reason for not using the collected PRO data is that providers do not know how to interpret the data and changes in measures. For those who shared PRO data with patients, many expressed that the data displays do not help patients understand the results. Consequently, providers often do not communicate the results to patients and rarely utilize the data for clinical care. The lack of feedback to patients who submit data may act as a disincentive for these patients to provide PRO data in the future, because they may feel their time answering PRO questions is not warranted without a better understanding of their health status based on the results.

Opportunities

Among the topics discussed during the meetings, most participants felt it is very important to know how to use PRO data effectively. Participants also emphasized that relevance to patients is paramount. There needs to be a virtuous cycle of actionable data. First, a process is needed to integrate PRO data into the EHR. Providers need to receive training on how to interpret and use PRO data in their workflow to best optimize patient care (e.g., improve communication and increase shared decision making). Providers can also use PRO data for better population health management (e.g.,

reaching out to patients when noticing changes in measures). Patient education is needed to help patients understand how to access and interpret PRO data. Patient-friendly data displays are essential in helping patients understand the data. It would motivate patients to submit data if they can comprehend the results without the presence of clinicians.

Potential research areas

We need to develop and test health IT standards for storage and retrieval of PRO data to facilitate providers' easy access to data during clinical visits. Providers will also benefit from health IT research that determines how best to utilize data analytics and visualizations of PRO data to reduce providers' and patients' burden in understanding PROs and enable shared decision making. In addition, research is needed on how to optimally integrate conversations about PRO data into care plans while taking into consideration patients' preferences and goals.

Discussion

PRO data are not routinely used for clinical and care management in ambulatory care settings. Providers face barriers from measurement selection to data integration into clinical decision making. Providers share a similar experience when implementing generic or specific PROs. Many faced common challenges described earlier in the paper including lack of a business case, burdensome data collection for patients, and data not being available for providers at the point of care. While selected specialties have adopted the use of PROs, and some primary care physicians are increasingly using them, much more work is needed to enable widespread use of PROs in primary care. Given the wide range of medical conditions seen in ambulatory care settings, there is a need to harmonize measures, and to identify and gain consensus around the best measure to be used in a given situation.

Many challenges in the collection and use of PRO data could be addressed with health IT-enabled approaches. Many PRO implementations utilizing health IT have resulted in large-scale data collection, real-time data sharing with providers, and seamless data integration, presentation, and use [12, 21–31]. Despite these successful examples, there is still a need to develop user-friendly data collection tools and data displays as well as processes to integrate data into providers' workflow so that PRO data can be used effectively. Although health IT provides opportunities to promote PRO implementation, it also has some associated challenges especially with data integration into EHRs or other IT systems. When one institution, which successfully used PROs, converted from a home-grown system developed specifically for PRO use to a commercial EHR system, much of the PRO functionality was lost. It took a few years for the functionality to improve gradually through time-consuming interactions with the EHR vendor [32].

Using health IT for PRO implementation requires resources to ensure the system functionalities meet the needs of the clinical teams. A recent article commented on the resources needed for each of the three common methods to import PRO data into the EHR: custom-built local (institutional) solutions, EHR vendor-embedded PROs, and independent commercially constructed products [33]. All of the methods have both hardware and software requirements. The cost for a commercial product ranges from $4000 to $7000/year. The cost for EHR-embedded PROs depends on the type of PRO instruments used. For example, annual costs for using PROMIS® computer adaptive tests range from $3000 to $15,000 for $\leq$ 500,000 to > 2,000,000 ambulatory visits within one EHR. Custom-built solutions are typically taken on at a large institution where the cost can amount to hundreds of thousands of dollars. However, the authors pointed out that a more customized platform allows for greater flexibility such as the addition of required PRO instruments under alternative payment models.

In order for providers to fully embrace PROs in clinical care, providers need to make a cultural shift to discuss quality of life with patients as well as understand how various symptoms impact a patient's daily life [34]. It is also important to consider different patients' preferences when engaging patients in the process. There are risks to collecting patient information that is not used. A common refrain is that communication is often lacking between the provider and the patient regarding the patient's responses to PRO measures. Aside from frustrating patients, not using the data runs the risk of discouraging patients from continuing to provide potentially useful information from their own perspective.

One potential key facilitator to productively share and use PRO data is to highlight the value proposition in doing so for both providers and patients. Providers could learn from applications such as Google Maps or Waze to set up a fair exchange with patients and other providers. These popular navigation systems incorporate "driver-reported outcomes" with a reciprocity agreement that people donate data from their phones and they get alerts in return from other drivers. Similarly, a PRO data exchange might be established to facilitate insightful sharing and feedback between providers and patients.

Conclusion

In summary, opportunities exist to advance the use of PROs in clinical practice. Research is needed for measures selection including identifying appropriate cutoff points and

accompanying action plans. Providers will also benefit from research validating the benefits of PRO use. Health IT can be utilized to address challenges in data collection and integration with EHRs or separate IT systems. Successful PRO implementation requires strong leadership and institutional support especially for health IT investments. Although there is concern about the health IT costs, if implemented well, there is strong potential for a significant return on investment through improved patient engagement and outcomes, and the ability to influence the health care value equation.

As healthcare delivery moves toward value-based care, patient outcomes and care quality became increasingly important. Providers' reimbursement is driven by their performance under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) Quality Payment Program. Commercial payers are following Centers for Medicare & Medicaid Services (CMS) lead to implement various value-based care payment programs. PRO data can be greatly utilized to help providers track individual patient's progress as well as manage population health.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The technical expert panel meetings were conducted as a consultation exercise with individuals who have expertise in PROs and health IT. Ethical approval was therefore not obtained.

Informed consent For this type of study, formal consent is not required.

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