

## ARTICLE

# PROMs: Opportunities, Challenges, and Unfinished Business

Catherine H. MacLean, MD, PhD, Vinicius C. Antao, MD, PhD, MSc, Mark A. Fontana, PhD, Harvinder S. Sandhu, MD, Alexander S. McLawhorn, MD, MBA

Vol. 2 No. 11 | November 2021

DOI: 10.1056/CAT.21.0280

Leaders at the Hospital for Special Surgery (HSS) in New York, New York, have developed a framework to enhance and expand the use of both general and condition-specific patient-reported outcome measures (PROMs). Over the past 3 years, they have built 28 different PROMs into the electronic health record system and developed clinical decision-making tools. This effort, detailed in this article, addresses industry-wide developments and limitations and outlines how HSS has incorporated solutions to support patient engagement, clinical care, health care research, and quality-driven activities. The authors address the costs of customized programs and the nationwide challenges that impede widespread adoption of PROMs and offer a way forward.

Although patient-reported outcomes (PROs), which describe health status as reported by the patient such as pain, function or quality of life, are among the most important measures of health from the patient's perspective,<sup>1,2</sup> they have not been widely integrated within clinical care across health systems.<sup>3,4</sup> PRO measures (PROMs), psychometrically validated patient surveys that measure PROs, can be used to inform clinical decisions,<sup>5-7</sup> assess and predict outcomes of care,<sup>8,9</sup> and measure health care quality.<sup>10</sup> Patient satisfaction is higher when PROMs are used to inform clinical decisions,<sup>11,12</sup> perhaps because this focuses care on outcomes that matter to patients. Not surprisingly, when treatment is targeted at achieving improvements in PROs, those outcomes are better.<sup>13-15</sup> This all begs the question as to why PROMs are not routinely used as a standard of care. Unfortunately, the reasons are many. Fortunately, they are all fixable. Using our organization's ongoing journey to fully implement PROMs as a standard of care, we describe in this article the opportunities PROMs afford, a framework to incorporate them into the care delivery of a learning health organization,<sup>16</sup> and the unfinished business that needs to be completed to use PROMs as measures of quality to drive improvements in population health across the United States.

## PROMs Defined

PROMs are standardized, validated questionnaires completed by patients to evaluate how they feel about their health status. These can be broadly categorized into general health and condition-specific measures. The first group can be used for any disease or condition and usually focuses on general well-being, mental health, and/or quality of life. Condition-specific PROMs usually concentrate on the symptoms of a disease, such as the mobility, function, or pain levels of a certain region of the body, including the ability to perform daily tasks or specific activities. PROMs collected at several time points during care episodes can be used to monitor patient progress. They additionally facilitate communication between clinicians and patients and may help to improve the quality of health care. Increasingly, PROMs may be required by payers to authorize services<sup>17</sup> and are being used in some quality measures.<sup>18</sup>

## Opportunities: Why We Embarked on the Journey

Our institution, the Hospital for Special Surgery (HSS), is an academic musculoskeletal specialty care organization in New York, New York. We perform 35,000 orthopedic procedures and conduct 520,000 outpatient visits for nonsurgical musculoskeletal care annually. Pain, functional status, and quality of life are the outcomes of primary interest for most musculoskeletal diseases; as such, validated PROM instruments are helpful in quantifying these outcomes.<sup>19</sup> HSS has a long history with PROMs, including the development, validation, and utilization of PROMs for research.<sup>20,21</sup> We use more than 100 PROM instruments to collect information across 69 different research registries, including more than 367,000 patients who have been enrolled, in some instances, for as long as 25 years. We estimate that this represents more than 20 million individual data elements. Consequently, the clinical staff at HSS are familiar with PROMs. Some have independently incorporated them into their clinical practice, some use them for research, and the remainder are regularly exposed to discussions of PROM-defined outcomes at clinical and research conferences.

“

---

*Our vision is to create a virtuous cycle through which routinely collected PROMs will inform clinical decisions, measure response to treatment over time, and be fed into registries, through which we can evaluate factors related to patient outcomes.*

---

In 2016, we determined that the routine collection of PROMs should become a standard of care at our institution. There was no single driving force for this decision, but rather a confluence of factors. Although PROMs were already being collected regularly for research, the results were generally not available at the point of care, which our clinicians saw as a missed opportunity to better understand how patients were doing and to determine whether therapies were effective using validated tools. At the same time, we were seeking to make the care we delivered more patient-centric, considering patients' views on their physical health, health-related quality of life, emotional well-being, and health care experience. PROMs are a way of collecting these elements directly from patients. Lastly, as a stand-alone specialty hospital without any built-in

referral sources, differentiation on quality is key to our ability to attract patients. Focus groups with our patients that explored what mattered to them in terms of quality identified patient reports of *getting better* — which could be assessed through PROMs — as very important.

Although we have not yet fully achieved our vision — for reasons we will describe in this article — we continue to advance and are currently collecting PROMs from more than 82,000 patients annually as a standard of care; all of this information is also available for our internal research. We describe in this article the factors that were critical to our success and those that are impeding our progress.

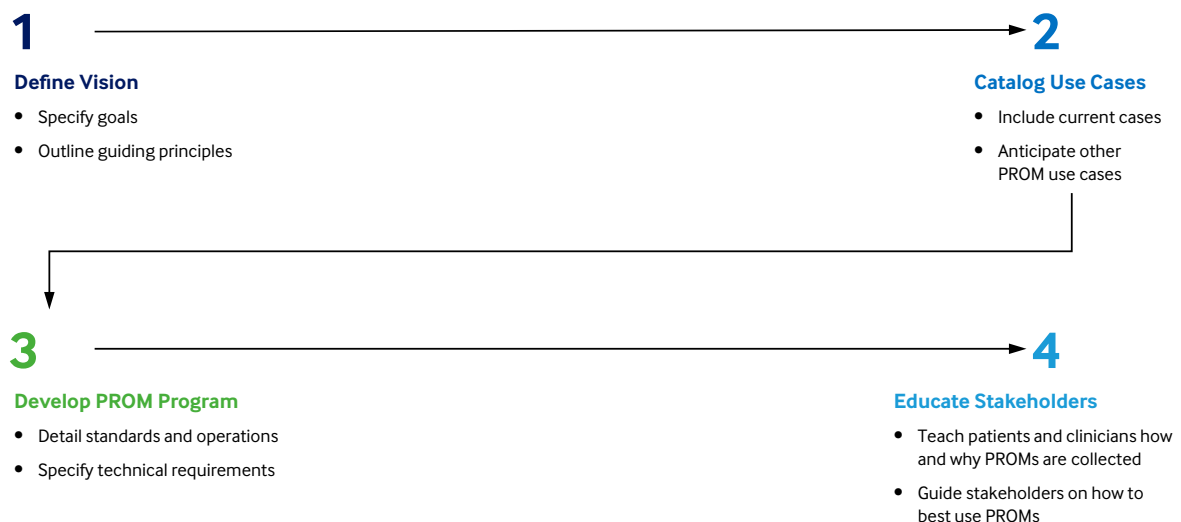
## Framework for the Collection and Use of PROMs in a Learning Health Organization

Frameworks considering the use of PROMs in clinical care<sup>22</sup> and within a learning health system<sup>23</sup> have been described elsewhere. These frameworks enumerate in broad terms the “who, what, when, where, and why” of using PROMs in care delivery and for research. Based on our own experience, we describe here a focused framework to guide the implementation of PROM use within learning health organizations (Figure 1).

Organizations will differ in their PROM needs and desires. For example, some organizations may collect PROMs strictly for research and not use them for clinical care, whereas others may

FIGURE 1

### Hospital for Special Surgery’s Four Steps for the Collection and Use of Patient-Reported Outcome Measures (PROMs) in a Learning Health Organization



Source: The authors

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

use them only for clinical care. The instrument used and how it is incorporated into workflows will differ across such organizations. As such, it is key for each organization to define its own vision, specific goals, and guiding principles. This will inform and be informed by listing current and anticipated institutional use cases for PROMs. This, in turn, will enable organizations to efficiently and effectively develop or refine a PROM program, detailing standards, operations, and technical requirements. A key component of any program will be to educate clinicians and patients on the how and why of PROM collection.

## **Step 1. Define Vision, Specific Goals, and Guiding Principles**

As with any initiative that touches multiple stakeholders with different interests and priorities, success requires obtaining the perspectives of and, ultimately, endorsement from all involved.<sup>24,25</sup> In most organizations, this will include leaders and staff in clinical care, research, and administration at the earliest stages of development of a PROM program. Informed by patient preferences, this group should frame the vision, goals, and guiding principles of the program to reflect the interests of all stakeholders. This will engender ownership from all stakeholders. Endorsement of the program by leaders will signal its importance to the organization, increasing its likelihood of success. Communication about the organizational plan is key to focus efforts and prevent silos. While patients will be key stakeholders in any PROM program, the manner in which they are engaged will differ. Depending on their scope and priorities, existing patient and family advisory councils could be used to inform a PROM strategy. In other instances, patients might be recruited specifically to inform the development of the PROM program.

### *Our Experience*

Our first step was to convene a series of focus groups with patients in which we discussed what matters to them in terms of quality generally and PROMs specifically. Informed by our findings in these groups, we established a core PROM working group that is responsible for guiding the development of the organizational vision and execution of the program. This group includes senior leaders from value, operations, and data management, each of which leads a focused PROM working group. Additionally, we established a PROMs advisory group comprising clinicians from each service line/clinical department as well as leaders from research and administrative units. Reporting into that advisory group are the following:

- a clinical work group focused on clinical applications of PROMs, such as which PROMs to collect and how they should be displayed in the electronic health record (EHR);
- an operational work group focused on the collection of PROMs within our existing clinical and administrative workflows; and
- a research work group focused specifically on the application of PROMs for quality improvement and assessment.

“ *A PROM inventory should address which PROMs are being collected, for what purpose, among which patients, at what times, and by whom across the organization.* ”

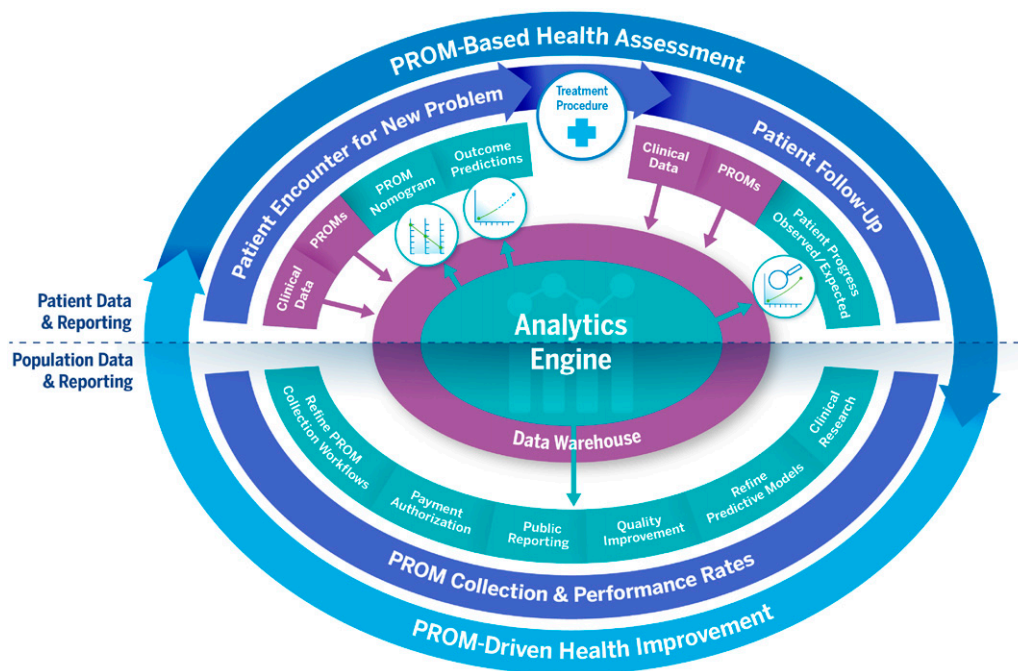
Our vision is to create a virtuous cycle through which routinely collected PROMs will inform clinical decisions, measure response to treatment over time, and be fed into registries, through which we can evaluate factors related to patient outcomes (Figure 2).

Through this cycle, information about factors related to PROs will then inform clinical care through the formation of predictive models, which can assist clinicians and patients in making shared decisions about best care choices. At the same time, longitudinal clinical and PROM data will be used to drive research on best care practices and new therapeutics. Routine PROM collection also can

FIGURE 2

### A Virtuous Cycle for Effective PROM Use

A learning health system requires robust use of clinical data to inform clinical practice. This same concept applies for the effective use of patient-reported outcome measures (PROMs) and the need for a central data warehouse and analytics engine.



Source: The authors

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

streamline required PROM reporting for authorization of payments for some procedures. Also, because we anticipate future requirements to report PROMs as quality measures, we want to ensure that a system of routine PROM collection will improve the quality of care delivered, afford operational efficiencies, and enable the ability to meet evolving payment and regulatory requirements.

To unify PROM efforts across the organization, we developed a set of guiding principles (Figure 3), which were discussed and endorsed at an organization-wide town hall meeting.

Specifically, HSS staff agree on the following principles. First, to enhance operational efficiency and reduce patient frustration, patients should be asked the right questions at the right time without redundancy or duplication. Second, to promote the patient’s engagement in and understanding of their care, they should have a clear understanding of what information they are asked to provide and why. Third, to inform clinical decision-making and promote patient-centered care, all PROM data should be available to all clinicians who care for the patient at the point of care. Finally, to support a learning health system and ensure accuracy, PROM data collected across the enterprise should be stored consistently in a central warehouse accessible to quality and research areas.

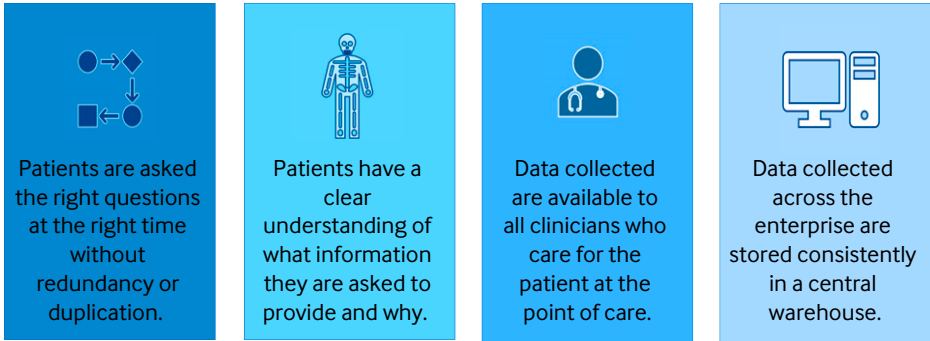
## Step 2. Define All Current and Anticipated Institutional Use Cases for PROMs

PROMs may be used for a myriad of purposes by many different areas within individual health systems. A systematic evaluation of PROM usage within an organization will ensure that needed PROMs are collected; this is foundational to the development of an efficient PROM collection system in which individually collected PROMs can be used for many purposes.

FIGURE 3

### Guiding Principles for PROM Collection and Use

In support of its vision and goals for patient-reported outcome measure (PROMs), the Hospital for Special Surgery has established four guiding principles on the collection and use of such data.



Source: The authors  
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

“ *To inform the development of a future state in which all needed PROMs are collected efficiently, it is key to understand the reason why each of the PROMs is collected, any specific requirements around the collection of the PROM, and whether a different PROM would fulfill the requirement.* ”

A PROM inventory should address which PROMs are being collected, for what purpose, among which patients, at what times, and by whom across the organization. Specific data elements that should be collected are detailed in Table 1.

Organizations should cast a wide net across different organizational units to include — at a high level — clinical services, research, and administration. Across clinical services, consider specific service lines, departments, and divisions — including medicine, surgery, nursing, rehabilitation, and respiratory therapy. Depending on organizational structures, consider physical units such as certain floors in a hospital or clinic or call centers that may contact patients for various purposes. A combined top-down, bottom-up approach will identify PROMs collected by units/groups and by individual clinicians.

To inform the development of a future state in which all needed PROMs are collected efficiently, it is key to understand the reason why each of the PROMs is collected, any specific requirements around the collection of the PROM, and whether a different PROM would fulfill the requirement. For example, a clinical area may collect a specific PROM because they

**Table 1. Items to Collect from Clinical and Business Units for an Institutional PROMs Inventory**

1. Name of unit
2. Specific purpose or requirement for collection (e.g., determine clinical state, report to registry, or authorization for payment)
3. Whether there are any data use constraints (e.g., per patient consent if collected under research proposal)
4. PROM instrument collected (official name) or desired to be collected
5. Why this particular PROM is being or should be collected (e.g., clinician preference or reimbursement requirement)
6. Whether different PROMs could fulfill the requirement to collect and, if so, which ones
7. Characteristics of patients who are/will be targeted for collection
8. Mechanism deployed to collect PROM (e.g., paper survey, notification from EHR, or telephone call)
9. Where the completed PROMs are stored (e.g., in the health record, in a research registry, or in a file on a computer)
10. Whether PROM scores are shared with patients
11. Time points at which the PROMs are collected (e.g., at all office visits or before/after procedures)
12. Current collection rates (e.g., proportion of patients identified for collection at each time point who complete the survey)
13. Characteristics of PROMs currently collected and possible alternative (e.g., number of items/time to complete or licensing requirements/cost)

EHR = electronic health record, PROM = patient-reported outcome measure. Source: The authors.

participate in a regional or clinical registry that requires a certain PROM; in this case, a different PROM would not be a reasonable alternative. In other cases, an area may have a broad purpose that could be fulfilled by many different PROMs; for example, understanding pain or functional status using a standard scale to inform care decisions or obtain payment authorization<sup>17</sup> may not require a specific tool.

Analyses should be done with an eye toward a future state in which all institutional needs are met in a way that is efficient and patient centered. The analyses should describe institutional needs; current institutional efforts, including redundancies; and current and anticipated human and financial resources. At the same time, the analysis should detail (1) the effort required by patients to complete PROMs, (2) whether there is any redundancy across different PROMs that patients are asked to complete, and (3) whether patients are given any feedback on the PROMs collected.

### *Our Experience*

PROMs are used by several groups at our institution. Clinicians use PROMs to inform care decisions. Researchers use PROMs as primary or secondary outcomes in clinical trials and epidemiological studies. The quality department uses PROMs as part of ongoing accountability and quality improvement initiatives. The value office uses PROMs to relate the cost of care to outcomes. Finally, a variety of administrative staff in different parts of the organization use PROMs to obtain authorization for some procedures. PROMs collected as a standard of care must also be available to the medical records department for release to patients and other authorized entities.

We compiled a comprehensive inventory of all registries and other forms of patient data collection and their respective PROMs. Next, we assessed all PROMs already built into HSS's then-newly implemented EHR, Epic. Finally, we assembled a short list of the most commonly used PROMs for each relevant domain and condition.

## **Step 3. Develop or Refine PROM Program Defining Standards, Operations, and Technical Requirements**

Program effectiveness and efficiency depends on the development and alignment of program standards, operations, and technical platforms. The defined standards should inform the operational plan, which in turn should inform choices in IT.

### *Standards: Two Key Components to Define*

Two standards that must be defined are (1) which PROMs the program will use and (2) the target collection rates for them. There are several considerations for each of these standards.

#### *PROM Selection*

First, one must decide whether to use general health or condition-specific instruments or both. General health questionnaires may be useful to describe common health-related quality-of-life



domains and enable comparison with the general population, but they may not be sensitive enough to capture longitudinal changes. In contrast, condition-specific instruments may be useful to assess certain symptoms, but they may leave out other domains that are important for a patient's health. For example, the impact of depression on recovery after total knee replacement surgery may not be captured by a knee-specific instrument.

---

“ *Some clinicians at our institution who routinely use PROMs to inform clinical decisions have achieved a PROM collection rate for patient encounters of nearly 100%. Operationally, these physicians will not enter an examination room unless the assigned PROMs have been completed.*

---

Second, it is important to choose between profile and preference measures. Profile measures are composed of several independent domains, which provide multiple scores and, occasionally, a summary score. Although these measures may be advantageous for providers to have an overview of different aspects of a patient's health, they are often long and burdensome to complete. Conversely, a preference measure uses various domains to produce a single score, which is an estimate of burden of disease, but may not allow for clinically pertinent information on specific outcome domains.

Finally, in deciding between single- or multi-item scales, one must consider that single-item instruments allow for the measurement of more domains, but, in general, these instruments are less reliable for measuring changes over time. At the same time, multi-item scales have more reliability, sensitivity, and content validity, but they take more time to complete compared to single-item ones.<sup>26</sup>

In addition to these deliberations, specific features of the instruments must be evaluated: response formats (verbal descriptor scale or numeric rating scale), focus of assessment (severity, frequency, interference, and bother), time burden, psychometric evidence (face validity and floor/ceiling effect), recall periods, and the availability of cutoff points that are meaningful for score interpretation. Moreover, PROMs need to be culturally appropriate for patients, and one must obtain appropriate licenses and permissions for use when required.<sup>26,27</sup>

Even after these considerations, many similar PROMs may be available for the same condition or domain. For example, the Veterans RAND 12-item Health Survey (VR-12), the Patient-Reported Outcomes Measurement Information System (PROMIS) Scale v1.2 – Global Health (PROMIS-10), and the 12-Item Short-Form Health Survey (SF-12) all produce physical and mental health scores and have a similar number of questions.

### *Collection Rate Targets*

It is essential to define the desired response rate for each PROM at each collection time point. While a 100% across-the-board response rate would be ideal, institutions must strike a balance between response rates and resources. Specific clinical, business, and research needs should be considered within the context of the practical collection of the PROMs. For example, it is easier to collect

PROMs from patients who are physically present in a care setting. Likewise, it is easier to collect PROMs using a standard operating procedure (e.g., collect PROMs from all patients at all clinic visits) than a complex one (e.g., collect PROMs based on specified time points that differ across patients depending on the procedure).

### *Our Experience*

We decided that as part of the standard of care at our institution, both a general health and disease-specific measure should be collected for all patients to allow for a holistic assessment of patients' health. We used a pragmatic approach to choose which general health measure to adopt for standard of care collection. The latest version of the SF-12 (v2) requires a paid license for use, and both the SF-12 and VR-12 employ complex algorithms for score calculation, making implementation more difficult. Therefore, we chose the PROMIS-10, which is free to use and uses simple addition to calculate raw scores, followed by a straightforward conversion to T scores.

The selection of condition-specific PROMs for standardized collection at the organization level was more challenging. Most service lines have been collecting PROMs for many years through their [almost 70 research registries](#), comprising almost 100 instruments, which are administered through a dozen different platforms. In addition, some departments, such as rehabilitation, needed to collect specific PROMs to comply with insurance/payer requirements.

After compiling the inventory of PROMs mentioned earlier, we met with the service lines to discuss implementation that aimed to balance useful clinical data and operational efficiency. Therefore, we sought agreement across different providers that we would select the minimum necessary number of PROMs with the fewest items for any given condition, and those same PROMs would be used by all providers for that condition. Although some providers would have to give up on an instrument they were used to collecting, they would have the benefit of benchmarking across all providers who used common PROMs and the ability to evaluate longitudinal data across the continuum of care for a given patient.

---

“ *The benefits of collecting PROMs electronically and integrating them with EHRs outweigh the complexities of implementation, especially if data can be used to improve clinical care and for the purposes of comparative effectiveness research.* ”

---

Despite ample agreement on which PROMs to collect and build into the institutional EHR, some service lines continue to collect their legacy instruments to support existing research projects or commitments with external registries with defined collection standards. One proposed alternative to collecting these extra PROMs is the use of crosswalks across instruments if they are available (e.g., between PROMIS-10 and VR-12<sup>28</sup>). However, the implementation of ongoing score conversion has proven to be complex, and we have hence decided to collect both instruments in certain instances.

To inform our collection rate targets, we reviewed our past performance in both clinical and research registry activities and considered what rates would be needed for clinical, research, and quality applications. Additionally, we considered whether the PROM would be collected within the context of a clinical encounter or as part of a nonencounter follow-up survey. We determined that the PROM collection rate at clinical encounters should be very high to inform clinical care; in addition, we have greater operational control over collection at that time point. Currently, some clinicians at our institution who routinely use PROMs to inform clinical decisions have achieved a PROM collection rate for patient encounters of nearly 100%. Operationally, these physicians will not enter an examination room unless the assigned PROMs have been completed. Consequently, nursing staff and patients ensure that these PROMs are completed. Informed by this experience, we have set our PROM completion target for patient encounters at 90%, with a stretch goal of 95%. For PROMs collected as follow-up surveys independent of a clinical encounter, we looked to our research registry experience, for which we have achieved response rates ranging from 39% to 98% depending on resources that are devoted to the effort. We have set our target at 80%, with a stretch goal of 85%. We anticipate that these targets will fulfill research and quality requirements related to representative samples.

### *Operations: Determine How PROMs Will Be Collected, Stored, and Reported for Each Clinical, Quality Assessment, and Research Function*

In addition to the mode of administration, key considerations in the operationalization of PROM collection are responder and collection burden, which can be exacerbated by long surveys and multiple attempts to complete the same or different PROMs.

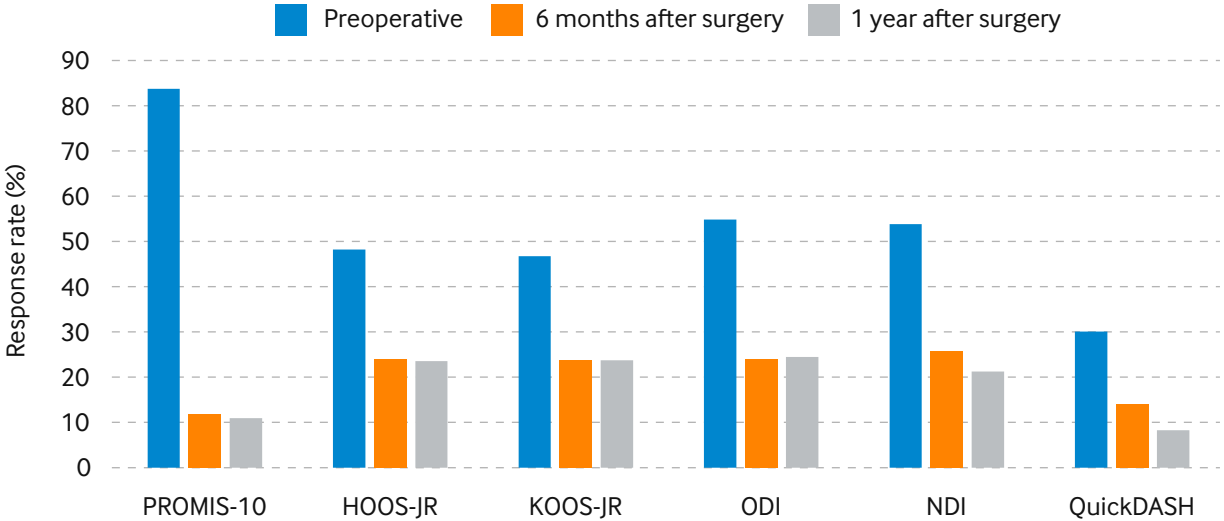
Most legacy PROMs instruments were originally developed for paper-and-pencil administration. With the increasing use of technology and the development of EHRs, many instruments have been converted to electronic administration, and some have been developed specifically to take advantage of that application, such as the PROMIS banks. These can be administered through the application of computerized adaptive testing, in which specific items are assigned to patients based on responses to the previous item. This technique greatly reduces the number of questions needed, potentially reducing survey fatigue, while maintaining reliability and precision.<sup>29</sup> Moreover, some surveys can be administered through automated voice systems and, depending on their length and complexity, simply asked over the phone. Although paper PROMs can offer accessibility and ease of administration in the clinic, they do not allow for automatic scoring and require considerable resources if intended to be collected through mail at time points when patients are not in the clinic. Therefore, the ideal method of collection is electronic; this allows patients to complete PROMs both at the clinic or on their own electronic devices and may permit automatic score calculations, depending on software capabilities.

Although some studies demonstrate high response rates for PROM collection, especially for baseline/preoperative surveys, these may often be below 50%,<sup>30,31</sup> in particular for follow-up surveys, which may lead to bias and hinder the representativeness of the data, despite the importance of PROMs for patients, providers, and health systems as a whole. Some studies

FIGURE 4

## PROMs Response Rate by Instrument and Collection Time Point (Calendar Year 2020)

PROMIS-10 surveys are collected at the preoperative time point through phone calls and the patient portal. All other time points for PROMIS-10 and condition-specific PROMs are collected through the patient portal only.



HOOS-JR = Hip Disability and Osteoarthritis Outcome Score Short Form, KOOS-JR = Knee Injury and Osteoarthritis Outcome Score Short Form, NDI = Neck Disability Index, ODI = Oswestry Disability Index, PROM = patient-reported outcome measure, PROMIS-10 = Patient-Reported Outcomes Measurement Information System Scale v1.2 – Global Health, QuickDASH = Quick Disabilities of the Arm, Shoulder and Hand.

Source: The authors

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

suggest that email reminders,<sup>32</sup> text message reminders, and in-clinic electronic tablets may help increase patient PROM participation.<sup>33</sup>

### Our Experience

At our institution, PROMs response rates vary greatly depending on the purpose of collection (e.g., registry or standard of care), procedure or condition, mode of collection, and time point. Figure 4 shows response rates for various PROMs that are collected as part of standard of care, through our EHR’s patient portal.

Our highest collection rates occur when we deploy multiple methods. For example, our new-patient PROMIS-10 collection rate is more than 80% as a result of a workflow that includes an email to the patient before their initial consult, an in-person reminder to complete the instrument at the time of the visit, and, for surgical patients, a telephone survey by nurses who contact all

patients within 24 hours of surgery (if it had not previously been completed). When we use only an EHR-generated email request to complete the follow-up PROMs, our rates are lower than 50%.

---

“ *Our objective was to develop a method to collect PROMs as a routine component of care delivery for all of our patients, much like recording height and weight. In addition, we wanted to do so at clearly defined time points, including before and after any clinical encounter.* ”

---

While calling patients is effective for obtaining responses, it is resource intensive and not scalable outside of existing workflows. We wanted to have sustainable solutions and most recently made changes to the electronic delivery of PROMs through our EHR portal. First, we changed the language on autogenerated email notifications to make them specific about the collection of health questionnaires, instead of the generic reminders (“You have a new message on the Portal”). Second, we embedded a link that takes the patient directly to the questionnaire (to avoid users going to the portal landing page and not finding the questionnaire). Next, we set up reminders to go out 3 days before the questionnaire due date (if patients have not yet completed their PROMs). Lastly, we developed a [web page](#), which includes a [short video](#) that encourages patients to complete PROMs; we provide a link to that web page in the survey invitation email as well as in the questionnaire page itself. Since implementation, we have achieved a significant increase in monthly completion rates through the portal (60%–82%) compared to the period before these changes were implemented (32%–45%).

Some registries that employ a large number of research assistants to call, email, and send letters to patients are able to achieve high response rates. For example, some of our sports registries have rates ranging from 74% to 95% for baseline and around 50% and 42% for 1- and 2-year follow-ups, respectively. Similarly, our joint replacement registries have baseline rates greater than 72% (primaries) and 96% (complex revisions) and 1-year follow-up rates around 63% (primaries) and 80% (complex revisions).

### *Technical Requirements: Select and Test the Platforms That Will Be Used to Collect and Display PROMs*

The implementation of electronic administration of PROMs by large health organizations is subject to many challenges. These include technological complexities, such as the need for electronic platforms to administer questionnaires, calculate scores, and display the results in an easily accessible way, preferably integrated with the EHR to facilitate use at the point of care. In addition, operational obstacles — such as staff reluctance to adopt new workflows and low patient completion rates — may also hinder implementation.<sup>34</sup> Nevertheless, the benefits of collecting PROMs electronically and integrating them with EHRs outweigh the complexities of implementation, especially if data can be used to improve clinical care and for the purposes of comparative effectiveness research.<sup>35</sup>

One way to collect PROMs electronically is to contract with an external vendor. Given the multitude of EHR and PROM collection vendors in the market, institutions have to be cognizant of the need for interoperability and standardization of measures across systems. One of the most common claims made by vendors is that their platforms can be easily integrated with EHRs. However, achieving a full integration means that, in addition to setting up the means for electronic transmission of data between systems (e.g., a Health Level Seven interface), one needs to make sure that each data point that is intended to be transmitted between the systems is mapped. This very labor-intensive process entails matching each of the question-and-answer options on each PROM to ensure that the data are going exactly where they are supposed to go. The use of a common, standardized language to identify each of these data elements would greatly facilitate integration and interoperability. The Logical Observation Identifiers Names and Codes ([LOINC](#)) system, a common terminology originally developed for laboratory and clinical observations,<sup>36,37</sup> could serve this purpose. It now includes some 590 surveys, including more than 200 PROMIS instruments. One of the advantages of LOINC is that researchers can request additional codes to be added to their ever-growing database.

The process for an external vendor to use EHR data to trigger automatic assignment of PROMs at specific intervals requires that certain appropriate data elements from the EHR must be available. For example, working with an external vendor, we wanted to trigger PROMs for specific body parts, which were not captured as discrete data fields in the EHR. This required building those fields in the EHR and training staff to ensure collection, which added complexity to the implementation. So far, no vendor has achieved a full two-way integration with the EHR at our institution.

Another way of collecting PROMs is to have them built directly into the EHR. This has several advantages, including not having to use an additional vendor and having the ability to see PROMs scores directly in the chart and even to use these results as part of the clinical notes. Another value of this approach is that such integration can facilitate the use of PROMs, which may greatly enhance the process of shared decision-making.<sup>38</sup> Nevertheless, the most common EHRs have limited capabilities to customize questionnaires and patient portals.<sup>35</sup> Even if the EHRs have those capabilities, they may not be as flexible as some specialized vendors in terms of customization and the ability to calculate complex scores.

### *Our Experience*

Over the past 3 years, through August 2021, we have built 28 different PROMs into our EHR system, which are being deployed automatically, at specific time points, for patients in 12 service lines ([Appendix](#)). The implementation of PROMs across an institution that performs more than 30,000 surgeries and has more than 365,000 outpatient visits in a year was challenging. Our objective was to develop a method to collect PROMs as a routine component of care delivery for all of our patients, much like recording height and weight. In addition, we wanted to do so at clearly defined time points, including before and after any clinical encounter. The data collected would need to be available in the EHR — allowing for use in care plans — as a large data set for quality improvement initiatives, and they also need to be available for research and to fulfill regulatory needs. The implementation was divided into two phases: (1) collection of a general health PROM (PROMIS-10) and (2) collection of condition-specific PROMs.

To identify the optimal collection points for the PROMIS-10, we mapped patient journeys across the institution, considering all physical, electronic, and telephonic touch points. We looked at the implications of collecting data at those specific points and categorized those by cost, time, staffing needs, EHR portal enrollment levels, Epic EHR integration availability, and any significant customization of Epic that would be necessary.

We determined that collecting the PROMIS-10 during an existing phone call to the patient the day prior to surgery would be the most effective solution and a good way to pilot the implementation. It would have minimal impact on the nursing workflow and would not add an additional point of contact for patients. We believed we would have good compliance, as patients are motivated to take this call, and, historically, 90%–95% of patients speak with one of the nurses before surgery. First, we customized the nurse’s flowsheet to include the PROMIS-10, developed custom operational reports to measure the collection rates (e.g., by caller, by surgeon, by the type of surgery, etc.), recruited one additional nurse for the estimated increase in call time, and trained all nurses in the new workflow. In addition, we administered the PROMIS-10 through our EHR portal, which would be a low-cost method with no increased burden on our staff. To avoid redundancy in responses, we built a method into the nurse flowsheet to identify patients who had completed the survey prior to the call. Finally, we added the postoperative, 6-month, 1-year, and 2-year follow-up questionnaires to the portal. These efforts went live as of December 2016.

---

“ *PROMs can improve the patient-clinician encounter by bringing into focus the issues that are important to patients and facilitate shared decision-making.* ”

---

Building on the work we did with the PROMIS-10, we likewise built the EHR infrastructure to administer condition-specific PROMs. First, starting in January 2018, we obtained the official versions of all instruments and authorization for use, if required. Then, each PROM was custom built, in a way that would enable automatic deployment according to prespecified triggers (e.g., surgery or visit scheduling or specific procedures), score calculation, and trending over time, with scores available at the point of care. Moreover, we built logic to avoid duplicate assignments (e.g., if a given postoperative time point coincided with an office visit). In some instances, we had to use questions on electronic intake forms or scheduling workflows to trigger PROMs, adding to the complexity of the implementation. The building process was very resource intensive from an IT perspective, using more than 860 hours of development in the last 12 months alone, through August 2021, at a cost exceeding \$80,000. Costs to develop a custom platform are likewise high.<sup>39</sup> We estimate that it takes approximately 40 hours to build and test an average-length PROM into Epic.

Also, we have considered the response burden placed on patients within the context of all clinical and research communications and survey requests sent. As such, if multiple PROMs are sent to patients, we send them at the same time, if appropriate. Likewise, PROMs are also collected in conjunction with other patient surveys. For example, patients who have not

completed preoperative PROMs will be asked to complete them telephonically as part of a preoperative phone call from a nurse the day before surgery. At our institution, where most clinicians are additionally interested in using PROMs for clinical research, an extra challenge is in the coordination of efforts to collect PROMs data as a standard of care and also for research purposes; we need to avoid duplicate requests for the same survey and instead handle on the back end any access to that PROM by both clinical and research users. We have not fully solved this problem, but we are working to develop processes and reporting that will detail which PROMs are required for each patient for each standard of care and each research need as well as a defined mechanism to collect these data. We are evaluating both informed distributed and centrally coordinated command-and-control methods.

The population at our institution is majority white (80%) and English speaking. We have seen no differences in response rates across race or ethnicity in terms of completion of either the baseline or follow-up PROMs. Ensuring that patients are able complete PROMs in their native language is an ongoing challenge for which we are actively seeking solutions. Although we have obtained officially translated versions of all PROMs we collect, translated versions do not exist for all languages spoken by our patients. Implementation of translated versions is difficult to automate because the language variable is often not reported within our EHR. Additionally, the patient portal of our electronic medical record (EMR) through which we are communicating to patients about PROMs is only available in English and Spanish. Related to this, we would expect literacy to impact response rates and possibly responses on PROMs. We are currently evaluating this. Our current approach to collecting PROMs from patients who do not speak English or have poor literacy skills is to make available language-appropriate instruments or to have a staff member read the instrument items to patients and complete it on their behalf at the point of care.

## **Step 4. Educate Clinicians and Patients on Why PROMs Are Collected and How to Use Them to Greatest Advantage**

As PROMs are not widely used as a standard in care delivery, most clinicians have little experience in using them to inform clinical decisions. In the United Kingdom, where PROMs are used to assess care quality, general practitioners report that PROMs are useful for shared decision-making but they also report use challenges, including lack of integration into clinical systems and insufficient knowledge about how to best leverage them.<sup>40</sup> In care settings, PROMs can be used to assess and diagnose; track pain, functional status, and quality of life; and monitor disease progression or response to therapy.<sup>6</sup> At the same time, PROMs can improve the patient-clinician encounter by bringing into focus the issues that are important to patients and facilitate shared decision-making.<sup>41,42</sup> The maturity of PROM incorporation into clinical care varies across diseases. For example, PROMs are used commonly enough in the management of nonmalignant pain to support a systematic review, concluding that PROMs enable pain assessment, decision-making, the therapeutic relationship, and evaluation of treatment and may influence outcomes.<sup>43</sup> Furthermore, the use of PROMs for kidney care has been endorsed by stakeholders, and efforts are underway to determine which PROMs should be used and how they can incorporate the patient voice into clinical care, clinical trials, and health care policy.<sup>44</sup>



## *Our Experience*

In a virtuous cycle of PROM use (Figure 2), successful collection facilitates the meaningful use of PROMs in clinical practice, which reinforces the importance of collection for both clinicians and patients. As such, we supposed that the best way to achieve high response rates would be for patients and providers alike to understand that the utilization of PROMs for clinical care is important, not only to track recovery and progress throughout the continuum of care, but also to inform treatment options, such as surgery indication, through a shared decision-making process.

The seamless integration of PROMs into clinical care and accompanying EMR builds has been challenging, but we have employed several strategies to address these hurdles.

First, it is incumbent on the entire care team to recognize the clinical importance of proper PROM collections during patient encounters. Just as primary care physicians would be reticent to provide clinical consultation without vital signs being collected by the rooming nurse, physicians must ensure that the care team appreciates that the consultation is not complete unless the PROMs have been completed and reviewed. Nursing and registration staff must be aware that the data collected will directly impact the diagnosis and consequent treatment recommendations for individual patients. Furthermore, all providers should recognize that PROMs can help predict treatment outcomes, a critical component of the informed consent discussion and shared decision-making. An effective implementation strategy should include a PROM-completed identifier that must be triggered in the EMR before the treating physician is notified that the patient is ready for evaluation.

“

---

*Just as primary care physicians would be reticent to provide clinical consultation without vital signs being collected by the rooming nurse, physicians must ensure that the care team appreciates that the consultation is not complete unless the PROMs have been completed and reviewed.*

---

Second, the patient must be directly engaged in the PROM collection process. Emphasis should be placed on the value to the individual patient and to the quality of their care, rather than on the value to research studies or registries. Comments such as “This is a way for me to ‘take the temperature’ of your knee condition” are useful in this regard. This not only affirms that patients’ effort is valuable, but it also incentivizes them to provide accurate information. Likewise, sharing of PROM tracking graphics also encourages patients to participate more fully in their care and motivates them to continue to be compliant with future PROM collections. Ideally, the patient should be motivated to complete the online data collection in preparation for the impending clinic visit. Also, the physician should discuss the findings of the PROM early in the interaction with the patient, further signifying the importance of this assessment.

Third, physicians should consider administering PROM collections on each visit rather than at selected intervals. This reduces confusion among support staff regarding when to administer the questions and avoids the default, “We can skip it this time.” PROMs collections should be imbedded into the culture of the clinic such that the workflow is optimized for it. In fact, patients who are compliant with previsit completion should be rewarded by shortening their wait time and prioritizing their rooming. Likewise, physicians should be notified of such compliance so that they can express appreciation for the “participation in care.”

Finally, PROM completion metrics should be shared among all clinic staff and all providers at regular intervals. Outlier data should be investigated and discussed among physician, advanced practice provider, nursing, registration, and practice scheduling staff to determine causation and remedy the situation. Institutions may consider employing dedicated personnel to facilitate previsit PROM collections to optimize throughput during in-person clinic days, further improving the productivity of the clinic.

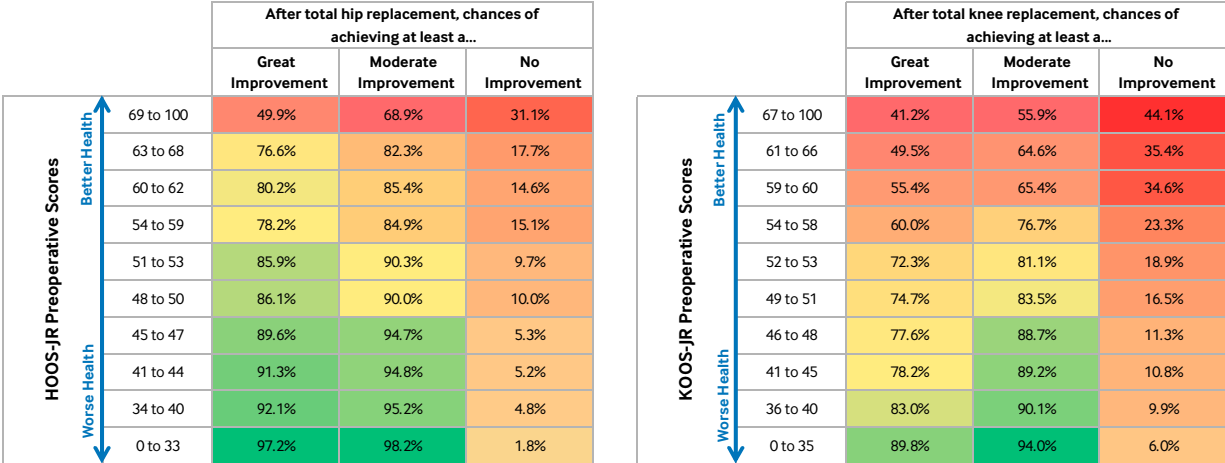
### Future Clinical State

Some of our surgeons are using PROM scores based on insights from predictive models we have developed<sup>21</sup> to discuss with patients their likelihood of improvement after surgery (Figure 5).

FIGURE 5

### Patient Decisions Aids to Understand Likely Outcomes

The use of decision aid tools engages the patient in their care and reinforces the importance of collecting personalized PROM data. HOOS-JR = Hip Disability and Osteoarthritis Outcome Score for Joint Replacement, KOOS-JR = Knee Injury and Osteoarthritis Outcome Score for Joint Replacement, PROM = patient-reported outcome measure.

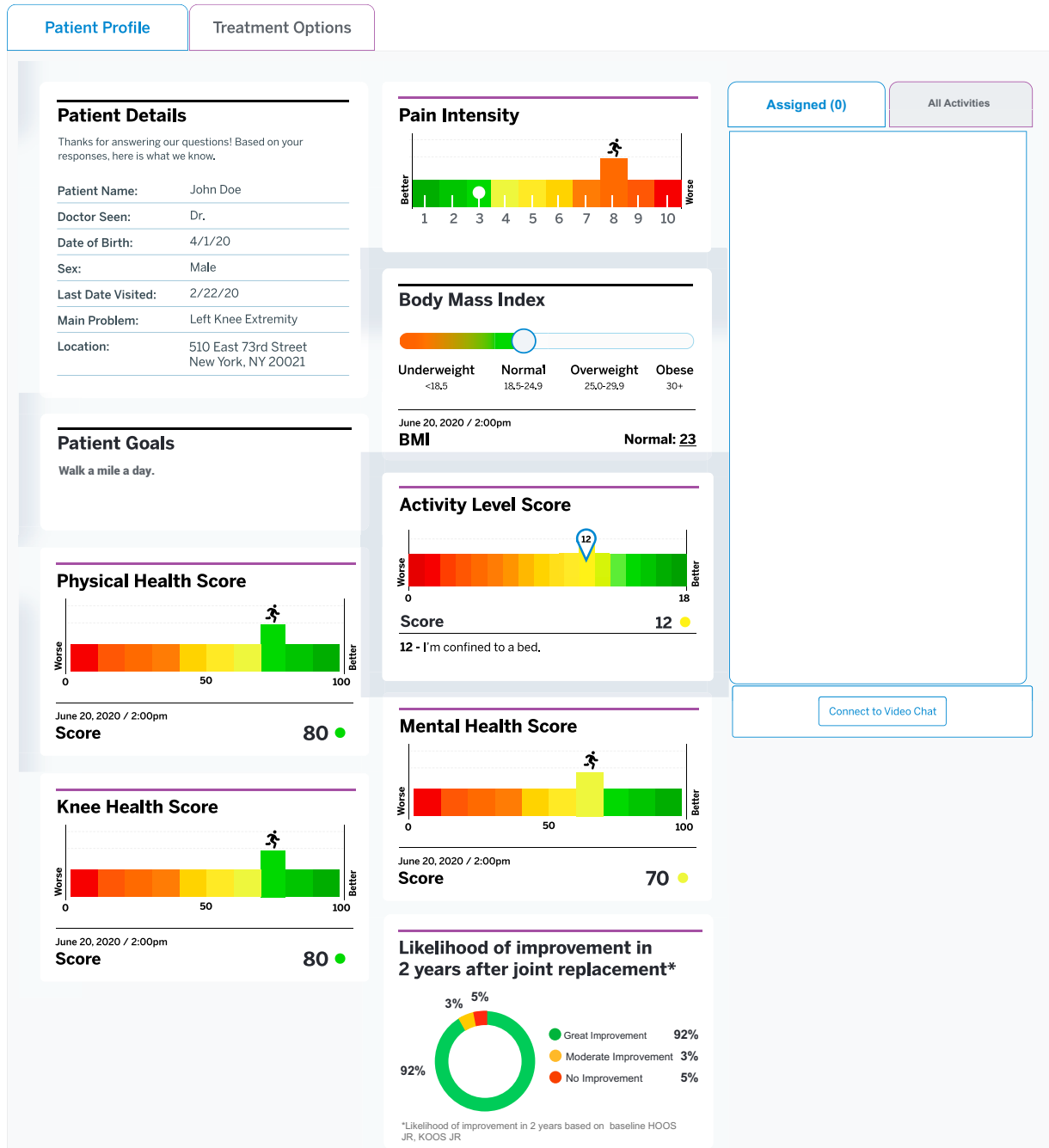


Source: The authors  
 NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

FIGURE 6

## Preconsultation Report for Patients

This report offers a concise graphic presentation of key health metrics to allow the physician and patient to discuss the patient’s unique situation and the prospects for success based on the course of action selected. BMI = body mass index, HOOS-JR = Hip Disability and Osteoarthritis Outcome Score Short Form, KOOS-JR = Knee Injury and Osteoarthritis Outcome Score Short Form.



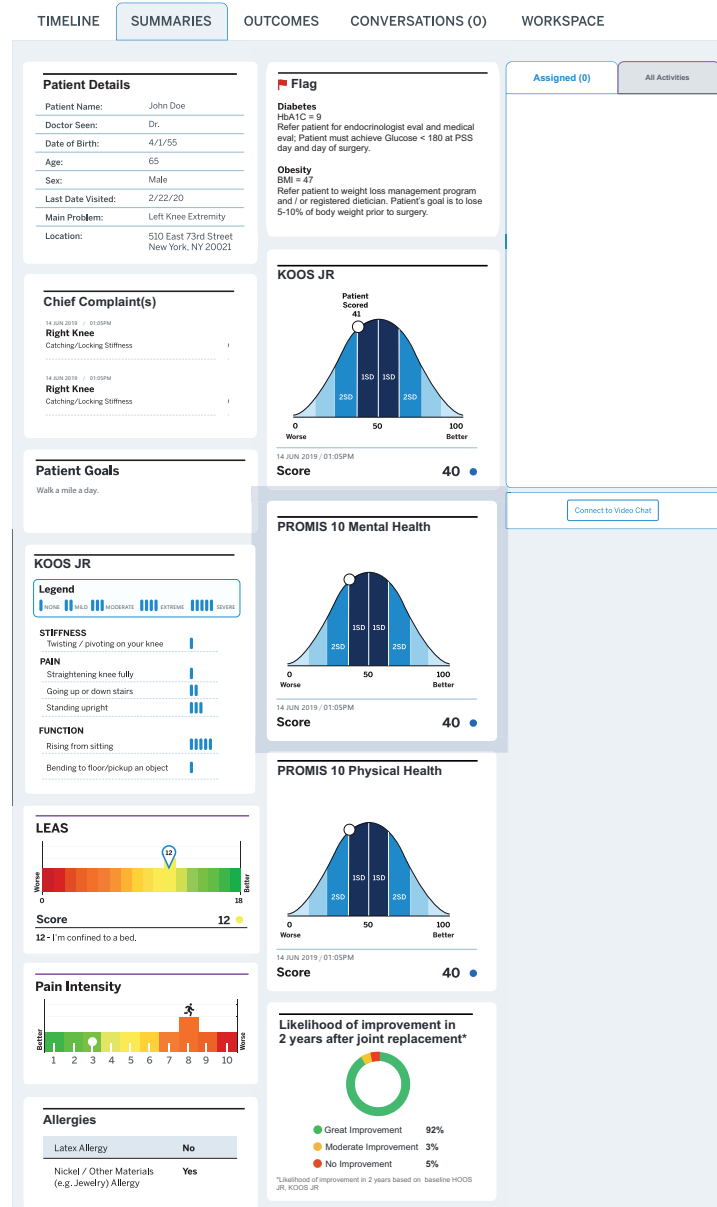
Source: The authors

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

FIGURE 7

## Preconsultation Report for Physicians

This report offers a concise graphic presentation of key health metrics to allow the physician to assess the patient’s unique situation and the prospects for success based on the course of action selected. Of note, this version includes sections for red-flag considerations, allergies, and other factors. BMI = body mass index, HbA1C = glycated hemoglobin, HOOS-JR = Hip Disability and Osteoarthritis Outcome Score Short Form, KOOS-JR = Knee Injury and Osteoarthritis Outcome Score Short Form, LEAS = Lower Extremity Activity Scale, PROMIS-10 = Patient-Reported Outcomes Measurement Information System Scale v1.2 – Global Health , PSS = presurgical screening.



Source: The authors

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

These decision aids facilitate informed discussions about treatment options between patients and providers. Unsurprisingly, clinicians who discuss baseline PROMs with their patients consistently score high on common measures of shared decision-making<sup>45</sup> and communication.<sup>46</sup> We have also developed a Personalized Health Management Tool that consists of a smart intake that collects PROM and other relevant clinical information in a patient-friendly way and delivers to the patient, in real time, a summary of their responses — along with predictions of likely outcomes after a procedure or treatment; a companion clinician-friendly summary is simultaneously generated (Figure 6, Figure 7).

In a pilot study, 11 patients from 3 providers were asked to complete their intake forms on both the traditional EHR and the tool. Providers were asked to review the reports generated by the tool during the visits. Both groups overwhelmingly liked the user experience and information provided by the tool. Through semistructured interviews, we found that 7 of 11 patients receiving joint replacement preferred it to the intake form available through our EHR. However, the integration of this tool with our EHR, which would allow for automatic deployment of the intake form based on visit scheduling and subsequent storing of tool data in the EHR, presents a substantial hurdle that would need to be overcome before this tool could be broadly integrated into clinical practice.

## **Unfinished Business: Steps Needed to Realize the Potential of PROMs**

Although much good work has been done to develop, implement, and assess PROMs in the context of clinical care and research, the full potential of PROMs to improve the health of our population is unrealized, largely because they are not collected in a consistent and routine manner. In our view, the single largest barrier to widespread adoption of PROMs in care delivery is the intensity of resources needed to incorporate them into clinical workflows. While PROMs can be built into EHRs, this is labor intensive. Assuming that the cost to build a single 10-item PROM into an EHR is \$3,700 and that an average hospital would want to implement at least 50 different PROMs across service lines and departments, the total cost per hospital would be \$185,000. This means the combined cost to the approximately 6,000 hospitals in the U.S. health system would be more than \$1 billion. From a health system standpoint, it is incredibly inefficient for every hospital to do a custom build to collect the exact same data elements. Standards for PROM collection through EHRs should be defined and vendors required to implement them. These standards should include tagging PROM questions and responses with standard unique labels (e.g., LOINC) to facilitate data management and interoperability between EHRs and vendors that collect PROMs.

“

*The full potential of PROMs to improve the health of our population is unrealized, largely because they are not collected in a consistent and routine manner. In our view, the single largest barrier to widespread adoption of PROMs in care delivery is the intensity of resources needed to incorporate them into clinical workflows.*

Another barrier to adoption is clinician inexperience in using PROMs. Few clinicians encounter PROMs in their medical training. As detailed earlier, clinician education at the site of service that covers both the clinical applications of PROMs and the operations around how to use PROMs within a delivery setting is essential to the effective use of PROMs in clinical care. More in-depth education about the underlying psychometric properties and clinical application of PROMs in medical school and postgraduate training would better equip physicians to understand patients and their outcomes.

Much work remains to be done to facilitate the effective use of PROMs as performance measures. As with all quality measures, the purpose of those based on PROMs would be to improve the health of populations through measurement and reporting, which would focus the attention of health care providers on related quality improvement and afford consumers the opportunity to choose providers based on related quality. All requirements that are used to develop valid and reliable quality measures generally also apply to PROM-based measures.<sup>47,48</sup> As with any outcome measure, PROM-based quality measures will require risk adjustment. Additional considerations specific to PROM-based quality measures include ensuring the validity of the underlying PROM and the setting of standards for how high versus low quality would be defined based on PROM responses. For example, a quality threshold could be defined based on the percentage of patients achieving some change in a PROM score over time, such as a minimal clinically important difference or a substantial clinical benefit.<sup>20</sup> Alternatively, a quality threshold could be based on achieving a predefined level, such as a patient-acceptable symptom state<sup>49</sup> or some other clinically meaningful score that indicates good health.

Currently, there are 10 quality measures based on PROMs endorsed by the National Quality Forum (NQF).<sup>18</sup> There are an additional 17 PROM-based quality measures in the 2021 U.S. Centers for Medicare & Medicaid Services (CMS) Merit-Based Incentive Payment System.<sup>50</sup> Between these 2 groups, 16 measures are based on achieving some defined degree of change in a PROM, 5 on achieving a defined PROM threshold, and 6 on achieving either a defined change or achieving a threshold. The NQF is conducting the CMS-sponsored Building a Roadmap from Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures project, which will provide guidance on the development of PROMs as performance measures.<sup>51</sup>

## Looking Ahead

PROMs hold the promise to promote health based on patient-centered outcomes. They are currently being used effectively by some institutions — but not ubiquitously — to assess the health of patients, to determine their response to treatment, and to predict likely treatment outcomes. Widespread adoption of PROMs in clinical care would be accelerated by providing clinician education about PROMs and by making them readily available within and interoperable across different EHRs and data registries. PROM-based performance measurement would almost certainly accelerate the collection of the related PROMs, although not necessarily their incorporation into clinical care. Thoughtful utilization of PROMs within

institutions could lead to a virtuous PROM cycle (Figure 2) that supports clinical care, research, and quality activities all directed at improving patient-centered health outcomes.

**Catherine H. MacLean, MD, PhD**

Chief Value Medical Officer, Hospital for Special Surgery, New York, New York, USA

Professor of Medicine, Weill Cornell Medical College, New York, New York, USA

**Vinicius C. Antao, MD, PhD, MSc**

Senior Director, Health Outcomes Strategy, Center for the Advancement of Value in Musculoskeletal Care, Hospital for Special Surgery, New York, New York, USA

**Mark A. Fontana, PhD**

Senior Director, Data Science, Hospital for Special Surgery, New York, New York, USA

Assistant Professor, Department of Population Health Sciences, Weill Cornell Medical College, New York, New York, USA

**Harvinder S. Sandhu, MD**

Co-Chief, HSS Spine, Hospital for Special Surgery, New York, New York, USA

Associate Professor of Orthopedic Surgery, Weill Cornell Medical College, New York, New York, USA

**Alexander S. McLawhorn, MD, MBA**

Assistant Attending Orthopedic Surgeon, Hospital for Special Surgery, New York, New York, USA

Assistant Professor of Orthopedic Surgery, Weill Cornell Medical College, New York, New York, USA

## Appendix

[Hospital for Special Surgery's 28 PROMs Built into EHR](#)

## Acknowledgments

We thank Randy Herbertson at The Visual Brand and Alessandra Taverna-Trani at HSS for their help in creating Figures 2 and 3, respectively. Additionally, we recognize the considerable efforts that the entire HSS staff and our patients have made to advance patient-centered care through PROM collection.

*Disclosures: Catherine H. MacLean is co-chair of Building a Roadmap from Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures, a technical advisory panel for the NQF, Washington, DC. Vinicius C. Antao, Mark A. Fontana, Harvinder S. Sandhu, and Alexander S. McLawhorn have nothing to disclose.*

## References

1. Brédart A, Marrel A, Abetz-Webb L, Lasch K, Acquadro C. Interviewing to develop patient-reported outcome (PRO) measures for clinical research: eliciting patients' experience. *Health Qual Life Outcomes* 2014;12:15 <https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-12-15> <https://doi.org/10.1186/1477-7525-12-15>.
2. Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167 <https://www.bmj.com/content/346/bmj.f167> <https://doi.org/10.1136/bmj.f167>.
3. Nguyen H, Butow P, Dhillon H, et al. Using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine head and neck cancer care: what do health professionals perceive as barriers and facilitators? *J Med Imaging Radiat Oncol* 2020;64:704-10 <https://onlinelibrary.wiley.com/doi/epdf/10.1111/1754-9485.13048>.
4. Kilic L, Erden A, Bingham CO III, Gossec L, Kalyoncu U. The reporting of patient-reported outcomes in studies of patients with rheumatoid arthritis: a systematic review of 250 articles. *J Rheumatol* 2016;43:1300-5 <https://www.jrheum.org/content/43/7/1300> <https://doi.org/10.3899/jrheum.151177>.
5. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 2013;13:211 <https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-211> <https://doi.org/10.1186/1472-6963-13-211>.
6. Field J, Holmes MM, Newell D. PROMs data: can it be used to make decisions for individual patients? A narrative review. *Patient Relat Outcome Meas* 2019;10:233-41 <https://pubmed.ncbi.nlm.nih.gov/31534379/> <https://doi.org/10.2147/PROM.S156291>.
7. Kendrick T, El-Gohary M, Stuart B, et al. Routine use of patient reported outcome measures (PROMs) for improving treatment of common mental health disorders in adults. *Cochrane Database Syst Rev* 2016;7:CD011119 <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011119.pub2/full?cookiesEnabled> <https://doi.org/10.1002/14651858.CD011119.pub2>.
8. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf* 2014;23:508-18 <https://qualitysafety.bmj.com/content/23/6/508> <https://doi.org/10.1136/bmjqs-2013-002524>.
9. Rogers SN, Barber B. Using PROMs to guide patients and practitioners through the head and neck cancer journey. *Patient Relat Outcome Meas* 2017;8:133-42 <https://www.dovepress.com/using-proms-to-guide-patients-and-practitioners-through-the-head-and-n-peer-reviewed-fulltext-article-PROM> <https://doi.org/10.2147/PROM.S129012>.



10. Chow A, Mayer EK, Darzi AW, Athanasiou T. Patient-reported outcome measures: the importance of patient satisfaction in surgery. *Surgery* 2009;146:435-43 [https://www.surgjournal.com/article/S0039-6060\(09\)00180-9/fulltext](https://www.surgjournal.com/article/S0039-6060(09)00180-9/fulltext) <https://doi.org/10.1016/j.surg.2009.03.019>.
11. Garcia-Gutierrez S, Quintana JM, Aguire U, et al. Impact of clinical and patient-reported outcomes on patient satisfaction with cataract extraction. *Heal Expect* 2014;17:765-75 <https://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2012.00801.x>. <https://doi.org/10.1111/j.1369-7625.2012.00801.x>.
12. Schroeder GD, Coric D, Kim HJ, Albert TJ, Radcliff KE. Are patient-reported outcomes predictive of patient satisfaction 5 years after anterior cervical spine surgery? *Spine J* 2017;17:943-52 [https://www.thespinejournalonline.com/article/S1529-9430\(17\)30075-X/fulltext](https://www.thespinejournalonline.com/article/S1529-9430(17)30075-X/fulltext) <https://doi.org/10.1016/j.spinee.2017.02.008>.
13. Salaffi F, Carotti M, Ciapetti A, Gasparini S, Filippucci E, Grassi W. Relationship between time-integrated disease activity estimated by DAS28-CRP and radiographic progression of anatomical damage in patients with early rheumatoid arthritis. *BMC Musculoskelet Disord* 2011;12:120 <https://bmcmusculoskeletdisord.biomedcentral.com/articles/10.1186/1471-2474-12-120> <https://doi.org/10.1186/1471-2474-12-120>
14. Movahedi M, Weber D, Akhavan P, Keystone EC. Modified disease activity score at 3 months is a significant predictor for rapid radiographic progression at 12 months compared with other measures in patients with rheumatoid arthritis. *ACR Open Rheumatol* 2020;2:188-94 <https://onlinelibrary.wiley.com/doi/10.1002/acr2.11123> <https://doi.org/10.1002/acr2.11123>.
15. Vermeer M, Kievit W, Kuper HH, et al. Treating to the target of remission in early rheumatoid arthritis is cost-effective: results of the DREAM registry. *BMC Musculoskelet Disord* 2013;14:350 <https://bmcmusculoskeletdisord.biomedcentral.com/articles/10.1186/1471-2474-14-350> <https://doi.org/10.1186/1471-2474-14-350>.
16. Agency for Healthcare Research and Quality. About Learning Health Systems. March 2019. Accessed September 4, 2021. <https://www.ahrq.gov/learning-health-systems/about.html>.
17. UnitedHealthcare. Commercial Medical Policy. Knee Replacement Surgery (Arthroplasty), Total and Partial. May 1, 2021. Accessed June 8, 2021. <https://www.uhcprovider.com/content/dam/provider/docs/public/policies/index/commercial/knee-replacement-surgery-total-partial-05012021.pdf>.
18. National Quality Forum. Measures, Reports and Tools. 2021. Accessed June 8, 2021. [https://www.qualityforum.org/Measures\\_Reports\\_Tools.aspx](https://www.qualityforum.org/Measures_Reports_Tools.aspx).
19. Haywood KL. Patient-reported outcome I: measuring what matters in musculoskeletal care. *Musculoskelet Care* 2006;4:187-203 <https://onlinelibrary.wiley.com/doi/10.1002/msc.94> <https://doi.org/10.1002/msc.94>.
20. Lyman S, Lee Y-Y, McLawhorn AS, Islam W, MacLean CH. What are the minimal and substantial improvements in the HOOS and KOOS and JR versions after total joint replacement? *Clin Orthop Relat Res* 2018;476:2432-41 [https://journals.lww.com/clinorthop/Fulltext/2018/12000/What\\_Are](https://journals.lww.com/clinorthop/Fulltext/2018/12000/What_Are)

[the Minimal and Substantial Improvements.24.aspx](#) <https://doi.org/10.1097/CORR.000000000000456>.

21. Fontana MA, Lyman S, Sarker GK, Padgett DE, MacLean CH. Can machine learning algorithms predict which patients will achieve minimally clinically important differences from total joint arthroplasty? *Clin Orthop Relat Res* 2019;477:1267-79 [https://journals.lww.com/clinorthop/Fulltext/2019/06000/Can\\_Machine\\_Learning\\_Algorithms\\_Predict\\_Which.3.aspx](https://journals.lww.com/clinorthop/Fulltext/2019/06000/Can_Machine_Learning_Algorithms_Predict_Which.3.aspx) <https://doi.org/10.1097/CORR.000000000000687>.
22. Porter I, Gonçalves-Bradley D, Ricci-Cabello I, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. *J Comp Eff Res* 2016;5:507-19 <https://www.futuremedicine.com/doi/10.2217/cer-2015-0014> <https://doi.org/10.2217/cer-2015-0014>.
23. Franklin P, Chenok K, Lavalee D, et al. Framework to guide the collection and use of patient-reported outcome measures in the learning healthcare system. *EGEMS (Wash DC)* 2017;5:17 <https://egems.academyhealth.org//article/10.5334/egems.227/> <https://doi.org/10.5334/egems.227>.
24. Swanson JC, Lee Y, Thompson PB, Bawden R, Mench JA. Integration: valuing stakeholder input in setting priorities for socially sustainable egg production. *Poult Sci* 2011;90:2110-21 <https://www.sciencedirect.com/science/article/pii/S0032579119307473?via%3Dihub> <https://doi.org/10.3382/ps.2011-01340>.
25. Rawson R, Hooper P. The importance of stakeholder participation to sustainable airport master planning in the UK. *Environ Dev* 2012;2:36-47 <https://www.sciencedirect.com/science/article/abs/pii/S2211464512000528?via%3Dihub> <https://doi.org/10.1016/j.envdev.2012.03.013>.
26. Aaronson N, Elliott T, Greenhalgh J, et al. User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. Version 2. International Society for Quality of Life Research. January 2015. Accessed September 3, 2020. <https://www.isoqol.org/wp-content/uploads/2019/09/2015UsersGuide-Version2.pdf>.
27. Chan EKH, Edwards TC, Haywood K, Mikles SP, Newton L. Implementing patient-reported outcome measures in clinical practice: a companion guide to the ISOQOL user's guide. *Qual Life Res* 2019;28:621-7 <https://link.springer.com/article/10.1007%2Fs11136-018-2048-4> <https://doi.org/10.1007/s11136-018-2048-4>.
28. Schalet BD, Rothrock NE, Hays RD, et al. Linking physical and mental health summary scores from the Veterans RAND 12-Item Health Survey (VR-12) to the PROMIS(®) Global Health Scale. *J Gen Intern Med* 2015;30:1524-30 <https://link.springer.com/article/10.1007%2Fs11606-015-3453-9> <https://doi.org/10.1007/s11606-015-3453-9>.
29. Cella D, Gershon R, Lai J-S, Choi S. The future of outcomes measurement: item banking, tailored short-forms, and computerized adaptive assessment. *Qual Life Res* 2007;16(Suppl 1):133-41 <https://link.springer.com/article/10.1007%2Fs11136-007-9204-6> <https://doi.org/10.1007/s11136-007-9204-6>.

30. Howard JS, Toonstra JL, Meade AR, Whale Conley CE, Mattacola CG. Feasibility of conducting a web-based survey of patient-reported outcomes and rehabilitation progress. *Digit Health* 2016;2: 2055207616644844 <https://journals.sagepub.com/doi/10.1177/2055207616644844> <https://doi.org/10.1177/2055207616644844>.
31. Peters M, Crocker H, Jenkinson C, Doll H, Fitzpatrick R. The routine collection of patient-reported outcome measures (PROMs) for long-term conditions in primary care: a cohort survey. *BMJ Open* 2014;4:e003968 <https://bmjopen.bmj.com/content/4/2/e003968> <https://doi.org/10.1136/bmjopen-2013-003968>.
32. Triplet JJ, Momoh E, Kurowicki J, Villarroel LD, Law TY, Levy JC. E-mail reminders improve completion rates of patient-reported outcome measures. *JSES Open Access* 2017;1:P25-8 [https://www.jsesinternational.org/article/S2468-6026\(17\)30006-2/fulltext](https://www.jsesinternational.org/article/S2468-6026(17)30006-2/fulltext) <https://doi.org/10.1016/j.jses.2017.03.002>.
33. Roberts N, Bradley B, Williams D. Use of SMS and tablet computer improves the electronic collection of elective orthopaedic patient reported outcome measures. *Ann R Coll Surg Engl* 2014;96: 348-51 <https://publishing.rcseng.ac.uk/doi/10.1308/003588414X13946184900769> <https://doi.org/10.1308/003588414X13946184900769>.
34. Wagle NW. Implementing patient-reported outcome measures. *NEJM Catalyst*. October 12, 2017. Accessed September 5, 2021. <https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0373>.
35. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. *J Clin Epidemiol* 2013;66(Suppl):S12-20 [https://www.jclinepi.com/article/S0895-4356\(13\)00154-6/fulltext](https://www.jclinepi.com/article/S0895-4356(13)00154-6/fulltext) <https://doi.org/10.1016/j.jclinepi.2013.04.005>.
36. Forrey AW, McDonald CJ, DeMoor G, et al. Logical observation identifier names and codes (LOINC) database: a public use set of codes and names for electronic reporting of clinical laboratory test results. *Clin Chem* 1996;42:81-90 <https://academic.oup.com/clinchem/article/42/1/81/5646177> <https://doi.org/10.1093/clinchem/42.1.81>.
37. Huff SM, Rocha RA, McDonald CJ, et al. Development of the Logical Observation Identifier Names and Codes (LOINC) vocabulary. *J Am Med Inform Assoc* 1998;5:276-92 <https://academic.oup.com/jamia/article/5/3/276/712535> <https://doi.org/10.1136/jamia.1998.0050276>.
38. Kotronoulas G, Kearney N, Maguire R, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol* 2014;32:1480-501 <https://ascopubs.org/doi/10.1200/JCO.2013.53.5948> <https://doi.org/10.1200/JCO.2013.53.5948>.
39. Baumhaur JF, Dasilva C, Mitten D, Ruber P, Rotondo M. The cost of patient-reported outcomes in medicine. *NEJM Catalyst*. January 25, 2018. Accessed September 29, 2021. <https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0272>.

40. Turner GM, Litchfield I, Finnikin S, Aiyegbusi OL, Calvert M. General practitioners' views on use of patient reported outcome measures in primary care: a cross-sectional survey and qualitative study. *BMC Fam Pract* 2020;21:1-10 <https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-019-1077-6>.
41. Hvitfeldt H, Carli C, Nelson EC, Mortenson DM, Ruppert BA, Lindblad S. Feed forward systems for patient participation and provider support: adoption results from the original US context to Sweden and beyond. *Qual Manag Health Care* 2009;18:247-56 [https://journals.lww.com/qmhcjournal/Abstract/2009/10000/Feed\\_Forward\\_Systems\\_for\\_Patient\\_Participation\\_and.5.aspx](https://journals.lww.com/qmhcjournal/Abstract/2009/10000/Feed_Forward_Systems_for_Patient_Participation_and.5.aspx) <https://doi.org/10.1097/QMH.0b013e3181bee32e>.
42. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract* 1999;5:401-16 <https://onlinelibrary.wiley.com/doi/pdf/10.1046/j.1365-2753.1999.00209.x>.
43. Holmes MM, Lewith G, Newell D, Field J, Bishop FL. The impact of patient-reported outcome measures in clinical practice for pain: a systematic review. *Qual Life Res* 2017;26:245-57 <https://link.springer.com/article/10.1007%2Fs11136-016-1449-5> <https://doi.org/10.1007/s11136-016-1449-5>.
44. Nair D, Wilson FP. Patient-reported outcome measures for adults with kidney disease: current measures, ongoing initiatives, and future opportunities for incorporation into patient-centered kidney care. *Am J Kidney Dis* 2019;74:791-802 [https://www.ajkd.org/article/S0272-6386\(19\)30847-9/fulltext](https://www.ajkd.org/article/S0272-6386(19)30847-9/fulltext) <https://doi.org/10.1053/j.ajkd.2019.05.025>.
45. Légaré F, Kearing S, Clay K, et al. Are you SURE?: assessing patient decisional conflict with a 4-item screening test. *Can Fam Physician* 2010;56:e308-14 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2920798/>.
46. Freel J, Bellon J, Hanmer J. Better physician ratings from discussing PROs with patients. *NEJM Catalyst*. June 20, 2018. Accessed September 16, 2021. <https://catalyst.nejm.org/doi/abs/10.1056/CAT.18.0150>.
47. National Quality Forum. Patient-Reported Outcomes in Performance Measurement. January 10, 2013. Accessed June 8, 2021. [https://www.qualityforum.org/publications/2012/12/patient-reported\\_outcomes\\_in\\_performance\\_measurement.aspx](https://www.qualityforum.org/publications/2012/12/patient-reported_outcomes_in_performance_measurement.aspx).
48. Qaseem A, Tierney S, Barrett ED, MacLean CH, Dunn A, Fitterman N; Performance Measurement Committee of the American College of Physicians. Recommending caution in patient-reported outcome-based performance measurement. *Ann Intern Med* 2021;174:1161-2 <https://www.acpjournals.org/doi/10.7326/M19-3603> <https://doi.org/10.7326/M19-3603>.
49. Kvien TK, Heiberg T, Hagen KB. Minimal clinically important improvement/difference (MCII/MCID) and patient acceptable symptom state (PASS): What do these concepts mean? *Ann Rheum Dis* 2007;66(Suppl 3):iii40-1 [https://ard.bmj.com/content/66/suppl\\_3/iii40](https://ard.bmj.com/content/66/suppl_3/iii40). <https://doi.org/10.1136/ard.2007.079798>.

50. U.S. Centers for Medicare & Medicaid Services. Quality Payment Program. 2021 Quality Measures: Traditional MIPS. Accessed June 8, 2021. <https://qpp.cms.gov/mips/explore-measures?tab=qualityMeasures&py=2021>.
51. National Quality Forum. Building a Roadmap from Patient-Reported Outcome Measures to Patient-Reported Outcome Performance Measures. Accessed June 8, 2021. [https://www.qualityforum.org/Building\\_a\\_Roadmap\\_from\\_Patient-Reported\\_Outcome\\_Measures\\_to\\_Patient-Reported\\_Outcome-Performance\\_Measures.aspx](https://www.qualityforum.org/Building_a_Roadmap_from_Patient-Reported_Outcome_Measures_to_Patient-Reported_Outcome-Performance_Measures.aspx).