Care Redesign   New Marketplace   Leadership   **Patient Engagement**

CAPTURING THE PATIENT VOICE

The Cost of Patient-Reported Outcomes in Medicine

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We define Patient-Reported Outcomes (PROs) as assessments that directly capture the medical symptoms of the patient such as physical function, pain, and mental and social health well-being without interpretation of the patient's responses by their clinician. The direct entry of this PRO electronically into the health record allows for graphic display of the data for easy interpretation of individual progress as well as aggregation of the data over common grouping such as diagnosis, surgery type, or patient characteristics. Capturing the voice of the patient through PROs and immediately incorporating this information into the electronic health record is critical to advance quality medical care.

Numerous publications and multispecialty consensus guidelines highlight the important organizational steps regarding PRO collection including governance, staff training, visualization, frequency, and ethical and legal considerations. Despite these endorsements and

> *Currently, technological barriers as well as perceived cost challenges obstruct the wider adoption of PROs in clinical settings."*

resources, the adoption of PROs by medical providers for immediate use in clinical settings has been slow. A program of real-time utilization of PROs can have profound positive influences on shared decision-making, quality improvement, and strategic allocation of institutional resources. Currently, technological barriers as well as perceived cost challenges obstruct the wider adoption of PROs in clinical settings.

There are three common methods to import PRO data into the electronic health record (EHR): custom-built local (institutional) solutions, EHR manufacturer–embedded PROs, and independent commercial constructed products. All have both hardware and software requirements. The factors that determine which of these options is best for a program include the available resources (personnel and hardware) for information technology (IT) construction, the ability to locally customize the product with PRO content experts, and, of course, the financial budget allocated for the program. If there is a larger, diverse provider and patient population, it may be more economical to build an institutional custom-built system.

> *As alternative payment models begin to specify the collection of specific PRO instruments, it is likely that a more customized platform may be required to meet that demand."*

The Medicare Merit-based Incentive Payment System (MIPS) reimbursement and bundled payment pilots have made routine collection of PROs a useful strategy in justifying and optimizing compensation for patient care. As more patients and conditions are covered under these reimbursement models, greater investment by health care systems in PRO collection can be anticipated. Additionally, as alternative payment models begin to specify the collection of specific PRO instruments, it is likely that a more customized platform (either institutional or commercial) may be required to meet that demand. Table 1 provides the advantages and challenges with each PRO distribution and collection platform.

Advantages and Challenges of Different Patient Reported Outcome Collection Systems

PRO Distribution and Collection Systems	Advantages	Challenges
Custom built	Tailored workflow, seamless integration, customized patient experience, fast updates, ability to experiment freely, outputs and research available and can be linked and personal health identifiers and with other EHR elements. Allows for the addition of required PRO instruments for bundled payment models and MIPS.	In-house development requires IT and clinical content expertise and maintenance.
Electronic Medical Record	Seamless integration with existing EHR; less expensive than Custom and potentially quick to implement.	Rigid workflows and patient experience, customization options may be limited, slow updates, annual costs for computer adaptive tests such as PROMIS (CAT) assessments are based on ambulatory visit volume within one EHR* • <= 500,000 Ambulatory Visits = $3000

| | | • > 500,000 but <= 2,000,000 Ambulatory Visits = $7500
• > 2,000,000 Ambulatory Visits = $15,000

PROMIS PRO Short Forms are available with raw scores only and not converted to t-scores.
2018 estimated costs

Limited PRO assessments available currently (2018). May not have required PRO instruments for pay-for-performance initiatives. |
| **Commercial Product** | Customizable PROs for many different providers and groups; IT needs provided by vendor including programming and data housing | Change in output formats (reporting) is difficult and slow, viewing of data is only accomplished on a separate dashboard outside the electronic record; data mining is difficult.

With one commercial vendor 2 FTEs required for programs to ensure patient completion of assessments; cost per provider can range from $4K-$7K/year*
average range of costs 2014-2017

Changes with the addition or deletion of PRO instruments for |

deletion of PRO instruments for pay-for-performance initiatives may be costly or delayed.

Source: Authors

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Table 1. Click To Enlarge.

Examples of institutional custom-built programs include the University of Rochester, University of Utah, and Washington University. The advantages of this type of program include flexibility in content, ability to tailor workflow and integration, and the capacity to change collection over time. The data display for both review and analysis can also be altered and customized. Scoring and updates can be completed in real time. Data sharing with other groups is easily performed.

> *The computer hardware requirements for a custom PRO program may seem extensive; however, much of the equipment is likely already in place for other institutional endeavors."*

The challenges include the need for IT expertise, provider content knowledge and interest, and ongoing resources for program maintenance. Institutions that employ IT specialists and can identify a central IT PRO leader may opt for this strategy. Clinician champions are required to help select content, and they will require salary support. The computer hardware requirements for a custom PRO program may seem extensive; however, much of the equipment is likely already in place for other institutional endeavors. Table 2 lists the hardware and personnel costs associated with a unique, custom-built PRO collection system.

Example Cost of Custom Built Platform

Server Infrastructure	**$600/month**
4x Web Servers	$450/month
1x Mobile Device Management Server	$100/month
2x Database Servers	$50/month
Device Costs	**$550/device**
iPad (life expectancy of 3-4 years)	$400/device
Case	$70/device
Charging Cabinet	$35/device
Mobile Device Management License	$45/device/year
Salary and Benefits	**$610,000/year (cost estimates)**
2x Software Engineers	$180,000/year
1x EHR Analyst	$95,000/year
1x IT Support	$65,000/year
0.4 FTE Physician PRO director	Variable cost (100-300,000/year)
1 FTE PRO Administrator	70,000/year

Source: Authors

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Table 2. Click To Enlarge.

Despite the plethora of commercially available EHR platforms utilized in health care, embedded PROs have been limited to static forms or simple branching questionnaires that have been found to take more time and be more burdensome to the patient than newer IT using Computer Adaptive Technology (CAT) capabilities within the EHR programming. One such PRO is the Patient-Reported Outcome Measurement Information System available as static forms or CAT methodology, the PROMIS short form 10 (PROMIS 10), available in two of the most widely used EHR vendors for over 5 years. This assessment is free; however, the data analysis is limited to raw scoring only. This limits the utility of this instrument unless the raw score is secondarily converted to a t-score for comparison. PROMIS CAT methodology capitalizes on item response theory (IRT), in which the next question presented is based on the previously answered question. This PROMIS CAT capture increases the accuracy and efficiency over short forms. There are a wide array of PROMIS CAT assessments on focused domains such as physical function, pain, and depression. PROMIS CAT assessments will be available in one EHR in 2018 — however, this will require both an EHR software upgrade and additional usage fees. Unlike the short forms, a numeric score will be available; however, further customization for different patient populations and different instruments will be limited. Exporting PRO data from within the EHR system, as well as linking PRO data to other personal health identifiers for research, may be difficult.

> *Implementation of routine PRO collection is paramount to measuring and maximizing value in health care."*

There are numerous commercial vendor "add-on" products for PRO collection and display. As might be expected, these can range from very basic to extremely customized programming, and the cost varies accordingly. These products distribute the outcome assessments and registration materials directly to the patient in the clinic, via email or through electronic text messaging. The patient's contact information must initially be collected by medical personnel and linked to the commercial product, which can be burdensome. Some systems solicit the patient via text or email to open a web-enabled link, and to complete the PRO assessments. This approach may allow integration within the EHR using HL7 feeds. In this strategy, the raw data collected is maintained on the vendor's server. Viewing of the data is usually via the manufacturer's platform and not within the institution's electronic record. Standard reports are available; however, data linkage with the EHR fields for research exploration is both slow and limited in scope.

Implementation of routine PRO collection is paramount to measuring and maximizing value in health care. Although there is understandable concern over the IT costs inherent in incorporating PRO into the clinical care workflow, there is a substantial return on investment seen through improved patient engagement, advancement in clinical research, and the ability to influence the health care value equation. PRO implementation projects require both leadership and institutional support to advance. The University of Rochester Medical Center leadership, as well as leaders at the University of Utah, the Cleveland Clinic, and Partners HealthCare made PRO collection across the health care system a priority and part of both the strategic and business plans of the institution. As pay-for-performance initiatives and bundled payment projects continue to advance, the patient's voice, through PROs, will tell providers, insurers, and health care administrators what surgeries, medications, and other therapies improve their symptoms and quality of life. Institutions with robust PRO data will be well positioned to compete in the marketplace.

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DISCUSS　　　**HIDE 3 RESPONSES**

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Professor Dame Lesley Fallowfield

A great paper delineating many of the challenges but some of the issues were just as apparent when introducing the electronic record itself and for capturing info from scans etc. PROs are more and more important given the emphasis (often industry driven) given to stressing marginal benefits such as PFS without proper elucidation of the harms.

January 25, 2018 at 12:42 pm

John Sharp

I do not see mention of Apple Research Kit. This is another option for developing iPhone-based questionnaires used in research and clinical practice. Use cases are here: https://www.apple.com/researchkit/

February 07, 2018 at 1:52 pm

Andre Dias, Myia Labs

Great article. An additional cost to consider in your decision matrix is the cost (in employee time) of reacting to PRO data once it is collected (especially if your rollout plan includes longitudinal data capture after the patient has gone home). This is important from a patient satisfaction perspective (if a patient spends time completing a questionnaire they will only remain engaged if this data is used in their care). It is worth noting that this additional cost should not dissuade you from PRO implementation (there clear and scalable examples of using this information to improve clinical efficiency which makes up for the additional time investment).

February 10, 2018 at 3:34 am

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